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Type 2 diabetes management among older American Indians: beliefs, attitudes, and practices

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ABSTRACT

Objective: The purpose of this study was to examine beliefs, attitudes, and practices of older American Indians regarding their type 2 diabetes mellitus (T2DM) management. T2DM is one of the leading causes of morbidity and mortality among American Indians. American Indians are more than twice as likely to have T2DM and have over three times a T2DM mortality rate as Whites.
Design: Study participants were older members of a federally recognized tribe who had T2DM. A low-inference qualitative descriptive design was used. Data were collected through semi-structured in-depth qualitative interviews with a mixed inductive, deductive, and reflexive analytic team process.
Results: Our study sample included 28 participants with a mean age of 73.0 ± 6.4 years of whom 16 (57%) were women. Participants' mean self-confidence score of successful T2DM management was 8.0 ± 1.7 on a scale from 1 to 10 with 10 representing the greatest amount of confidence. Participants' mean HbA1c was 7.3% ± 1.5%. Overall, participants discussed T2DM management within five themes: 1) sociocultural factors, 2) causes and consequences, 3) cognitive and affective assessment, 4) diet and exercise, and 5) medical management.
Conclusions: It is important to be aware of the beliefs and attitudes of patients. Lay understandings can help identify factors underlying health and illness behaviors including motivations to maintain healthy behaviors or to change unhealthy behaviors. Such information can be helpful for health educators and health promotion program staff to ensure their efforts are effective and in alignment with patients' realities.

Introduction

Thirty million Americans aged ≥ 18 years or 12% of the U.S. adult population are estimated to have diabetes. An additional 84 million Americans aged ≥ 18 years, 34% of the U.S. adult population, are estimated to have prediabetes (Centers for Disease Control and Prevention 2017). Estimates project that the number of persons in the U.S.

with diabetes will increase 54% between 2015 and 2030, with associated health care spending increasing 53% to $622 billion (Rowley et al. 2017). Type 2 diabetes mellitus (T2DM), the most common type of diabetes, places extreme burdens on the U.S. health care system, costing $245 billion in 2012 (American Diabetes Association 2013). Older adults have the highest percent of T2DM; more than a quarter of persons aged ≥ 65 years nationwide suffer from T2DM (Centers for Disease Control and Prevention 2017).

American Indians experience the highest prevalence of T2DM of any race or ethnic group (Centers for Disease Control and Prevention 2017). Indeed, American Indians are more than twice as likely to have T2DM (Cobb, Espey, and King 2014) and three times as likely to die from T2DM as Whites (Cho et al. 2014; Espey et al. 2014). Consequently, the T2DM epidemic is a top priority for the Indian Health Service[1] as well as for the study's participating tribe, among whom 60% of tribal members aged ≥ 65 years have this condition. T2DM is consistently one of the top five admitting diagnoses in the tribe's hospital. Between 2013 and 2014, the tribe's hospital saw an 11% increase in patients diagnosed with T2DM (Eastern Band of Cherokee Indians 2015). T2DM age-adjusted total health care expenditures for persons with T2DM are over three times higher than for persons without T2DM, consuming 37% of all medical costs for the Indian Health Service (O'Connell et al. 2012).

Lifestyle management is a critical component of T2DM care. Recommendations include weight management, physical activity, smoking cessation, and emotional well-being (American Diabetes Association 2018). Overall, American Indians experience high rates of obesity, physical inactivity, smoking, and low levels of emotional well-being (Barnes, Adams, and Powell-Griner 2010; Cobb, Espey, and King 2014; Curyto et al. 1998; Denny et al. 2005; Goins et al. 2017; Henry J. Kaiser Family Foundation 2016; National Center for Health Statistics 2014).

Examinations of the 2000–2010 Behavioral Risk Factor Surveillance System (BRFSS) and the 2004–2008 National Health Interview Survey data of American Indians and Alaska Natives aged ≥ 18 years found higher prevalence of obesity, physical inactivity and current smoking compared to Whites (Barnes, Adams, and Powell-Griner 2010; Cobb, Espey, and King 2014). Similarly, data from the 2001 and 2002 BRFSS show that American Indians and Alaska Natives aged ≥ 55 years had higher prevalence compared to Whites of obesity (29% vs. 22%), physical inactivity (37% vs 29%), and current smoking (27% vs. 14%) (Denny et al. 2005).

Regarding emotional well-being, American Indians have been shown to experience disproportionately high rates of mental illness (Henry J. Kaiser Family Foundation 2016; National Center for Health Statistics 2014). Compared to older adults of other races and ethnicities, older American Indians have higher prevalence rates of depressive symptomatology and psychological distress (Curyto et al. 1998; Kim, Bryant, and Parmelee 2012).

While such quantitative information is insightful, these data do not capture the lived experience of those with T2DM. Lay understandings are valuable because they can help identify factors that influence lifestyle management including motivations to engage in healthy behaviors, maintain healthy behaviors, or to change unhealthy behaviors. Social and cultural settings can influence health understandings, experiences of illness, and health-related behaviors (Conrad and Barker 2010). Despite the T2DM epidemic in Indian Country, there has been relatively little research that has examined T2DM-related understandings and experiences among American Indians.

Thus, we used a broad descriptive qualitative approach to examine one tribe's older American Indians' beliefs, attitudes, and practices with respect to their T2DM management. We identified and analyzed those beliefs, attitudes, and practices in the context of how participants talked about their diagnosis, management behaviors, and their overall day-to-day experiences.

Theoretical orientation

Our study was informed by two theoretical frameworks, including a social constructivist perspective (Berger and Luckmann 1966; Creswell 2013) and explanatory models of illness (Kleinman 1978; Kleinman, Eisenberg, and Good 1978). A social constructivist perspective to knowledge generation is one that is ontologically relativist, epistemologically subjectivist, and methodologically hermeneutic and dialectic. People understand their experiences through relationships with others and the context in which they occur. A socially constructed reality is interpreted through language and past experiences. Individuals make sense or meaning from these experiences and express them through culture and language (Creswell 2013). Using a social constructivist perspective, we attended to individual and the participant group's perspectives as well as meaning within a community. In this study, the community is not only a living location but also the context in which participants encounter health messaging and medical guidance related to T2DM.

The explanatory models of illness framework posits that individuals create conceptual models to make sense of an illness and that cultural groups share similar models (Kleinman 1978; Kleinman, Eisenberg, and Good 1978). Each society has cultural systems surrounding health, including specific symbolic meanings, values, and behavioral norms associated with different illnesses. Illness is experienced in three arenas according to this theoretical framework, which includes the popular, professional, and folk arenas. The popular arena includes the family and the larger community context and this is where the vast majority of illness is managed. The professional arena is the formal health care system and the folk arena refers to non-professional healing specialists and practices. This framework focuses on what illness and health mean to individuals and on how attitudes and actions towards treatment are formed. Understanding patients' explanatory models can help identify approaches that support their engagement in health promoting behaviors.

Together, these two theoretical frameworks guided our study to focus on the experience of American Indians with T2DM. We included community leaders in study design and in data interpretation to assist in understanding the language and cultural content of these experiences. We examined participants' language use around understandings of T2DM as individuals and as community members. We also explored the popular, professional, and folk arenas as experienced by our study participants when they chose to share them naturally.

Methodology

Research design

We used a low-inference qualitative descriptive design to provide a situated understanding of participants' life experiences using their naturalistic expressions. Low-inference refers to relying on verbatim accounts of what participants said and minimizing the extent to which

we as researchers reconstructed what the participants were sharing. We conducted semi-structured in-depth interviews with a purposive sample of older American Indians with T2DM. The tribe's institutional review board (IRB), tribe's health board, and tribal council approved this project. The Principal Investigator's academic home and the tribe signed an IRB authorization agreement, which permitted the academic institution to cede review to the tribal IRB.

Participants

We identified potential participants from the surviving Native Elder Care Study participants, which was conducted with the same tribe. The first author (RTG) was the Principal Investigator of the Native Elder Care Study, which adhered to community-based participatory research principles. For the Native Elder Care Study, data from 505 participants were collected between July 2006 and August 2008. To be included in the study, participants had to be enrolled tribal members, aged ≥ 55 years, noninstitutionalized, cognitively intact, and residing in the tribe's service area. More detail about the Native Elder Care Study's methodology is described elsewhere (Goins et al. 2011).

For our current study, eligibility included being an original participant in the Native Elder Care Study, residing in the tribe's service area, and having self-reported T2DM. With our existing computerized files of the Native Elder Care Study participants, we sent letters to those who had indicated that they had T2DM and who were still alive. We were able to link our participant information with information from public state death records to remove the names from our mailing list of those who had since passed away. The letter provided the study objectives and local telephone number of the Principal Investigator if the individual was interested in participating. Our first mailing was sent to 372 persons and a second mailing was sent 15 days later removing those who had already responded and those whose first letter could not be delivered ($n = 35$). A total of 47 interested participants responded to the letters by calling the Principal Investigator who confirmed their study eligibility; 28 ultimately participated. Of the 19 who did not participate, six did not have T2DM. Ten did not show to or canceled a scheduled interview or did not return calls. A married couple declined to participate because they wanted their interviews together, which was not part of the study protocol. Finally, an interview was scheduled with one participant but not conducted due to the interviewer's safety concerns.

Data collection

The study questions and design emerged from ongoing discussions with the project's Community Advisory Board (CAB), which was assembled based on the Principal Investigator's 18 years of experience conducting research with this particular tribe. The CAB consisted of four members who were selected because they were in key stakeholder positions at the tribe as it related to T2DM and/or health programs for older tribal members. All four members were American Indian with three who are enrolled members of the participating tribe. Two of the CAB members were practicing physicians at the tribe with expertise in T2DM and geriatrics. The other two members were licensed nurses who were lead administrators in the tribe's public health and hospital systems.

We collected data with semi-structured qualitative interviews using an interview guide. The guide was initially developed and piloted during summer 2015 with a convenience sample of six tribal members (4 women, 2 men) who were aged ≥ 60 years and had self-

Table 1. Interview guide.

1. How long have you had type 2 diabetes?
2. What do you think about having diabetes?
3. What is different between those who get diabetes and those who don't in the [tribe name removed]?
4. What do you think caused your diabetes?
5. How confident do you feel that you can successfully manage your diabetes on a scale from 1 to 10 with 1 representing no confidence and 10 representing the greatest confidence?
6. How do you manage your diabetes on a daily basis?
7. Overall, would you say that your diabetes is well-managed or poorly managed?
8. Can you share a time when you knew your diabetes was not as well managed as it could be?
9. What are the primary factors or reasons why you say your diabetes is well-managed/poorly managed?
10. Among those who have diabetes in the tribe, what do those people with well-managed/poorly managed diabetes do differently than you?
11. Who helps you with your diabetes?
12. What is the value in managing your diabetes well?
13. What are the consequences of not managing your diabetes well?
14. How do your feelings, such as feeling down, or tired, or out of energy, affect your ability to manage your diabetes?
15. What is it that you wish others understood about your diabetes?
16. Is there anything you need that you don't already have to better manage your diabetes?
17. Other than what the doctor has told you and what you have learned from experience, is there a [tribe name removed] way to deal with your diabetes?
18. In general, what are the factors that you believe that contribute to good diabetes control?
19. Are there any other thoughts you have about your diabetes and your ability manage it that you would like to share?

reported T2DM. The project's Principal Investigator conducted these piloted interviews accompanied by the project's graduate research assistant for training purposes. We revised the interview guide based on these pilot interviews and input provided by the study's CAB.

Our final interview guide which was used with the 28 eligible participants consisted of 19 main questions with probes (See Table 1). We determined participant's age and gender through the Native Elder Care Study data and current marital status was asked during the interview. We asked participants 'How confident do you feel that you can successfully manage your diabetes on a scale from 1 to 10 with 1 representing no confidence and 10 representing the greatest confidence?' We obtained study participants' most recent HbA1C laboratory results from the tribe's hospital. The HbA1C test reflects the average of a person's blood glucose levels over the past two to three months and is represented as a percent with $< 5.7\%$ considered normal, 5.7%–6.4% considered prediabetes, and $\geq$ 6.5% considered T2DM (American Diabetes Association 2018).

During fall 2015, twenty interviews were conducted by the project's Principal Investigator and eight interviews were conducted by the graduate research assistant trained for this study. Each interview was conducted in-person in a private location. Most interviews were conducted in the participant's home, one interview was conducted in the Principal Investigator's office, and the remaining interviews were conducted a room in a tribal building. Interviews lasted an average of 48 min. The interviews were digitally audio-recorded, and professionally transcribed. These transcriptions were audited by three of the study's investigators for completeness and accuracy. We received written informed consent and permission to obtain hospital laboratory HbA1c results from the participants who received $75 for their contribution.

Analyses

All individual transcripts, interviewer field notes, and team debriefing notes formed the data for analyses. A well-established mixed inductive, deductive, and reflexive analysis

(Jones et al. 2015; Thomas 2006) was conducted through team processes led by a senior PhD-prepared qualitative researcher. The analytic team consisted of five investigators with nursing, gerontology, public health, and geriatric perspectives and experience in community-based research. Triangulation of interpretations among this interdisciplinary team strengthened credibility of the analyses (Creswell 2013).

Data analyses commenced in summer 2015 and continued for 13 months. Transcripts were read individually by team members using a gestalt and then line-by-line approach to *in vivo* coding using participant language to answer the question: What is important in the day-to-day management of T2DM in this population? We explored what T2DM means to them and how they operationalized T2DM management in their daily lives. The team-based analytic process consisted of individually reading each transcript, coming together to discuss words, phrases, and text segments that characterized how participants talked about good T2DM management. Attention was paid to what was said, the context it was offered in, and the language used. Common ideas were grouped as codes and into themes.

An emergent coding schema was developed and an intra- and inter-interview theme analysis was conducted to identify emerging patterns. We used a low-inference interpretive approach to stay closer to description. Naming and meaning of themes were developed through iterative consensus discussions across the team and considered in the context of current understandings of T2DM in the literature. Developing analyses were presented to the study's CAB to test the potential transferability of the contextual interpretations. Investigator triangulation and an iterative design was used to ensure emergent findings were re-contextualized to check meanings in subsequent interviews. An audit trail of team discussions, theme development, and the refinement of the analytic framework was maintained through audio recordings and note taking. Data display strategies reflected the dynamic interplay of individual, community, and medical experiences related to T2DM. Analyses was continued until saturation was reached, concluding that no new information would be obtained by pursuing additional interviews. We obtained CAB input on the emerging results prior to finalizing.

Results

Table 2 presents characteristics of the 28 participants. The mean age was 73.0 ± 6.4 years with slightly more than half (57%, $n = 16$) were women and half (50%, $n = 14$) were married. The mean self-confidence score of successful management was 8.0 ± 1.7 with one participant who indicated that s/he did not know. The range of HbA1C values was 5.5% (36 mmol/mol) to 12.2% (110 mmol/mol) with a mean of 7.3% ± 1.5%.

The day-to-day experiences of T2DM for participants in this study provide a snapshot of beliefs, attitudes, and practices from one American Indian community. Participants talked about their T2DM management within five broad themes: 1) sociocultural factors, 2) causes and consequences, 3) cognitive and affective assessment, 4) diet and exercise, and 5) medical management. Each of the themes are defined and further discussed below. Table 3 provides exemplar quotes from our study participants for each of the themes. In this table, examples of sociocultural factors are indicated with an underline as they appeared within quotes that also represented the other themes, reflecting this theme's pervasive influence on the other themes.

Table 2. Participant characteristics.

	Range	Mean (SD)	% (n)
Age, $N = 28$	61–89	73.0 (6.4)	
Female, $N = 28$			57.1 (16)
Married, $N = 28$			50.0 (14)
Successful Management Self-Rating, $N = 27$	5–10	8.0 (1.7)	
HbA1C, $N = 26$	5.5%–12.2%	7.3% (1.5)	

Notes: SD = Standard Deviation. One participant did not provide a response to the successful management self-rating question and two participants did not have HbA1c laboratory values at the tribal hospital.

Sociocultural factors

Sociocultural influences were present for most of the participants. Sociocultural factors discussed with respect to T2DM management included elements of their Native culture, southern Appalachian culture, and socioeconomic status. Specific factors discussed included spirituality, traditional Native foods (e.g. Sochan, bean bread), southern Appalachian foods and foodways (e.g. sweet tea, cooking with fat back, fried food), the social aspect of food, historical trauma, the way things were done when they were younger, resistance to the medical establishment, traditional medicine, and financial circumstances related to food consumption.

Causes and consequences

Ways participants understood their T2DM were ascertained by asking directly and their indirect communication regarding what they thought caused their T2DM. Participants were asked what they believed were the consequences of both managing and not managing their T2DM well. The most frequently reported cause of the participants' T2DM diagnosis was hereditary, while many others indicated that diet alone, their body weight, or a combined lack of exercise and poor diet were the reason for their diagnosis. Some participants felt that getting T2DM was inevitable. Only a couple of participants discussed that their T2DM was due to both lifestyle factors and heredity. A more affluent lifestyle from when they were children and the affordability of fast food and other unhealthy foods were identified as pivotal to the causes of increases in T2DM prevalence in the community. Also, one participant reported that Agent Orange caused his T2DM and another participant reported that a steroid shot was the cause if his diagnosis.

With respect to consequences attributable to poor T2DM management, participants mentioned dying, going on dialysis, amputation, vision loss, loss of independence, and compromised mental health. Alternatively, effective T2DM management can result in feeling good, being able to spend time with family, and participating in activities. Improved management behaviors were often in response to the negative consequences if changes were not made.

Cognitive and affective assessment

Cognitive and affective assessment refers to the way participants intellectually and emotionally framed their relationship to the diagnosis, management of their condition, and its potential impact on significant others. As participants shared experiences and practices related to their T2DM, they discussed how their cognition and emotions affect their

Table 3. Themes and example quotations

Male	Female
Causes and Consequences	
I think it's hereditary. Most of my family's been – whether it's type 2 or the other one, type 1, they've all had it.	I always thought it was inherited … I blame my mom for it … No. I don't know what – I hadn't really thought of what caused it.
I'm not saying the food's bad out there, it's just – back when my folks were growing up, there were not additives to the food, no preservatives.	Well I think probably I really caused it by myself, of drinking too many soft drinks, too many Pepsis.
My eating habits, more or less, and cut out my exercise. See, I used the burn wood into my stove. I used to cut wood all the time. I worked outside, I mowed grass, but since I got about 70 or something, I guess I slowed down doing a lot of these things, and didn't exercise, and don't like I should.	And I figured it was in my family, so there was a chance that I was going to get it. But, I could keep my weight at even, keep it and eat right and exercise and I wouldn't get it. But, I knew there was always that chance there that I would get diabetes.
Affluence, more money, and more better jobs. Our success is killing us.	Probably not eating properly and I think it's hereditary because I have it on my dad's side and my mother's side.
Well, you start developing all kinds of, mostly developing kidney problems and high blood pressure. Your organs start going bad on you.	I feel bad. Like I want to sleep, sleep, sleep.
Death and suffering, and not being able to see your grandchildren marry and have other children, or become productive members of our society.	I could be like the people I see walking around with no limbs and blind and having somebody leading them around …
Some of them lose their limbs, legs, have a stroke, or have a heart attack. I've come close to them. Diabetes warns me about that stuff. If I don't take care of this, I might go to that side, and I don't want it.	I'd be piled up in the bed giving up and feeling depressed and down on myself and I wouldn't be very good company for anybody. I could be hateful..that would not be good.
Cognitive and Affective Assessment	
A lot of other people, sometimes they tell you how look good, or how you feel. Some people will just tell you, "You look good. Keep doing what you're doing." That gives you encouragement instead of being depressed about having that diabetes.	As far as that goes, I don't think – if I do feel that way, I don't let it take me over. I fight it off.
Being spiritually connected to Mother Nature allows me to be, to exist and to accept what's here.	If I'm going to be here for my family then I must. I must do it. I must take care of myself.
The only time I got depressed was first time I was proven wrong on that diabetes control. They said that that's going to be my lifetime disease, and I didn't like it, and so it stayed, let it come out, and I kept that anger inside of me.	So my routine for a long time, I'm not going to say it over this, but I go and talk to myself, I tell you. You're going to go out and tear up today. You're going to do this and you psych yourself up.
A strong will, education, dedication and I guess a mind set to do – it's a mind game in one of the ways I say – you've got to have a strong mind, a strong will power, and a strong dream with education. Without them you're going to fail miserably.	Well it sort of gives you the feeling like what's the use. You just want to give up and not try to do the right thing.
Diet and Exercise	
The amount of food we have in modern day eating is nothing compared to what their ancestors ate. They ate a handful of food, and we eat a bucketful.	I switched to the oil and for everything to season my greens and my beans. I just, too, I just eat smaller, instead of getting seconds, I eat one plate.
Well, I try to, like I said, try to stop from eating a lot of sugar and a lot of salt. I try to drink a lot of water.	Only that I don't fix a lot of greasy food anymore. I try to do a lot of baking the food, the chicken, the meat, grilling.
Mixed messages. We send out messages with our mouth but we don't act out the messages with our body about trying to live healthy. Every time they have a so-called Indian Dinner, it's fatback grease and bean bread and fried cabbage and fried potatoes in the fatback and all the things that our bodies used to tolerate but don't no longer. So we have mixed messages.	Just eating too much grease, wrong things. And they are always harping about eating the right things, and then they'll have all these Indian dinners served for benefits, and there's always the wrong type of food to eat.
I don't know that it's necessary if you've got a lot of yard work, gardening and all of that. I don't think you've got to get out here and kill yourself walking two or three miles a day. By the time you get through with all that, you're pretty well whipped.	Accept that you have it and accept that there's no cure, but there is steps and procedures to manage it. And that would include your lifestyle, whether it be native dancing or running track or going to the recreation center and combining both.

Table 3. Continued.

Male	Female
I get out every once in a while and walk around. Like I was telling you, I go and feed the guineas. That's exercise, you know, walking out there and back.	So, now in addition to walking, I'm doing those stretching exercises which really take time … I'd say probably maybe an hour to an hour and a half a day extra that I didn't do before.
Medical Management	
But it's a daily chore and a daily fight. It's either I'll take the pill or I'll take the shot and eat what I want to or take a shot and don't exercise. I've gained 25 pounds and take a shot and don't worry about it. That's a choice a person has got to make …	I do my foot exams every four or five weeks, and the doctor just whenever I need refills, or if I have a problem I'll call and I can go that day.
I'm not following the traditional way. Like I said, they got some herbs because I talked to the old elder. We talk about medicine. He said, "I know medicine. I know what to take, but I can't take it because the doctor says they're the doctors. I'm not the doctor."	… when I first became diabetic, the doctors were saying not to use Indian medicine.
I keep up with what the doctors tell me, how to take that insulin and how to take metformin. Keep that up and make my doctor's appointment.	I used to be so mad at the doctors. They would always call my dad non-compliant diabetic. Now I'm compliant, you know.
They started me on some medicine and everything, so I just started taking the medicine. I did what I was told to do. Ever since then I've been on a pill.	Oh, it's just, you just have to deal with it. I don't like having it, but it's here and I do my best to do what the doctors tell me to do. I take my medication regularly like I'm supposed to.

Note: Underlined text identifies quotes illustrative of sociocultural factors

ability to manage their condition. That is, some participants expressed a strong sense of self-awareness and ownership of their diagnosis. Others discussed psychological ways they framed their management in order to stay focused and motivated. A few male participants appeared to be disconnected from their diagnosis as they heavily relied on immediate family members such as a spouse for primary responsibility of routine T2DM management tasks. Other participants were either in denial or simply indifferent to their diagnosis. Expressions of tiredness, anger, anxiety, depression, and optimism were also heard. Last, many framed their T2DM diagnosis as beneficial in that it prompted them to take better care of their health and/or served as motivation to be healthy for their loved ones.

Diet and exercise

Both diet and exercise played a key role as all of the participants immediately discussed these two lifestyle components related to T2DM management. More in-depth discussions with our participants about lifestyle factors demonstrated a disproportionate focus on diet-related issues compared to exercise. The centrality of food in the community and the significance of food and gathering were evident. Food is more than sustenance as there was a notable social component to it both with their family members and with the larger community for specific events. There were discussions of diet changes (e.g. no salt, no sugar, less or no more soda, drinks more water, canola oil instead of lard, less carbohydrates) and portion control. Conversely, some participants expressed a resistance to diet recommendations from physicians and dieticians. There were concerns shared about limited healthy food choices in the community, higher costs of such foods, difficulty of grocery shopping in terms of reading labels, and determining best food choices.

Additional concerns were voiced about the seemingly mixed messages in the community between the importance of healthy diets for those with T2DM and the unhealthy food choices at community events.

With respect to exercise, everyone knew it was an expectation for good management, but some participants indicated they had not increased their level of exercise after their diagnosis. Many participants talked about incidental daily walking that occurred with other routine activities such as checking the mailbox, taking their dog out, and shopping at a local big box retailer. Other participants, however, actively engaged in routine exercise including walking, jogging, and stretching. Many reflected on the 'old ways' of getting physically active that included hard manual labor for the entire day and walking everywhere they needed to go. These old ways were described as a normal daily rhythm in the community when they were younger. For some, participation in any form of exercise was limited due to other health conditions such as osteoarthritis and chronic obstructive pulmonary disease.

Medical management

The theme coined 'medical management' captures a set of identified beneficial behaviors prescribed by western medicine. Participants discussed their experiences of 'doing what they are supposed to do' in terms of daily blood sugar checks, taking their prescribed medications, getting their feet checked, trimming their toe nails, routine doctor visits, and weight loss. Respondent's typical response to what they did on a daily basis to manage their T2DM encompassed these western medicine rituals that align with what was expected of them. Some participants kept a daily log of their blood sugar checks, which provided them useful management information. There was a propensity to place a value judgment on the number of prescribed medications the participants took and whether they had to give themselves a daily insulin shot. More intense medical management activities discussed included insulin shots, dialysis, kidney transplant, and gastric bypass surgery. Participants would gauge how well they were doing with their T2DM management by the degree of medical management they engaged in with greater adherence to medical management indicative of better management. Participants referred to their own extreme situations (e.g. hospitalization) and extreme situations observed in others (e.g. dialysis, amputation) as an indication of their management effectiveness. Overall, participants would segregate what they did with respect to what they were told by physicians, diabetes educators, and other health care professionals rather than thinking about all of these things in totality regarding their T2DM management. That is, our participants did not discuss what they did in direct response to what had been recommended to them by providers.

In addition to identifying the themes, we also examined how the themes collectively related to each other as depicted in the Figure 1. Conceptually, sociocultural factors appeared to influence the remaining four themes first through causes and consequences. Understanding and beliefs of T2DM causes and consequences, in turn, influenced how the participant's intellectually and emotionally framed or coped with their T2DM. Cognitive and affective strategies with respect to the participant's experience with their T2DM, would then affect their diet, exercise, and medical management behaviors. Diet and exercise were usually discussed together and the final theme, medical management, was

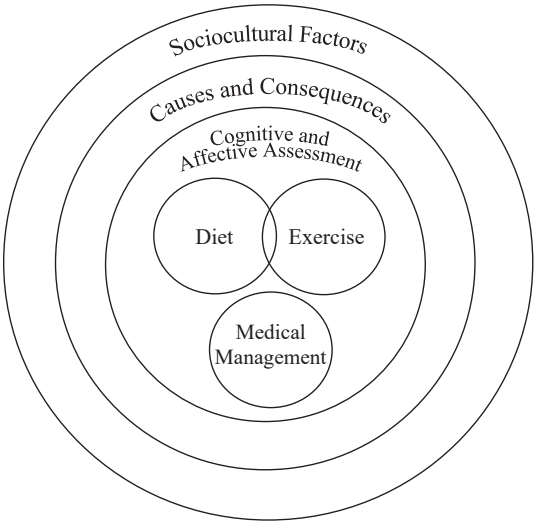

Figure 1. Conceptual diagram of how themes relate.

discussed exclusively from issues of diet and exercise. This disconnect between diet and exercise with medical management highlights the way in which T2DM can be constructed in this community as a problem of western disease. Participants viewed medical management as that, medical in nature, doing what 'they' tell you to do when you go to the clinic. Where diet and exercise were part of everyday living as natural occurrence if eating and moving at home.

Discussion

We used a low-inference qualitative descriptive design to provide an understanding of older American Indians' life experiences with T2DM management using their naturalistic expressions. Five themes – sociocultural factors, causes and consequences, cognitive and affective assessment, diet and exercise, and medical management – emerged from the interview data. We were able to gain insight into the participants' socially constructed reality of day-to-day experiences living with T2DM within this particular tribal community (Berger and Luckmann 1966; Creswell 2013). Further, a conceptual diagram emerged from our study as how the participants made sense of their T2DM and we were shown to the extent to which their T2DM was experienced in the popular, professional, and folk arenas (Kleinman, Eisenberg, and Good 1978).

Sociocultural factors inherently affect beliefs, attitudes, and/or practices that in turn affect participants' ability to consistently manage their condition. Community values and practices about coming together were intertwined with sharing food; yet traditional foods have been replaced with unhealthier substitutes since colonization, a phenomenon experienced across many indigenous cultures (Foley 2005; Kuhnlein and Receveur 1996). Sociocultural factors also can affect engagement in regular exercise. For example, prior research shows that more frequent traditional physical activities and traditional food use among Alaska Native communities is associated with greater self-identification with

their Alaska Native culture (Redwood et al. 2008). Some of our participants identified a direct link between less engagement in traditional American Indian culture and T2DM.

Beliefs about the causes and consequences of T2DM also shaped participants understanding and response to their condition. Earlier research found that Indigenous populations in the United States, Canada, and Australia attributed T2DM to factors such as not adhering to 'tradition,' thus resulting in an out-of-balance lifestyle (Garro 1995; Lang 1985, 1989; Thompson and Gifford 2000). More recent studies with American Indians found that lifestyle factors such as diet, lack of exercise, obesity, and genetics primarily constitute their understandings of causes of T2DM (Jacobs et al. 2014; Lautenschlager and Smith 2006; Newman et al. 2014). Lastly, fatalistic belief systems among Americans Indians have been identified in which T2DM is seen as an inevitable outcome for those with a family history and little could be done to slow its course (Cavanaugh et al. 2008; Taylor et al. 2004). Among our study participants, fatalistic beliefs with respect to causes and consequences was not a dominant theme.

A number of studies suggest that the third theme, cognitive and affective processes, act as mediators of behavior change and maintenance in T2DM management (Hampson, Glasgow, and Foster 1995; Wdowik et al. 2001). Another study that examined perceptions of T2DM among American Indians also identified 'affective response' in terms of their T2DM, which was predominately fear (Cavanaugh et al. 2008). Other prior research has also identified and reported on the emotional challenges (Shaw et al. 2013), fear, and apathy towards T2DM among American Indians (Jacobs et al. 2014). Overall, our participants did not speak about fear per se but rather how they used their T2DM diagnosis as a motivator to make necessary changes. We also heard apathy from some participants towards their T2DM diagnosis.

Diet and exercise was the fourth theme that emerged, which has been found in other qualitative research on American Indians' perceptions on T2DM (Lautenschlager and Smith 2006). We observed a connection between social participation and food at community events. At these events, there is a substantial amount of comfort foods known to improve mood and sense of well-being (Tryon, DeCant, and Laugero 2013). Our participants discussed a tension between the important community mechanism of social integration at such gatherings and effective T2DM management.

Regarding exercise, some study participants were committed to being active while others were not. Although the community has plenty of resources for exercising, encouraging structured physical activity is a fairly new concept to the older generation and uncommon among older American Indians (Coble and Rhodes 2006). Moreover, participants reflected that calories were normally expended in their youth through routine daily tasks, similar to findings from a study with Zuni tribal members (Newman et al. 2014). Discussion of the importance of physical activity being integrated into daily routine activities is similar to what was found as a result of the National Geographic 'Blue Zones' project for communities where this was commonplace tended to have healthier residents (Buettner 2015).

Study participants were well-versed in standard recommended medical management practices. It was insightful to discover that among our participants there was not a connection between diet and exercise with medical management. Older American Indians who align closely with their Native culture have been found to have a lack of trust of the medical establishment, reluctance to seek formal care, and less likely to follow a prescribed

T2DM regimen (Henderson 2010). Yet, in our study, only a few of the participants expressed resistance to the medical establishment and/or prescribed management behaviors.

Our theoretical frameworks help guide interpretation of these themes and the implications for future work. Social constructivism helps to understand that participant realities are interpreted through past experiences, language and community norms. Our participants often judged what they did or how they managed their T2DM in terms of others around them and how these others conformed to medical management expectations. The messaging about T2DM control and having good numbers is an appropriate medical benchmark but has not fully translated into American Indian community norms and values about the relationship between food access and practices. Similarly, individuals create conceptual models to make sense of illness which are influenced by the cultural systems operating in the community living context. Our study illustrates that there are cultural systems evident in a single American Indian community that seem to be functioning in isolation of one another: traditional and western meanings of health. T2DM is generally viewed as a disease of western practices not a disease consequence of diet and exercise norms existing in an American Indian community today. T2DM remains a construction of professional formal health care rather than an illness that can be influenced by the popular arena of family and community.

There are several study limitations that warrant acknowledgement. Although this study was motivated by an interest in T2DM among older American Indians, the data make it difficult to distinguish between specific American Indian sociocultural influences from other various sociocultural factors at play in the participants' life including, southern Appalachian and socioeconomic influences. Given the diversity across American Indian communities with respect to culture, language, and beliefs, future research is needed with other American Indian tribes in similar and other geographic regions. Also, these data were only collected at a single interview. It is possible that if more than one interview per participant was conducted, greater rapport would have been established potentially yielding more information regarding attitudes, beliefs, and practices. Although member checking was not conducted with the study participants, the transferability of these findings was enhanced by the context validation received through the input of the CAB.

In spite of these limitations, our study has several strengths we would like to highlight. First, due to the lack of published research on the same topic, our study will improve understandings of the participants' explanatory models of T2DM diagnoses and management. Our results captured the role of beliefs, attitudes, and both cultural and medical practices within the whole scope of T2DM management in a population that experiences the highest rates of T2DM. Our results also illustrate the role of cognitive and affective processes in T2DM management in this population. In contrast to past characterizations of T2DM beliefs as being fatalistic (e.g. Cavanaugh et al. 2008; Taylor et al. 2004), we did not find fatalism to be an overly dominant mindset among the participants. We also identified the perceived paradox of cultural traditions for social integration and the offering of unhealthy foods at community events.

Our study results can also be beneficial with respect to identifying opportunities to translate findings into local practice and/or policy or for other communities seeking to

improve T2DM outcomes for its residents. For instance, given that some of the participants discussed having caregivers involved in their day-to-day management speaks to the importance of involving these caregivers in the overall T2DM care plan. Providers need to determine who is taking the lead in the day-to-day T2DM management activities of their patients. If a caregiver is taking the lead in the patient's T2DM management and they are not at the medical appointments, this can negatively impact the patient's ability to follow a management plan. Our participants' comments regarding the higher costs of healthy foods may justify the expansion of existing tribal efforts. Currently, the tribe has a 'Grow a Row' program that provides fresh fruits and vegetables to tribal members from local gardens to those who cannot afford them. Lastly, health care providers are in a unique position of firsthand knowledge and authority where they can serve as impactful advocates for policy changes at the tribe. It has been suggested that health care providers can champion for their local community to undertake a health impact assessment to identify how the built and food environments can be improved in the community (Gary-Webb et al. 2014).

To ensure effective health promotion and clinical efforts, it is important to take into account these socially and culturally constructed aspects of how T2DM is experienced and their respective influence on T2DM management. Research on lay understandings of health can uncover motivations for engaging in healthy behaviors and seeking treatment, which can be useful for educators, other practitioners, and program staff. This improved insight can ensure that efforts are in tune with patients' realities. Information generated from our study can be particularly helpful for diabetes educators with little or no experience working with American Indians. The 'one-size-fits-all' approach to health care and health promotion does not work when health beliefs, attitudes, and practices are constructed both at the individual and community levels. With the goal to support people's need for T2DM management, recognition of lay beliefs and their influence on health-related behaviors is essential.

Note

1. Indian Health Service is the federal agency responsible for providing health services to American Indians and Alaska Natives who are enrolled members of a federally-recognized tribal tribe or tribal entity.

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