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Developing a culturally tailored multi-generational intervention to prevent and manage type 2 diabetes in American Indian families living in rural settings: findings from a focus group study.

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Abstract

The study purpose was to understand the characteristics of interventions that would be most relevant and beneficial to address the diabetes-related needs and challenges of rural American Indians/Alaska Natives (AIAN) with T2D and their families. In an exploratory study design, we held a total of seven focus groups in Florida and rural Oklahoma. Groups included 3–13 individuals (62 total, 77% were female, mean age 55.3 (11.4) years and mean duration of diabetes 10.4 (SD 9.1) years) who were referred by staff from HealthStreet, Consent2Share mechanism, and by tribal educators. All groups were moderated by the same American Indian research team member using a discussion guide with open-ended questions, followed by probes. Findings revealed themes centered on optimal intervention components, barriers to type 2 diabetes-prevention and management (T2D-PM), personal experiences with T2D, and impact of family

behaviors on T2D-PM. Findings indicate that the participants desire diabetes programs that include family members and a hands-on, culturally meaningful approach. Creating an intervention based on the AIAN community's insights that include the entire family may improve T2D-PM outcomes for this population.

Keywords

American Indian; Type 2 Diabetes; Prevention; Management; Intervention; Family; Multi-generational

The American Indian/Alaska Native (AIAN) population experiences the highest prevalence of type 2 diabetes (T2D) and has a disproportionate burden of diabetes complications compared to any other racial or ethnic group (ADA, 2017). AIAN youth with T2D experience diabetes related complications earlier in the course of their disease and require the use of insulin three times sooner than adults, highlighting the critical need to prevent T2D in this group (Dart et al., 2014; Nam, Janson, Stotts, Chesla, & Kroon, 2012). Due to genetic, cultural, and shared environmental factors (e.g., physical activity, dietary intake), T2D is often considered a family disease.

AIANs are comprised of 573 federally (Bureau of Indian Affairs, 2018) and more than 67 state recognized tribes (Salazar, 2016) each with its own culture, language, and traditions. These tribes are located in rural and urban areas and experience significant health and economic challenges. AIANs experience more than double the rates of poverty compared to the general population and many AIANs experience geographic isolation, cultural barriers, and discrimination (Sarche & Spicer, 2008). Disparities in health outcomes relevant to diabetes management and prevention have significant implications for the health and well-being of the AIAN population. It is essential to recognize tribal diversity by designing interventions that are culturally informed and built on the strengths and needs of the AIAN communities.

Culturally targeted interventions are more likely to reduce Hemoglobin A1C (HbA1c) in ethnic minority populations with T2D than care strategies that do not incorporate cultural nuances (Lagisetty et al., 2017; Nam et al., 2012). Further, culturally targeted interventions offer an opportunity to ground T2D-PM interventions in not only specific tribal history, values, and beliefs important to the AIAN community but also in health priority areas most relevant to the community. Although tribal cultures, values, and beliefs differ among tribes, certain cultural aspects cut across many tribes. One such example is the importance of family and extended family, which goes beyond blood relatives. These close multi-generational relationships provide opportunities for elders to share traditions and life lessons with family members, including positive health behaviors. Additionally, there is a sense of interdependence among family members, which can be a strength when managing and preventing a chronic illness such as T2D. However, many interventions focus only on patient outcomes or are viewed within the context of supportive behaviors for the person with T2D (Armour, Norris, Jack, Zhang, & Fisher, 2005; Baig, Benitez, Quinn, & Burnet, 2015). An essential step in developing and implementing an effective and useful multi-generational intervention is community input. It is imperative that we actively engage and listen to

community members to drive the focus of the research to ensure it is relevant and meaningful (Jernigan, 2010; Minkler, Blackwell, Thompson, & Tamir, 2003). Unfortunately, few culturally tailored multi-generational T2D prevention and management (T2D-PM) interventions have been developed or tested in the AIAN population. The purpose of this study was to systematically interact with rural AIAN communities to understand the characteristics of interventions that would be most relevant and beneficial to address the diabetes-related needs and challenges of AIANs with T2D and their families.

Methods

In an exploratory study design, we conducted one focus group in Florida and six focus groups in rural Oklahoma. The residents of the rural communities in Oklahoma were predominantly from one Southeastern American Indian tribe. During fall 2017, focus groups were held in local community centers convenient for most participants. Although the literature recommends that focus groups include between six and ten participants (Murray, 1997), our focus groups ranged between 3–13 due to participants changing from their original group or bringing additional eligible family/friends. 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. Inclusion criteria included individuals who: a) self-identified as American Indian; b) were told by a health care provider that they have T2D; c) were 18 years of age or older; d) speak and read English; and e) were willing to speak about their diabetes in a group setting. The University of Florida IRB and the Tribal IRB approved all procedures.

Prior to the start of the focus group, we provided each participant with an informed consent form that described the aims of the focus group and their rights as a participant. After they signed the consent form, we asked participants to complete a demographic questionnaire. Focus group sessions lasted 60–90 minutes and all sessions were audio recorded. To provide consistency, all seven focus groups were moderated by the same American Indian research team member using a focus group discussion guide with open-ended questions, followed by probes. The research team, with guidance from tribal diabetes educators, developed the guide (Table 2). Since the focus groups were held around breakfast or lunch times, we provided participants with a meal prior to the focus group. Additionally, each participant received a \$30 gift card and was entered into a door prize drawing.

Descriptive statistics were used to summarize demographic data and content analysis was used to analyze the data. We had the audiotapes of the focus groups professionally transcribed verbatim and a research team member checked the transcripts for accuracy. Data analysis included reading each focus group transcript for initial descriptions of the content. The lead author conducted the initial analysis and identified potential themes in the de-identified data. A matrix was created that summarized the content by focus group and topical area. Themes and subthemes were developed from reviewing and synthesizing responses from the focus groups. Field notes recorded by the first author were also reviewed to support identified themes. Three independent research team members compared themes and discussed discrepancies in themes until consensus was reached. We determined that

saturation had been reached by the seventh focus group and, therefore, did not conduct any additional focus groups. Consistent with focus group research, the analysis was completed at the level of the focus group rather than the level of the individual participant (Hughes & DuMont, 1993).

Results

We conducted seven focus group discussions (n=7) with a total of 62 AIAN participants. Demographic characteristics are detailed in Table 1. Mean age of participants was 55.3 (SD 11.4) years and the mean duration of diabetes diagnosis was 10.4 (SD 9.1) years. In all, 77% of participants were female and 71% had a GED, high school diploma, or vocational school diploma. Participants reported being financially comfortable (39%), just making ends meet (46%), and unable to make ends meet (15%). 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%).

Four main themes emerged that were related to aspects of an intervention that would help AIAN with their diabetes-related needs and challenges. The themes centered around intervention components, barriers to T2D-PM, sharing personal experiences as examples to inform interventions, and the impact of family behaviors on T2D-PM.

Intervention Components

In the focus groups, there was discussion about aspects of interventions to help manage T2D. Four sub-themes emerged about interventions: optimal intervention dose, who to include in the intervention, topics for intervention, and activities for intervention.

Optimal intervention dose.—Understanding what focus group participants consider an optimal dose for behavioral interventions is an important step in designing an intervention. When we asked participants the ideal duration for an intervention, only one group had a response and they agreed, “You want to have that support going and feel like you’re part of something...it needs to be a long-term thing [program].” In contrast, more conversation was generated and consensus was reached regarding frequency of the intervention. All but one focus group agreed that the frequency of the intervention should be monthly, stating they would be “willing to commit to a monthly program.” Participants suggested that the length of the sessions should range between thirty minutes and two hours per session. Several of the focus groups (4/7) urged us to consider offering weekly communications and check-ins using mobile devices, in addition to monthly meetings, as a way to provide added support and encouragement. One group suggested, “[we can receive] some tidbits, like every day some information about diabetes” while another group thought it would be beneficial for someone to text participants to say, “Hey, just checkin’ to see how you are doin’ today.”

Who to include in the intervention.—Most of the focus groups (6/7) expressed a desire to have a T2D-PM intervention that included family members. Reasons varied, with many focus groups (5/7) expressing concern that family members did not understand the seriousness of T2D and the impact it could have on their lives. One group said, “[educate]

the grandkids or kids, [so] your kids won't grow up, and end up with diabetes". Another group expressed the importance of including family members in the intervention by saying, "a family program is good so they [kids] can learn why pop and sweets are not good for them or us." Additionally, groups (4/7) were interested in a program design that included hands-on activities as well as face-to-face learning opportunities for both the person with T2D as well as family members.

Topics for the intervention.—Focus group participants had several topics that they felt were important to include in the intervention. These topics focused on the needs of all family members, children, and those with T2D. Some groups thought it was essential for family members, including children, to learn about healthy food choices (4/7), struggles of living with T2D including diabetes related complications (5/7), and ways to be supportive (2/7). One participant said, "Nowadays kids just [go through] drive-throughs and eat all that fatty food." Another person said, "[family members] have no idea of what we go through." Additionally, participants believed their children did not fully understand the degree of heritability of T2D (2/7) and therefore wanted to help them understand the importance of physical activity (3/7) to prevent and manage T2D stating, "We want to make sure our children don't develop type 2 diabetes." Participants also wanted information that would expand their own knowledge on healthy food choices (5/7) and help them better understand how to read food labels (2/7). Participants spoke about learning how to cook "traditional, Native foods or just foods in general without the fats and grease and learn other seasonings you can use instead of salt."

Activities for the intervention.—Lastly, the focus groups generated creative ideas for activities they would like to see as part of the intervention and that they felt families would find beneficial in preventing and managing T2D. Several of the focus groups (4/7) were interested in having cooking demonstrations where they could "bring [kids] in with you so they could learn how to cook." Groups discussed the importance of learning, as a family, how to cook healthy meals and wanted to have an opportunity to prepare the meal together after the demonstration. Several groups (3/7) were interested in having friendly competitions to encourage eating healthy, physical activity, and losing weight. Other groups suggested specific physical activities including chair volleyball (3/7), family-oriented games/activities (3/7), and traditional Native dancing (2/7). One group said since it is "family-oriented, we could bring our children and they'd get a kick out of watchin' the older people [play chair volleyball]." Another group said one form of physical activity families might enjoy is "fancy dances [where] they do fancy dance steps with exercise moves and they have girls and guys that'll do them.... they'll incorporate that to try to help people [learn] how to incorporate their dancing with exercise."

Barriers to T2D prevention/management

In the focus groups there was discussion of areas of need for interventions that support dealing with the challenges with managing T2D. Three sub-themes emerged around barriers to T2D prevention and management: medication taking, healthy eating, and physical activity.

Medication taking.—There were three common barriers noted in the focus groups related to medication taking: forgetting to take medication (4/7), feeling lazy (2/7), and medication side effects (2/7). In one focus group, a participant said,

I've been insulin dependent for probably about 6 years, so it should be a habit, I should be used to it you know, it should be a part of my life, but it's difficult [to remember].

In another focus group, a participant summed up the feelings of others, saying, "Sometimes you just get lazy about it" while another comment was, "I'm takin' insulin, and... there's days I don't feel like takin' [it]." Others described concerns related to medication side effects. In one focus group a participant said, "I don't take any pills or anything, 'cause they don't agree with me."

Healthy eating.—Most of the focus groups had extended conversations related to needing support to overcome barriers to healthy eating practices. For example, limited income was discussed in six out of seven focus groups as an important barrier to buying healthy foods. In one focus group, a participant said,

If you're on a limited income, especially if you're elderly you're trying to live on Social Security that is a huge issue. The foods that would help you try to control your blood sugar is gonna cost you more at the store.

In some focus groups, the participants had multiple generations living at home, which added additional concerns related to limited income.

I'm in the position where I have three of my grown boys living with me and grandchildren and trying to make it on one budget. Sometimes you cannot buy the foods that you need to buy. I mean you have to buy the cheapest stuff, and sometimes that's not the best.

Other barriers to healthy eating practices that were discussed included limited access to fresh produce (5/7), the low cost and ease of purchasing fast food versus cooking healthy meals (3/7), and the lack of healthy food choices at events (4/7). In the focus groups there was discussion of the lack of local stores that sold fresh produce due to the remoteness of where they live. One comment was, "Walmart has some food [fresh produce] in it. But it's a limited supply and anything that is more healthy for you is more expensive." Other comments were, "We really don't have any fresh produce stands," which often required them to travel outside their area to find larger stores or that it was easier and cheaper to buy fast food instead of cooking healthy meals. In one group, a participant said, "It's easier to, instead of making your dinner...drive down the road to Whataburger and get a burger and fries." Another said, "It takes longer to cook the right foods... I could do this for X amount of dollars, but if I fixed it this way, it's gonna cost a little bit more." Still others noted that attending different events made eating healthy difficult, saying, "We go to ballgames...it's hard to find the food that you need...Nachos and things like that is all they have at the ballgames...and you eat because you get hungry if you don't."

Physical activity.—In the focus groups, participants discussed their desire for the intervention to address ways to overcome barriers to physical activity including: lack of

time/motivation (5/7), no one to exercise with/lack of support (4/7), health concerns (6/7); and putting one's self last (3/7). Almost all participants in the seven focus groups acknowledged that lack of time and motivation was a major barrier. Many participants reported exercising alone and lack of support as barriers. One participant explained, "My family lives 3 hours and 4 hours away from me...it's hard...you don't have anybody to walk with." Another person said, "I need somebody there encouraging me...to go walking or go exercise...I am not very good about doing it on my own...that little bit of encouragement from somebody else helps." In six out of seven focus groups, the participants reported additional chronic health conditions and physical discomfort (i.e., arthritis, knee replacement, back pain) as barriers to physical activity. Several participants agreed with this comment by a participant, "I had double knee replacement...so I'm [limited] to what I can do as far as exercising." Another participant stated, "My feet has gotten so bad now I can't stand on 'em. I can't walk long periods [neuropathy]." Lastly, participants discussed "feeling guilty" doing things for themselves instead of their family. Although it is common for individuals, especially women, to care for others before themselves it can be detrimental in their ability to prevent or manage T2D. In one focus group, a participant said,

Got a lotta responsibility and you feel guilty for takin' that good dab of time that you need to apply to yourself... a lotta women, feel guilty for the time they take for themselves even if it's their health...they feel like if they are doin' somethin' even sometimes goin' for a walk... that energy should be put out to everybody else...

Sharing personal experiences as examples to inform interventions

The need for an intervention to include time to share personal experiences of being diagnosed and living with T2D was discussed during all seven focus groups. Participants expressed the desire to meet with others who shared similar experiences "...each one of us can say somethin', and you can say, 'Hey, I can relate to that.'" Participants also discussed the importance of having support when first diagnosed with T2D. One participant described her experience of learning she had T2D, "When I first found out I was diabetic, I just panicked... And I think it's the end of the world..." Another participant said, "When I first got diagnosed, I was in tears cuz it scared me." Most focus group participants felt this time of sharing together would help them to prepare for the coming challenges. Participants discussed the importance of "realiz[ing] people are feeling the same way that you do." Other participants discussed wanting to have fellowship with people who could understand and relate to the daily struggles of living with diabetes. One participant expressed the need to be in a group where people ask, "Are you doing good today?" The participant stated, "Sometimes you just need that little pat on the back and say, you know, 'I care about what happens to you, take care of yourself'."

Impact of family behavior on T2D prevention/management

Family interactions and behaviors were an important focus area for T2D interventions. All seven focus groups described both supportive and non-supportive family behaviors. Participants stressed the need to educate family members on how to be supportive. Five of the seven focus groups described supportive behaviors as when "family eats similar food as person with diabetes" and "when family members cook things we can eat when there is a

family gathering.” Keeping healthy foods in the house (3/7) was also described as supportive. One participant stated her husband stopped bringing unhealthy food home, “He don’t buy that stuff no more. He keeps it outta the cabinets for me.” Lastly, four of the seven focus groups described family members showing concern for their wellbeing without nagging or criticizing as supportive.

I don’t...[want family] pointing...saying, ‘take your medicine’... I just want them to show concern. Every now and then say, ‘how was your sugar?’ are you doing okay?’ I know we can’t make them say that but— we need that simple encouragement.

Focus groups also described interactions with family members that they considered non-supportive, such as eating unhealthy foods in front of them (4/7). One participant described how difficult it was when her kids and grandkids moved into her home,

They moved in [kids/grandkids] and all you smell is pizza rolls, tater tots, everything is frozen, popped in the oven and it brings back all those smells...their cooking is totally different from mine and it’s really really hard.

Another participant expressed frustration stating, “I think they [family] can make it worse ... They’ll go buy Little Debbie cakes, fruits, and all kinds of sweets. That’s not helpful.” Additionally, several of the focus groups (4/7) described non-supportive interactions when family members nag that “you gotta eat” or “you shouldn’t eat that.” Participants discussed they “don’t like to be told ‘you can’t eat that’ [it’s] more helpful to discuss what you can eat.”

Discussion

The study purpose was to understand the characteristics of interventions that would be most relevant and beneficial to address the diabetes-related needs and challenges of AIANs with T2D and their families. The findings from the focus groups provide essential information needed to develop a culturally targeted multi-generational intervention focused on AIANs with T2D and their families.

Family Intervention

Most participants expressed a desire to be involved in a diabetes program that included their family members. T2D family interventions are an underutilized approach that have been found to improve diabetes-related knowledge and HbA1c and to have a positive effect on dietary and physical activity behaviors in persons with T2D (Armour et al., 2005; Baig et al., 2015; Kovacs Burns et al., 2013; Pamungkas, Chamroonsawasdi, & Vatanasomboon, 2017; Scarton & de Groot, 2017). However, we know little about the impact of these interventions on family members. Baig and colleagues conducted a systematic review examining family-based diabetes interventions and found that of the 26 studies only nine measured family outcomes. Of the few studies that measured family outcomes, improvements in BMI, diabetes knowledge, diet, and physical activity behaviors were observed (Baig et al., 2015). It is also important to note only two of the 26 T2D family intervention studies were conducted in AIAN communities. Gilliland and colleagues (2002) conducted a community-

based study to examine the effects of a culturally tailored family intervention on self-care behaviors and A1c in 104 AIs with T2D living in New Mexico. In the study, the investigators compared a friends and family intervention group with an individual support control group. Participants in the friends and family group had less of a rise in their HbA1c level than those in the usual care group at the 1-year follow-up. Mendenhall and colleagues (2010) conducted study using a community based participatory research design with a Midwestern urban AI community. Patients with T2D (n=36), their family members, and providers met every other week for six months. Findings revealed a reduction in blood pressure (systolic $p=0.013$; diastolic $p=0.003$) and an improvement in HbA1c from baseline to 3-month follow-up ($p=0.002$). There was no change in weight from baseline to the 3-month follow up; however, at the 6 month follow up there was a significant improvement in weight loss ($p=0.012$). Participants in our focus groups were adamant that the way to manage and prevent diabetes in their community was to involve multiple family members. Future interventions should not only include family members but should also measure behavioral and biological outcomes for both the person with diabetes and his or her family members.

Barriers to T2D Intervention

Interventions need to focus on removing barriers around T2D prevention and management including medication taking, healthy eating, and physical activity. Medication taking plays an important role in diabetes management and is important in achieving positive diabetes outcomes; however, medication taking continues to be a challenge for those managing T2D and can lead to deleterious outcomes (Polonsky & Henry, 2016). Like other studies, those with T2D said that barriers to medication taking included forgetting medication, feeling lazy, and medication side effects. Previous studies also identified the cost of medication as a barrier to medication management (Capoccia, Odegard, & Letassy, 2016); however, cost was not brought up as a concern in our focus groups. The lack of discussion around financial concerns related to medication management may be due to the healthcare support participants receive from their tribe. Tribal members who use Indian Health Services do not typically pay for medication or supplies.

While financial concerns were not a barrier for medication management, they were a significant barrier for purchasing and eating healthy foods. Participants in our focus groups experienced both food insecurity as well as food deserts, both of which may influence HbA1c, self-management, and diabetes-related complications (Berkowitz et al., 2013; Berkowitz et al., 2015; Essien, Shahid, & Berkowitz, 2016; Wang et al., 2015). Food insecurities in our focus groups particularly impacted families with multiple generations living at home. In the AIAN culture it is common for extended families to live together and support and care for each other. Extended families are often comprised of more than blood relatives and may include those from outside the biological family. This extended network of family is a strength of AIAN communities; however, it can also cause a financial strain on the family. Additionally, participants described living in a food desert with some participants driving 60 miles or more to reach a large grocery store. Due to living in a food desert, participants often resorted to purchasing their food at convenience stores, bargain stores, or fast food restaurants, which promotes unhealthy eating for the entire family.

In addition to food insecurities and food deserts, we found that physical activity was a barrier to T2D prevention and management, a finding similar to other studies. The inverse relationship between physical activity and T2D is well established. For example, Lidegaard and colleagues conducted focus groups with participants living in Denmark and their findings on barriers to physical activity were similar to our findings; barriers included functional limitations, lack of time and support, and competing priorities (Lidegaard, Schwennesen, Willaing, & Færch, 2016). Additionally, Foulds and colleagues revealed in their systematic review that on average 47.9% (n=135,515) of AI adults and 37.2% of children and youth (n=711) reported not meeting the recommended physical activity levels (Foulds, Warburton, & Bredin, 2013). Physical inactivity is known to increase the risk of developing T2D as well as increasing the risk of diabetes-related complications. Therefore, it is imperative to find culturally appropriate ways to increase physical activity in this population.

Impact of family behavior on T2D prevention/management

Previous studies have revealed that T2D affects the entire family and patient and family interactions play an important role in diabetes self-management. This fact was supported by the conversations that took place in all seven focus groups related to supportive and non-supportive family behaviors. Much of the supportive and non-supportive behaviors discussed in the focus groups evolved around food. For example, supportive behaviors were seen as the family eating the same food as the person with diabetes and bringing food to events that everyone can enjoy. Keeping unhealthy food in the house and eating unhealthy food in front of the person with T2D were considered non-supportive. Additionally, participants spoke about loved ones nagging them about their food intake or lack of physical activity, which was non-supportive even though it was done out of love. Evidence suggests that family support has a positive impact on diabetes self-management behaviors such as physical activity, blood glucose monitoring, healthy eating, and medication taking (Pamungkas et al., 2017); however, few such studies have been conducted in the AIAN population (Baig et al., 2015; Scarton & de Groot, 2017). Future studies should focus on culturally tailored interventions that include multiple generations of AIAN families.

Incorporating Cultural Components

As participants in the focus groups discussed their thoughts and feelings about T2D prevention and management, some participants made comments on incorporating aspects of their culture into the program. For example, participants mentioned learning to cook traditional foods in a healthy way, using traditional Native dancing as a form of physical activity, and incorporating family friendly competition into the program (historically friendly competitions have been a common part of the Native culture). The cultural components of the focus group discussions may have been limited due to participants presuming that if the diabetes program was developed in conjunction with their tribe, it would have cultural components. The key cultural features offered, however, do mention important insights for development of a T2D intervention for AIAN families. Culturally targeted diabetes interventions have been shown to have a greater impact on improving HbA1c compared to “usual” care (Nam et al., 2012) and may benefit this population.

There were several study limitations. Some participants may have been uncomfortable fully disclosing their thoughts and feelings in a group setting and this reluctance may have limited the information we received. Another study limitation is that the majority of the participants were recruited from rural communities in Oklahoma and may not be generalizable to other American Indian tribes such as those living on reservations or in urban areas. Additionally, the diabetes educators attended some of the focus groups and this may have prevented participants from speaking freely about their practices, needs, and challenges around managing T2D. Despite these limitations, this study provides insight into identifying the relevant and beneficial features of intervention programs for prevention and management of T2D among this population.

Conclusion

Study findings provide a better understanding of the characteristics of interventions that would be most relevant and beneficial to address the diabetes-related needs and challenges of this AI community. An essential step in developing and implementing an effective and useful T2D prevention and management intervention in AIAN communities is encouraging community engagement of not only tribal community members but also tribal leaders. Each AIAN community has different health priorities and challenges as well as diverse views on conducting research. The research conducted has to be meaningful to the tribe and culturally relevant. Lastly, our study with the seven focus groups revealed the importance of having a diabetes intervention that does not require participants to meet more than monthly due to other family commitments. We found it was equally important for the intervention to involve multiple family members including children. Additionally, participants wanted to learn about healthy food choices, including traditional foods, ways to overcome barriers to T2D prevention and management, and how to experience positive family support. In learning these skills, participants did not want to passively listen to information, but instead they wanted a hands-on, culturally meaningful intervention. Future interventions should consider the needs and concerns of the community and should consider cultural and historical aspects that are important to the AIAN community.

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References

- Armour TA, Norris SL, Jack L Jr., Zhang X, & Fisher L (2005). The effectiveness of family interventions in people with diabetes mellitus: a systematic review. *Diabetic Medicine*, 22(10), 1295–1305. doi:10.1111/j.1464-5491.2005.01618.x [PubMed: 16176186]
- Baig AA, Benitez A, Quinn MT, & Burnet DL (2015). Family interventions to improve diabetes outcomes for adults. *Annals of the New York Academy of Sciences*, 1353(1), 89–112. doi:10.1111/nyas.12844 [PubMed: 26250784]

- Berkowitz SA, Aragon K, Hines J, Seligman H, Lee S, & Sarkar U (2013). Do clinical standards for diabetes care address excess risk for hypoglycemia in vulnerable patients? A systematic review. *Health Serv Res*, 48(4), 1299–1310. doi:10.1111/1475-6773.12048 [PubMed: 23445498]
- Berkowitz SA, Meigs JB, DeWalt D, Seligman HK, Barnard LS, Bright OJ, ... Wexler DJ (2015). Material need insecurities, control of diabetes mellitus, and use of health care resources: results of the Measuring Economic Insecurity in Diabetes study. *JAMA Intern Med*, 175(2), 257–265. doi: 10.1001/jamainternmed.2014.6888 [PubMed: 25545780]
- Bureau of Indian Affairs. Department of the Interior. (2018). Indian Entities Recognized and Eligible to Receive Services from the United States Bureau of Indian Affairs. *Federal Register*, 83(20), 4235–4241.
- Capoccia K, Odegard PS, & Letassy N (2016). Medication Adherence With Diabetes Medication: A Systematic Review of the Literature. *Diabetes Educ*, 42(1), 34–71. doi:10.1177/0145721715619038 [PubMed: 26637240]
- Dart AB, Martens PJ, Rigatto C, Brownell MD, Dean HJ, & Sellers EA (2014). Earlier onset of complications in youth with type 2 diabetes. *Diabetes Care*, 37(2), 436–443. doi:10.2337/dc13-0954 [PubMed: 24130346]
- Essien UR, Shahid NN, & Berkowitz SA (2016). Food Insecurity and Diabetes in Developed Societies. *Curr Diab Rep*, 16(9), 79. doi:10.1007/s11892-016-0774-y [PubMed: 27421977]
- Foulds HJA, Warburton DER, & Bredin SSD (2013). A systematic review of physical activity levels in Native American populations in Canada and the United States in the last 50 years. *Obesity Reviews*, 14(7), 593–603. doi:doi:10.1111/obr.12032 [PubMed: 23577646]
- Gilliland SS, Azen SP, Perez GE, & Carter JS (2002) Strong in body and spirit: Lifestyle intervention for Native American adults with diabetes in New Mexico. *Diabetes care*. 25(1), 78–83. [PubMed: 11772905]
- Hughes D & DuMont K (1993). Using focus groups to facilitate culturally anchored research. *American Journal of Community Psychology*. 21(6), 775–806.
- Jernigan VB (2010). Community-based participatory research with Native American communities: the Chronic Disease Self-Management Program. *Health Promot Pract*, 11(6), 888–899. doi: 10.1177/1524839909333374 [PubMed: 19376928]
- Kovacs Burns K, Nicolucci A, Holt RI, Willaing I, Hermanns N, Kalra S, ... Group DS (2013). Diabetes Attitudes, Wishes and Needs second study (DAWN2): cross-national benchmarking indicators for family members living with people with diabetes. *Diabetic Medicine*, 30(7), 778–788. doi:10.1111/dme.12239 [PubMed: 23701236]
- Lagisetty PA, Priyadarshini S, Terrell S, Hamati M, Landgraf J, Chopra V, & Heisler M (2017). Culturally targeted strategies for diabetes prevention in minority population. *Diabetes Educ*, 43(1), 54–77. doi:10.1177/0145721716683811 [PubMed: 28118127]
- Lidegaard LP, Schwennesen N, Willaing I, & Færch K (2016). Barriers to and motivators for physical activity among people with Type 2 diabetes: patients' perspectives. *Diabetic Medicine*, 33(12), 1677–1685. doi:doi:10.1111/dme.13167 [PubMed: 27279343]
- Mendenhall TJ, Berge JM, Harper P, GreenCrow B, LittleWalker N, WhiteEagle S & BrownOwl S (2010). The Family Education Diabetes Series (FEDS): community-based participatory research with a midwestern American Indian community. *Nursing Inquiry*. 17(4), 359–372. [PubMed: 21059153]
- Minkler M, Blackwell AG, Thompson M, & Tamir H (2003). Community-Based Participatory Research: Implications for Public Health Funding. *American Journal of Public Health*, 93(8), 1210–1213. doi:10.2105/ajph.93.8.1210 [PubMed: 12893597]
- Murray PJ (1997). Using Virtual Focus Groups in Qualitative Research. *Qual Health Res*, 7(4), 542–549. doi:10.1177/104973239700700408
- Nam S, Janson SL, Stotts NA, Chesla C, & Kroon L (2012). Effect of culturally tailored diabetes education in ethnic minorities with type 2 diabetes: a meta-analysis. *J Cardiovasc Nurs*, 27(6), 505–518. doi:10.1097/JCN.0b013e31822375a5 [PubMed: 21747287]
- Pamungkas RA, Chamroonsawasdi K, & Vatanasomboon P (2017). A Systematic Review: Family Support Integrated with Diabetes Self-Management among Uncontrolled Type II Diabetes Mellitus Patients. *Behav Sci (Basel)*, 7(3). doi:10.3390/bs7030062

- Polonsky WH, & Henry RR (2016). Poor medication adherence in type 2 diabetes: recognizing the scope of the problem and its key contributors. *Patient preference and adherence*, 10, 1299–1307. doi:10.2147/PPA.S106821 [PubMed: 27524885]
- Salazar M (2016). State recognition of American Indian tribes. *Legisbrief: National Conference of State Legislatures*, 24(39).
- Sarche M & Spicer P (2008). Poverty and health disparities for American Indian and Alaska Native children: Current knowledge and future prospects. *Annals of the New York Academy of Sciences*. 1136, 126–136. [PubMed: 18579879]
- Scarton LJ, & de Groot M (2017). Emotional and Behavioral Aspects of Diabetes in American Indians/Alaska Natives. *Health Educ Behav*, 44(1), 70–82. doi:10.1177/1090198116639289 [PubMed: 27179289]
- Wang EA, McGinnis KA, Goulet J, Bryant K, Gibert C, Leaf DA, ... Fiellin DA (2015). Food insecurity and health: data from the Veterans Aging Cohort Study. *Public Health Rep*, 130(3), 261–268. doi:10.1177/003335491513000313 [PubMed: 25931630]

Table 1.Sample demographic characteristics ($N = 62$)

Demographic	Range	Mean (SD)
Age	31 – 85	55.3 (11.4)
T2D duration in years (8 missing)	0.2 – 36.0	10.4 (9.1)
N (%)		
Gender		48 (77%)
Female		14 (23%)
Male		
Marital Status		
Married		31(50%)
Divorced/Single/Widowed		31 (50%)
Education (3 missing)		
<High School		5(8%)
High School/Vocational School/GED		42(71%)
College/some College		12(20%)
Employment (5 missing)		
Full/part time		21(37%)
Unemployed/retired/homemaker		26(42%)
Disabled		9(16%)
Other		1(.08%)
Income (3 missing)		
Comfortable		23(39%)
Just enough to make ends meet		27(46%)
Do not have enough to make ends meet		9(15%)
Healthcare Coverage (4 missing)		
Have Coverage		37(64%)
Don't have coverage		21(36%)
Healthcare Location (3 missing)		
Indian Health Services		40(68%)
Other		19(32%)
Health Problems (Other than type 2 diabetes)		
None		17(27%)
One chronic disease		25(40%)
Two or more chronic diseases		20(32%)

T2D = type 2 diabetes

Table 2.

Sample of focus group discussion guide questions

Questions from focus group discussion guide: Type 2 Diabetes
1. What does living with diabetes mean to you?
2. What are your biggest challenges in managing your diabetes?
3. How do you currently manage your diabetes?
4. Who in your family supports you in managing your diabetes?
5. Are there barriers to going to see your healthcare provider? Probe: Do you have transportation? How many miles do you have to travel?
6. What are your thoughts about family programs that include adults with diabetes as well as their children or grandchildren who have pre-diabetes or are at high risk of diabetes?
7. What would be the benefits and/or issues in having family members attend the program with you?
8. How would you describe a program that would work for you?
9. Should the program take place once a week, twice a month?
10. When would be a good time to meet? Probe: During weekends or weekday; evenings, or afternoons? Why?

Table 3.

Summary of focus group findings

Focus group findings
Community engagement and tribal leadership are essential when developing an intervention
Tribes will have different health priorities and challenges as well as diverse views on conducting research
The research conducted must be meaningful and culturally relevant to the tribe
Focus group members only wanted to meet monthly due to other family commitments
It is important to include multiple family members including children
Focus group participants want to learn about healthy food choices including traditional foods
It is important to have an active hands-on intervention
Making the intervention culturally sensitive and relevant is important

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