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Challenges to Managing Diabetes Among American Indians: Preliminary Findings From a Focus Group Study

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Purpose:

American Indians (AI) have the highest incidence rate of type 2 diabetes (T2D) diagnosis compared to other racial/ethnic minorities in the United States, which has subsequently led to a disproportionate burden of diabetes complications in the population. The genetic, cultural, and shared environmental factors surrounding T2D have often resulted in it being deemed a family disease. The presence of multigenerational and culturally competent interventions that have been constructed and put into practice are sparse, and the content and format likely to be helpful for the AI families unknown. The purpose of this study was to systematically interact with rural AI communities to gain a better understanding of the diabetes-related practices, needs, and challenges of AIs with T2D and their families, and the characteristics of interventions they would find most relevant and beneficial.

Method:

A total of 7 focus groups were conducted in Florida and with an AI tribe in rural Oklahoma. Focus groups were held in local community centers convenient for most participants. A semi-structured interview guide with open-ended questions was used to acquire data from focus groups ranging from 3 to 13 AI participants with T2D. Participants were referred by staff from HealthStreet, a community engagement program, Consent2Share mechanism, and by tribal diabetes educators. Using a script, we screened participants prior to the focus group to determine study eligibility, which included the participants being: a) self-identified as American Indian; b) told by a health care provider they have T2D; c) 18 years of age or older; d) able to speak and read English; and e) willing to speak about their diabetes in a group setting. The University of Florida IRB and the Tribal IRB approved all procedures.

All focus groups were audio recorded and transcribed verbatim. Descriptive statistics were used to summarize demographic data. A research team member checked the transcripts for accuracy. Then, three independent research team members compared themes and discussed discrepancies found in themes until consensus was reached. Field notes recorded by the first author were also reviewed to support identified themes.

Findings:

There was a total of 62 participants, 77% were female, with a mean age of 55.3 (SD 11.4) years and the mean duration of diabetes diagnosis was 10.4 (SD 9.1) years. Most participants had healthcare coverage (64%) and received their care from Indian Health Services (68%). Participants reported that in addition to T2D, they had at least one other chronic health condition (40%) or two or more chronic health conditions (32%). In all, 71% of the participants had either a GED, high school diploma, or vocational school. Participants also reported on whether they were financially comfortable (39%), just making ends meet (46%), or unable to make ends meet (15%).

Preliminary findings revealed themes centered around identifying intervention components, the impact of family behaviors on T2D-PM, barriers to T2D-PM, and personal experiences with T2D.
Participants provided feedback on intervention components, noting the preference that monthly sessions be between thirty minutes and two hours. Other focus group participants urged the use of weekly communication and check-ins using mobile devices, in addition to the monthly meetings, stating it would serve as additional support and encouragement. A number of focus group participants expressed a desire for an intervention that included family members because of their concern that family members did not understand the seriousness of T2D and its impact on those who have T2D.

Participants also shared other topics they felt were important to include in the intervention. Many of the topics were directed to family members including educating the family on healthy food choices and struggles of living with T2D including diabetes related complications. Participants also were concerned with alerting family members on how to be supportive. Lastly, participants offered creative ideas for hands on activities they would enjoy and find beneficial as part of the intervention. Participants wanted to “learn as a family” and suggested family type activities such as learning to cook a healthy meal together, friendly competitions to encourage eating healthy, physical activity, and losing weight. Other groups suggested specific physical activities such as chair volleyball, family-oriented games/activities, and traditional dancing.

Another theme identified the impact family support had on preventing and managing T2D. Supportive behaviors were seen as actions such as the entire family eating similar foods as the person with diabetes, keeping healthy foods in the house, and expressing concern for the person living with diabetes without ‘nagging’ or criticizing. Non-supportive behaviors were identified as eating unhealthy foods in front of individuals with T2D, having unhealthy foods in the home and ‘nagging’ the person with T2D on what they should not eat.

Focus group participants also discussed challenges around T2D-PM. Themes emerged around barriers related to medication adherence, healthy eating, and physical activity. Participants discussed three common barriers to medication management which included forgetting to take medication, feeling lazy, and medication side effects. Several groups mentioned barriers to healthy eating practices including limited income, limited access to fresh produce, the low cost and ease of purchasing fast food versus cooking healthy meals, and the lack of healthy food choices at events. Barriers to physical activity included lack of time/motivation, no one to exercise with/lack of support, health concerns, and putting one’s self-last. Overall, most participants acknowledged that lack of time and motivation were major barriers.

The fourth theme identified was the personal experiences of living with T2D. Responses from the participants yielded a spectrum of emotions they felt when first diagnosed with T2D. These emotions ranged from panic, fear, and depression, as well as feelings of self-blame due to failure to take action when first diagnosed with pre-diabetes.

Discussion:

Findings of the AI community’s insights and including the entire family in intervention development may offer a way to improve T2D-PM outcomes for this population. Themes identified in this study will guide development of interventions that are culturally sensitive and tailored to the individual and family. Findings indicate the need for a diabetes program that includes participants’ family members, in contrast to current interventions that mainly focus on the person with diabetes. . In the AI culture, family including extended family, often live together and support and care for each other. Future interventions should not only include family members but should also measure behavioral and biological outcomes for both the person with diabetes and their family members at risk for T2D. A multi-generational T2D-PM intervention may be an effective way to decrease the burden of diabetes diagnosis in this minority population.

Title:
Challenges to Managing Diabetes Among American Indians: Preliminary Findings From a Focus Group Study

Keywords:
American Indian, Family and Type 2 Diabetes

References:


Abstract Summary:
The immense disparity in the rates of Type 2 Diabetes (T2D) related complications among the American Indian (AI) population, has been connected to the unsuccessful management of T2D. Need for family
involvement and multigenerational participation are major factors in effective control and prevention of T2D in AI adults and youth.

Content Outline:

1. **Type 2 Diabetes (T2D) Disparity.**
   1. American Indians (AI) have the highest rates of diabetes compared to other racial/ethnic minorities in the United States.
   2. AIs also experience a disproportionate burden of diabetes-related complications.

2. **Management/Prevention of T2D.**
   1. Education on topics of healthy eating, exercising, and diabetes related complications found important.
   2. Intervention development centered on family and community support, and incorporation of weekly communication.

3. **American Indians and Family**
   1. Impact of family behavior, categorized as supportive and non-supportive behavior.
   2. Expression of desire for an intervention to include family members because of their concern that family members did not understand seriousness of T2D and its impact on those who have T2D.

First Primary Presenting Author

**Primary Presenting Author**
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**Professional Experience:** 2017-Present: Assistant Researcher in Exploration of Type 2 Diabetes Management and Prevention in Native Americans, as well as assisting in developing intervention for the project assisting in.

**Author Summary:** Is a senior student nurse at the University of Florida College of Nursing, and plans on attending graduate school to pursue a Ph.D in Nursing. She is currently assisting in research focusing on developing a culturally tailored multi-generational interventions for Native American living with type 2 diabetes.

Second Author
Lisa Scarton, PhD, RN
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**Professional Experience:** Dr. Lisa Scarton, a tribal member of Choctaw Nation of Oklahoma, is an assistant professor at the University of Florida (UF), College of Nursing. A Jonas Nurse Leader Scholar, she received her PhD from Indiana University in Indianapolis and completed her post-doctoral position at the UF College of Nursing. Her research focuses on family interventions for American Indians with type 2 diabetes (T2D). Her research with family caregivers of persons with T2D has underscored the importance the entire family plays in diabetes management and, in turn, has broadened her focus to include the entire family. She has disseminated her work in both nursing and diabetes focused journals as well as through presentations at local, regional, and national conferences. As well as led an initiative at the University of Florida’s Diabetes Institute that built collaborative relationships with key stakeholders and
explored ways to reduce diabetes health disparities in American Indian communities.

**Author Summary:** Dr. Lisa Scarton, a tribal member of Choctaw Nation of Oklahoma, is an assistant professor at the University of Florida (UF), College of Nursing. Her research focuses on family interventions for American Indians with type 2 diabetes (T2D).

Third Author
LaToya O'Neal, PhD
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**Professional Experience:** Dr. LaToya J. O'Neal is an Assistant Professor and Extension Health & Wellness Specialist in the Department of Family, Youth and Community Sciences at the University of Florida/Institute of Food and Agricultural Sciences. She is a trained medical sociologist with extensive experience in school and community-based interventions aimed at reducing inequality. Dr. O'Neal, has worked with African American women participating in community-initiated diabetes education program, and her current research focuses on reducing obesity-related chronic disease disparities among health vulnerable populations.

**Author Summary:** Dr. LaToya J. O'Neal is an Assistant Professor and Extension Health & Wellness Specialist in the Department of Family, Youth and Community Sciences at the University of Florida/Institute of Food and Agricultural Sciences. She is a trained medical sociologist with extensive experience in school and community-based interventions aimed at reducing inequality.

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**Professional Experience:** Dr. Diana Wilkie, a member of the Institute of Medicine, has devoted her research program to management of cancer pain and to end-of-life issues, as well as intervention development for individuals living with chronic illnesses. She has been continuously funded since 1986 from numerous organizations such as the National Institutes of Health, the National Cancer Institute and the Robert Wood Johnson Foundation — totaling more than $37 million.

**Author Summary:** Dr. Diana Wilkie, a member of the Institute of Medicine, has devoted her research program to management of cancer pain and to end-of-life issues, as well as intervention development for individuals living with chronic illnesses. She has been continuously funded since 1986 from numerous organizations such as the National Institutes of Health, the National Cancer Institute and the Robert Wood Johnson Foundation.

**Any relevant financial relationships? Yes**

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Signed on 06/05/2018 by **Diana Wilkie**