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Method of Developing a Culturally Tailored Diabetes Intervention for American Indians

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ABSTRACT

Background: American Indians have the highest prevalence of type 2 diabetes (T2D) compared to any other racial or ethnic group.

Objective: Developing a culturally tailored diabetes prevention and management intervention is one way to reduce diabetes-related health disparities among American Indian populations. The purpose of this article is to describe our approach for developing a diabetes prevention and management intervention study using Kolb's Experiential Learning Theory (ELT) as the framework.

Method: To ensure the intervention study was culturally meaningful and relevant we used community-based participatory principles by partnering with a team of nurse researchers, tribal diabetes educators, tribal leaders, and tribal community members who were involved in all aspects of the study process. We conducted seven focus groups predominantly in rural American Indian communities in Oklahoma. Using focus group findings, the team collaboratively designed and developed a multi-generational diabetes prevention and management intervention study. The intervention group sessions will focus on ways to prevent and manage diabetes while the control group sessions will focus on general health education topics that have been identified by the team as important and relevant.

Conclusion: Family interventions that involve multiple generations and provide emotional and behavioral support to those with T2D and family members at risk may provide our best chance at improving diabetes-related outcomes and reducing health disparities in this critical population.

KEYWORDS: Diabetes Mellitus, Health Services, Indigenous, Community Health Services, Family Health, Rural Health

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American Indians have the highest prevalence of type 2 diabetes (T2D) compared to any other racial or ethnic group.[1] Developing a culturally tailored diabetes prevention and management intervention is one way to reduce diabetes-related health disparities among American Indian populations.[2,3,4] The purpose of this article is to describe our approach to developing a culturally relevant intervention focused on T2D prevention and management. We include background literature on the need for the intervention, the theoretical basis of the intervention, and its development process and content. We conclude with several recommendations for future directions.

American Indians are 2.6 times more likely to be diagnosed with diabetes compared to non-Hispanic Whites of a similar age, and have a higher burden of illness, injury, and premature mortality.[1] Youth, particularly racial and minority youth such as American Indians, are developing T2D earlier in their lifetime and have an increased risk of developing serious complications.[5,6,7] These findings elucidate the disproportionate burden of T2D and associated complications that American Indians bear. The American Diabetes Association in their recent statement on reducing diabetes health disparities asserted that interventions must include individualized and culturally appropriate strategies.[8] Likely contributors to the inadequate effects are that few used community-based participatory methods involving the tribal community and often lacked culturally tailored strategies, which highlight gaps in the current literature and opportunities for future research.[9]

Prevention programs have been funded and implemented with American Indian populations with some benefit in preventing the onset of T2D, reducing weight, and improving

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glycemic control.[3,4] In 1997 Congress created the Special Diabetes Program for Indians (SDPI), which provides funding to Indian Health Services and Native communities across 35 states to help prevent and treat T2D.[10] Each tribal site decides on the type of diabetes treatment or prevention services they will provide based on the needs of the community. This program is a major factor in the decrease of diabetes complications and the leveling off of the prevalence of diabetes.[10] However, there is still much work to be done. Although several other T2D management interventions have been developed for American Indian populations, their effects have been less than optimal[9] and the programs do not fit all tribal members needs. Developing other culturally tailored diabetes interventions create an opportunity to expand on American Indian tribal history, traditions, values, and beliefs that may improve T2D outcomes.

A family history of T2D is a strong risk factor for developing T2D and much of diabetes prevention and management takes place within the family context. Evidence suggests family-based interventions for people with T2D may be effective in improving diabetes-related knowledge and glycemic control in the general population.[11,12] However, few T2D intervention studies have used this approach in American Indian populations.[9,12] Research also indicates the importance of engaging community members during intervention development and implementation.[2,9] Through community engagement, culturally tailored interventions may be better developed and received to create a lasting impact on the community. Toward that aim, we describe the method of developing a 6-month multi-generational diabetes prevention and management intervention culturally tailored to Choctaw Nation, an American Indian community in South Eastern Oklahoma.

Theoretical basis

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Kolb's Experiential Learning Theory (ELT) served as the framework for developing our T2D prevention and management intervention study. Kolb's ELT considers individual learning styles and suggests that including all four learning processes will facilitate individuals in a group to learn and apply the learning in other situations.[13] The learning processes includes: concrete experience, reflective observation, abstract conceptualization, and active experimentation.[13] Learning is achieved when individuals have access to all four parts of the learning cycle. Kolb asserts that individuals progress through all four parts of the learning cycle with each process being mutually supportive of and feeding into the next process.[13] According to the four-part learning cycle, concrete experiences (feeling) are exposures to any situation or experience that may elicit feelings or create mindful thinking for the learner. Reflective observation (watching) encourages the learner to actively reflect on the experience from different perspectives. Abstract conceptualization (thinking) provides details and facts about an abstract idea that helps the individual learn and build on the concrete experience. Finally, the learner applies what was learned through active experimentation (doing) to generalize abstract ideas to new experiences.[13] Kolb's ELT is particularly effective for interventions among cultures with a strong history of storytelling,[14,15] which is important in American Indian populations. Although Kolb's theory has not been used in American Indian populations it has successfully been used in T2D health promotion.[16,17,18] For example, a study was conducted in China among a sample of 400 participants with T2D to evaluate the influences of experimental learning on treatment attitudes and willingness to use insulin injections.[18] Findings from this study revealed that participants in the experiential learning intervention group had significantly higher insulin treatment attitudes, reduced psychological resistance to insulin use, and improved willingness to use insulin injections compared to the control group.[18]

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Development Process: Partnership

The success of developing an effective intervention study often depends on the early involvement of key stakeholders and the development of a trusting and collaborative relationship through the partnership. This partnership ensures that health issues important to the community are addressed and the intervention is culturally relevant and supports the community. For this reason, we used community-based participatory principles by partnering among a team of nurse researchers, tribal diabetes educators, tribal leaders, and tribal community members.

Partnership formation. The partnership between the academic researchers and Choctaw Nation was formed through the lead investigator who is a tribal member and a member of the community. The focus of the project was developed based on the lived experience of the lead investigator, who saw the impact T2D had on family, friends, and the greater tribal community. Based on this knowledge, the academic researchers approached tribal leadership with a desire to decrease the prevalence of T2D and improve T2D outcomes within the tribal community. The idea was met with great enthusiasm. Several face-to-face meetings as well as conference calls were held between the academic researchers and tribal partners to further design the study and develop next steps. The team (academic researchers and tribal partners) met weekly by conference calls throughout the development phases of the study. Additionally, we formed a tribal advisory board made up of tribal community members, tribal employees, and tribal leadership. The academic partners acknowledge with sincere gratitude the Choctaw Nation's leadership team, diabetes educators, members of the advisory board, and community for their contribution to this important work. The University of Florida IRB and the Choctaw Nation Tribal IRB approved all procedures.

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Focus groups. Our first step in designing the study was to reach out to tribal community members with T2D, using focus groups, to better understand what T2D intervention components they feel are needed within their community. The tribal diabetes educators, through their connections to the community, recruited participants for the focus groups. The lead investigator (Choctaw Nation tribal member), led the in-person focus groups using a moderator's guide that was developed by our team, including input from the advisory board. We conducted seven focus groups predominantly in rural American Indian communities in Oklahoma.[19] The focus groups ranged from 3-13 participants, with all but 2 groups having between 8-13 participants, and lasted approximately 60 minutes. Participants identified intervention components (i.e., intervention dose, cultural activities to include, topics to cover), barriers to T2D management, influence of family behavior, and shared personal stories[9] all of which were used to develop a diabetes prevention and management program (e.g., goal setting, physical activity, healthy meals, family support, medication management). Full details of the focus group methods and findings are published elsewhere.[19]

Content: Intervention Timing and Delivery Process

Our team met several times to discuss findings from the focus groups. The team determined, based on focus group findings, feedback from the advisory board, and current T2D programs being offered within the tribe, that the community would benefit from a multi-generational intervention study, which includes participants from two to three generations. For example, we will recruit a grandparent, parent, and youth between 11-18 years of age. The team then set to collaboratively design and develop the 6-month multi-generational diabetes prevention and management study material. The lead investigator and research assistants drafted the 6-monthly sessions for both the intervention and control groups using findings from the focus

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groups, ideas generated in our weekly team meetings, and suggestions from our tribal advisory board. The drafts were then shared with the tribal partners for edits and feedback. This iterative process took place over an 18-month timeframe.

Timing. Participants will be asked to attend 6-monthly in person intervention sessions and will complete study measures at the first and last sessions. Participants voiced the desire to only meet monthly instead of the typical weekly sessions seen in many interventions including the Special Diabetes Program for Indians.[10] Participants indicated that monthly sessions would be more convenient mostly due to family commitments (children's activities, work obligations). Participants suggested, in addition to monthly sessions, that diabetes educators communicate with them via a smart phone on a weekly basis (encouraging messages, brief T2D prevention/management points, fun homework assignments). In a family phone call 3 and 6 months after the last intervention session, the researcher will collect data to document intervention effects.

Delivery process. Diabetes educators who are already established within the tribal community will deliver the intervention to participants with support from the lead investigator. Each monthly intervention session will use all four processes of Kolb's ELT.

Process 1: Concrete experience (Real Life Experience) is the first learning process. To use concrete experience, each monthly session will begin with a "real-life experience" delivered by an elder, a Native leader within the community, or the diabetes educators who have a lived experience to share in the context of living with T2D. For example, adult family members and youth may hear from an elder on how they learned to manage their T2D successfully or the elder may discuss how it is possible for youth to prevent developing T2D. Process 1 allows

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participants to be exposed to other perspectives and ways of managing or preventing T2D and is done in a culturally meaningful way through storytelling.

Process 2: Reflective observation (Reflective Thought). The real-life experience from the first process will lead participants to the next process of the cycle, reflective thought. Here adult family members and youth will be asked questions such as what did you learn, what are your thoughts, how does it relate to your situation? Through reflective thought, participants will be able to engage with one another and share their personal thoughts and feelings. During process 2, we will also begin to discuss personal goals and what changes participants would like to see in management or prevention of T2D.

Process 3: Abstract conceptualization (The BIG Idea). In this process adult family members and youth will form new ideas based on conversations during the reflective stage. Participants will begin to apply the ideas to their own situation. The group facilitator will present information on the session topic to illustrate the relationship between the topic, concrete experience, and the participants' lives to encourage discussion of how best to apply the information in their own situation. In this process, a majority of diabetes prevention and management learning will take place.

Process 4: Active experimentation (Families in Action). Through active experimentation, participants synthesize what they have learned from the concrete, reflective, and abstract. The adults and youth turn the concepts, knowledge, and skills learned into goals that work for them. For example, adults may develop new goals as a family (eating one healthy meal a week together and walking one time a week together as a family) to improve T2D management. The youth may make personal positive behavior changes to prevent T2D such as increasing physical activity through participating in a sport.

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Future Directions

Our goal was to implement a feasibility pilot study in spring of 2020; however, due to the impact of COVID-19, we were forced to delay the feasibility study until spring or summer of 2022. We plan to recruit 34 Choctaw families who have T2D and who have at least one youth at risk of T2D. Participants will be assigned to either the T2D prevention and management group (experimental) or the health education control group. The diabetes educators and community health workers will lead the recruitment efforts. Feasibility will be evaluated by examining pre-post changes for improvement in relevant T2D outcomes (e.g., BMI (for youth), A1c (for adults), physical activity, dietary adherence, T2D knowledge). We will also use length of time required to recruit the sample, retention rate, and acceptability of the study procedures to determine feasibility. Study findings will be provided to tribal leadership through a written report and presentation.

The intervention group sessions will focus on ways to prevent and manage diabetes while the control group sessions will focus on general health education topics that have been identified by the team as important and relevant topics. Both groups will receive six face-to-face sessions with equal intensity and dose. Educational material was adapted and modified from several different sources including material from the American Diabetes Association, Center for Disease Control, and the National Diabetes Prevention Program. Topics for the monthly sessions are shown in table 1. All four of Kolb's processes are repeated for each monthly topic and examples of information from the abstract conceptualization process are provided in the table.

While this intervention study was developed based on the needs of Choctaw Nation, other tribal communities may also benefit from an intervention focused on specific T2D prevention and management messages and activities targeted at each of several generations (grandparents,

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parents/aunts/uncles, and children). Our goal is to build on the strengths of American Indian families by including multiple family members in the intervention and incorporating tribal traditions into managing and preventing type 2 diabetes as a family in culturally relevant way across the generations. After completion of this pilot study our team will meet to review findings, discuss what worked well and what areas need modification, and to decide whether we should move forward with larger studies to test first for efficacy and then for effectiveness of the intervention. With permission of the Choctaw Nation team members and leaders, once effectiveness is demonstrated, the intervention will be made widely available.

Conclusion

The disproportionately high rate of T2D in American Indian populations has underscored the importance of developing an effective T2D prevention and management intervention. In developing these interventions, it is important to draw on the community's strengths and knowledge. Future interventions may benefit from incorporating all components of community involvement from developing to delivering the intervention. Family interventions that involve multiple generations and provide emotional and behavioral support to those with T2D and family members at risk may provide our best chance at improving diabetes-related outcomes and reducing health disparities in this critical population.

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Table 1. Monthly Session Topics Delivered by Kolb's Experiential Learning Theory with Examples of Abstract Conceptualization (AC) Topics

Topics for Intervention: Delivered using all 4 of Kolb's Learning Processes	**AC Examples- for youth and adults**
T2D overview	Pre-diabetes, types of diabetes, risk factors, symptoms, causes, treatment
Physical activity	Importance, type and amount recommended, using pedometer
Healthy ways of eating	What is healthy eating, adjusting meal plan, ways to prepare traditional healthy meals
Healthy foods	Food budget, eliminating barriers to healthy foods
Family support	Supportive versus non-supportive behaviors, making healthy changes as a family
Positive thoughts	Emotional aspects of diabetes, coping strategies
Topics for Control: Delivered using all 4 of Kolb's Learning Processes	**AC Examples- for youth and adults**
Managing stress	How stress affects individuals, systems of stress, mechanisms of stress
Heart health	Risk factors, lifestyle changes, high blood pressure risk factors for youth
Depression	What is depression, symptoms, risk factors, and treatment strategies
Skin cancer	What is skin cancer, risk factors, ways to reduce risk
Eating disorders	Different types, symptoms, treatment strategies