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# Using community-based participatory research to improve care for American Indians/Alaska Natives with type 2 diabetes mellitus

Abstract: American Indians/Alaska Natives are at increased risk for type 2 diabetes mellitus. NPs have the opportunity to intervene with culturally appropriate interventions grounded in community-based participatory research. This article provides an overview of such care that can help improve outcomes.

By Rebecca Carron, PhD, RN, FNP

egan Smith just finished a primary care new patient visit with Jim Black Hawk, a 39-year-old male who identifies as American Indian (AI). Jim was accompanied on the visit by his wife Amanda. Jim and Amanda moved to Megan's western community 6 months ago from an AI reservation 200 miles away. Jim currently works fulltime in the local furniture factory making handmade oak furniture. He has private health insurance through his employer. Amanda is a homemaker and cares for the couple's daughter and son ages 8 and 10, respectively. Jim was diagnosed with type 2 diabetes mellitus (T2DM) 2 years ago at the reservation clinic. He came to see Megan to establish care as a new patient. Vital signs, fasting lab values, and medications included the following:

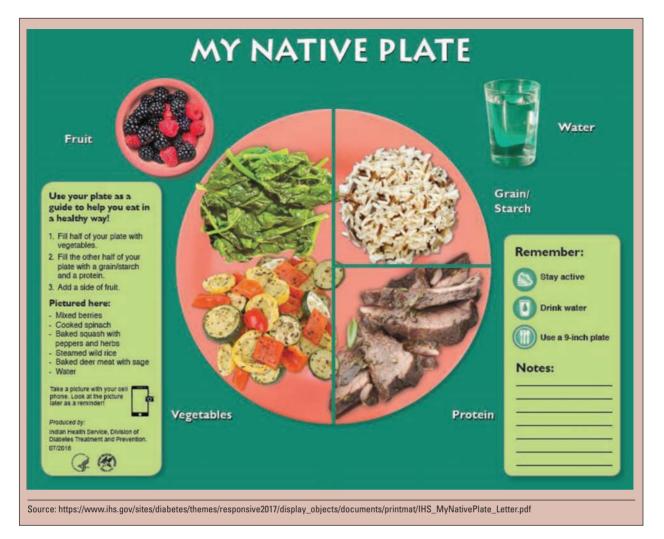
- Hemoglobin A1C: 7.5%
- Glucose: 131 mg/dL
- Total cholesterol: 253 mg/dL
- High-density lipoprotein: 25 mg/dL
- Low-density lipoprotein: 150 mg/dL
- Triglycerides: 250 mg/dL
- BP: 155/92 mm Hg
- Pulse: 84 beats/minute
- Height: 5'9" (175.3 cm)
- Weight: 210 lb (95.3 kg)
- Body mass index (BMI): 31 kg/m<sup>2</sup>

• Medications: metformin 1,500 mg/day, rosuvastatin 10 mg/day, verapamil 300 mg/day, losartan/hydrochlorothiazide 100/12.5 mg/day, potassium chloride 10 mEq/day

Megan wonders about providing the best culturally appropriate healthcare for Jim while improving his T2DM control. She has a friend at the University

Keywords: Alaska Natives, American Indians, community-based participatory research, nurse practitioners, primary care, type 2 diabetes





of Wyoming School of Nursing whose research focuses on health disparities in AIs/Alaska Natives (AI/ ANs). Megan decides to give her friend, Jessica, a call over lunch. Jessica fills her in on using findings from community-based participatory research (CBPR) in her action plan for Jim, recommends some reading material for Megan, and tells her to call back when she is finished to discuss applying the information to Jim. Megan's "homework" includes the following:

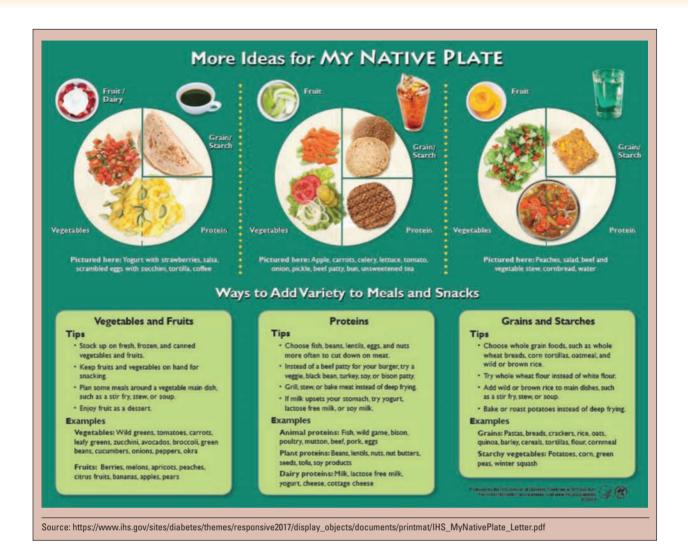
- T2DM in AI/ANs: Magnitude of the problem
- CBPR: Description and benefits for AI/ANs
- Landmark research studies
  - The Diabetes Prevention Program (DPP)<sup>1-3</sup>

 $\,\circ\,$  The Special Diabetes Program for Indians Diabetes Prevention (SDPI-DP) demonstration project  $^4$ 

The purpose of this article is to review Megan's "homework" and provide practical information and suggestions for caring for AI/ANs with T2DM based on CBPR. This treatment plan can help improve T2DM outcomes for Jim and other AI/AN patients.<sup>4</sup>

## The problem: T2DM in Al/ANs

According to the National Diabetes Statistics Report, 13% of adults in the US age 18 and older had diabetes in 2018, including 2.8% of the adult population with undiagnosed diabetes.<sup>5</sup> This compares with a total diabetes prevalence for US adults of 9.5% from 1999 to 2002. AI/AN adults had the highest prevalence of diagnosed diabetes in the country at 14.7%, followed by people who identify as Hispanic (12.5%), non-Hispanic Black (11.7%), non-Hispanic Asian (9.2%), and non-Hispanic White (7.5%).<sup>5</sup> The prevalence of diagnosed diabetes in AI/AN adult women was 14.8% and in AI/AN adult men, 14.5%.<sup>5</sup> These statistics are significant especially considering the size of the population that identifies as AI/AN. Based on the 2020 US



Census, the AI/AN population alone or in combination with other groups was 2.9% of all people living in the US.<sup>6</sup> Diabetes is the seventh leading cause of death in the US with an approximate mortality of 25.7 per 100,000 persons.<sup>5</sup> In 2017, the economic burden associated with diagnosed diabetes was \$327 billion.<sup>5</sup>

In spite of these ominous statistics about diabetes in the AI/AN population, there is good news to report.<sup>7</sup> In 1996, AI/AN individuals were five times more likely than White individuals to have kidney failure from diabetes due to uncontrolled glucose levels or BP and decreased access to care. Today, because of improved programs and resources including increased use of renoprotective medications, improved blood glucose and BP control, as well as increased testing for kidney disease, kidney failure from diabetes in the AI/AN population decreased by 54% between 1996 and 2013. How was this accomplished? The answer is team-based care leading to marked improvements in the health of AI/AN individuals living with diabetes.<sup>7</sup> Team-based care is grounded in CBPR.

### CBPR

CBPR is a research approach that is increasingly used with tribal communities and other minority groups to improve health.<sup>8</sup> CBPR integrates partnerships between researchers, community members, advisory boards, and other stakeholders to ensure shared decision-making between researchers and the community. CBPR is defined as

Embracing collaborative efforts among community, academic, and other stakeholders who gather and use research and data to build on the strengths and priorities of the community for multilevel strategies to improve health and social equity.<sup>8</sup>



A major difference between CBPR and traditional research methods is orientation. In traditional research, the researcher determines the research question, population to be studied, method, and outcome measures.<sup>8</sup> In CBPR, the problem, participants, method, and outcome measures are determined by the community in partnership with the researcher.<sup>8</sup> CBPR helps redress past research abuses, particularly in tribal communities, regarding power and privilege by focusing on a community-driven approach.<sup>8</sup> CBPR can be used with all types of research designs including qualitative focus groups, ethnographic studies, and/or survey studies.<sup>8</sup>

CBPR has several core principles. These principles relate to community, partnerships, balance, and equity: • Community: The essential element of CBPR. Community can include people in a geographical area or people with a shared commonality of ethnicity, culture, or gender identity, and the like. CBPR incorporates the strengths and resources of the chosen community.<sup>8</sup>

• Partnerships: All involved parties in CBPR participate and share control of the research process. Thus, inequities between the researchers and the community are minimized.<sup>8</sup>

• Balance: CBPR collects knowledge about community health problems and translates that knowledge into interventions to improve the health of the community. Balance exists between research and action.<sup>8</sup>

• Equity and determinants of health: CBPR examines social, cultural, biomedical, environmental, and economic determinants of health. Partnerships within the CBPR paradigm recognize that partners need to reflect on the history of past abuses, power, and/or privilege to develop and sustain partnerships and enhance health for the chosen community.<sup>8</sup>

#### Using CBPR for diabetes care in AI/AN populations

CBPR is a successful strategy to improve health disparities in minority populations.<sup>9</sup> A Cochrane Library review found that health interventions by community coalitions led to improved individual health outcomes and behaviors.<sup>9</sup> The most beneficial actions included health interventions by lay community outreach workers, group-based health education and support led by either peers or healthcare professionals, and changes in health and social care systems.<sup>9</sup> A scoping review of 178 studies using health-related participatory research by members of the Center for the Ethics of Indigenous Genomic Research found that while community engagement was common in research studies involving AI/AN participants, more community engagement was needed in the early stages of research.<sup>10</sup>

#### Diabetes Prevention Program

In order to provide healthcare to AI/ANs with T2DM, a review of the DPP is needed.<sup>1</sup> This landmark clinical trial by the Diabetes Prevention Program Research Group examined if a lifestyle intervention or treatment with metformin could prevent or delay the development of T2DM in 3,234 adults who were at high risk for the condition.<sup>1</sup> Inclusion criteria for participants were minimum age 25 years, a BMI of 24 kg/m<sup>2</sup> (22 for Asian participants) or higher, and elevated fasting or postload glucose levels. Participants were randomly assigned to one of three groups: 1) standard lifestyle recommendations with metformin 850 mg twice daily, 2) standard lifestyle recommendations with placebo twice daily, and 3) an intensive lifestyle modification program. The primary outcome was a diabetes diagnosis.<sup>1</sup>

The study found that the intensive lifestyle intervention reduced the incidence of diabetes by 58% (95% confidence interval [CI] 48%-66%) compared with placebo.<sup>1</sup> Treatment with metformin reduced the incidence of diabetes by 31% (95% CI 17%-43%) compared with the placebo group. In other words, to prevent one case of T2DM over 3 years, 6.9 people would need to participate in the lifestyle intervention versus 13.9 people needing to receive metformin.<sup>1</sup>

In summary, the DPP trial proved that a lifestyle intervention was effective in preventing the onset of T2DM in people at high risk.<sup>1</sup> Moreover, the lifestyle goals were not very extreme and included a 7% weight loss and at least 150 minutes of physical activity per week. Of the participants in the lifestyle intervention group, 50% achieved the 7% weight loss goal by week 24, and 74% met the physical activity goal of 150 minutes per week at 24 weeks, which marked the end of the lifestyle curriculum.<sup>1</sup>

#### Application of the DPP to AI/ANs with T2DM

The focus of this article is managing T2DM with CBPR in AI/ANs. So how does the DPP apply to CBPR and AI/ ANs? There were 3,234 participants in the three intervention arms of the DPP.<sup>1</sup> Of these, 171 or 5.3% identified as AI/AN. The majority of the DPP participants identified as White (54.7%) and female (67.7%). The DPP was subsequently translated into a DPP demonstration project for AI/ANs as the SDPI-DP, which embraced the principles of CBPR and was a collaborative effort involving 2,553 AI/AN participants representing 80 tribes in 18 states.<sup>4</sup> The participants were at least 18 years of age and met the criteria for prediabetes as in the DPP.<sup>4</sup>

The SDPI-DP intervention was similar to the DPP.<sup>4</sup> The intervention goal was a loss of at least 7% of body weight and increased physical activity.4 The program used the 16-lesson DPP educational program covering diet, exercise, and behavior modification.<sup>4</sup> A CBPR approach was used to adapt the curriculum to the local AI/AN culture and incorporated tribal languages, talking circles, native foods, and cultural practices such as drumming. Participants used tracking booklets to record diet intake and physical activity. Lifestyle coaches and educators included nurses, health educators, dietitians, exercise specialists, and other lay health workers.<sup>4</sup> The results of the program found that the incidence of diabetes was 4.0% per year, similar to the incidence of diabetes in the AI/AN lifestyle intervention arm of the DPP at 4.7%.4 For comparison, the incidence of diabetes in AI/ANs in the placebo group of the DPP was 12.9% per year.<sup>11</sup> The participants in the SDPI-DP lost approximately 9.6 lb or 4.4% of their average baseline weight and exercised more after the program. The researchers concluded that DPP was applicable to AI/ANs.<sup>4</sup> Based on this study, NPs should incorporate cultural elements into their care of AI/AN patients.

#### Barriers to T2DM management in AI/ANs

Further analysis of the SDPI-DP data revealed local characteristics that were barriers to lifestyle interventions.11 Higher diabetes incidence was associated with neighborhoods with lower median income. Lowerincome neighborhoods were also associated with less weight reduction, which might reflect lack of resources for lifestyle improvements in diet and exercise. Locales with higher populations of AI/ANs (such as reservations) had less weight reduction and less increase in exercise. In contrast, AI/ANs from neighborhoods with a higher median income had a 35% lower risk of developing T2DM, and areas with higher vehicle ownership also had better weight reduction possibly through better access to healthy food.<sup>11</sup> Consequently, NPs need to be aware of the neighborhood and personal economic characteristics of their AI/AN patients and make healthcare suggestions accordingly. Social justice work must continue to address health inequities in the AI/AN population.

A systematic review examined emotional and behavioral aspects of diabetes self-management in AI/

#### **Resources for NPs caring for AI/ANs with T2DM**

 Indian Health Service: www.ihs.gov/

 Indian Health Service: Diabetes Education Lesson Plans: www.ihs.gov/diabetes/clinician-resources/diabetes- education-lesson-plans/

 MyPlate: www.myplate.gov/eat-healthy/what-is-myplate

 Indian Health Service: My Native Plate:

www.ihs.gov/sites/diabetes/themes/responsive2017/ display\_objects/documents/printmat/IHS\_MyNativePlate\_ Letter.pdf

4. Diabetes Prevention Program materials and participant handouts/notebook: https://dppos.bsc.gwu.edu/web/dppos/lifestyle

ANs.<sup>12</sup> A total of 20 articles met the inclusion criteria. Several of the findings represent barriers to diabetes care. For example, AI/ANs who identified strongly with their cultural traditions were less likely to follow their practitioners' healthcare advice due to a lack of trust and traditions that encouraged nonadherence to diet, physical activity, and medication. However, a positive attitude to a treatment regimen was associated with positive adherence to the program. Poor mental health was associated with increased risk for diabetes. AI/ ANs with diabetes and depression had poorer glucose control compared with AI/ANs without depression. Effective social support at home could aid in diabetes self-management. A CBPR approach and use of culturally appropriate educational materials can enhance control of T2DM.12

Another CBPR study of 192 AI adults with T2DM in Minnesota and Wisconsin examined the effects of stressors and T2DM management.<sup>13</sup> Stressors included the following: diabetes-related stress (problems managing diabetes), family criticism (disapproval or criticism), daily hassles (everyday difficulties with life), microaggressions (racial insults), financial stress, and negative life events (moving, job change).<sup>13</sup> The results from focus groups, interviews, and healthcare records indicated that hemoglobin A1C levels were significantly and positively associated with diabetes distress. All stressors were positively and significantly associated with depressive symptoms. Diet and medication adherence were also affected by various stressors. The study concluded that stress plays a significant role in the behavioral, psychological, and physical health of AIs with T2DM.<sup>13</sup>

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NPs need to consider social histories for their AI/AN patients with T2DM to identify stressors that can affect self-management activities. Screening and treatment for depressive symptoms is essential.

Another study explored characteristics of T2DM interventions for AI/ANs in focus group sessions with 62 AI/AN participants with a mean age of 55.3 years and a mean duration of T2DM of 10.4 years.14 Findings reflected several important considerations for NPs caring for AI/ANs with T2DM. Participants desired a monthly program of 30 minutes to 2 hours per session as well as weekly check-ins and communications using their mobile devices. Participants also wanted family members included in the intervention sessions. Many of the participants were especially interested in having cooking demonstrations and sessions for the entire family so they could all learn to prepare healthy meals. Other suggestions included physical activities such as chair volleyball or traditional dancing. Participants emphasized the desire to include the entire family. The focus groups identified barriers to T2DM management including forgetting to take medications as well as unpleasant adverse reactions from medications.14 Financial concerns regarding the cost of healthy food was another barrier to care. Lack of time and motivation were barriers to physical activity. Nonsupportive family behaviors included bringing home unhealthy snack food choices. AI/AN culture was important to the participants, and they wanted to include traditional foods that were prepared in a healthy manner.<sup>14</sup> These suggestions can help NPs provide culturally appropriate care for their AI/AN patients with T2DM.

## ■ Translating the DPP and SDPI-DP to primary care for AI/ANs with T2DM

NPs can use this information about CBPR, the DPP, the SDPI-DP, and other research work involving AI/ANs and T2DM to provide culturally appropriate evidencebased care. For example, a pilot study by NPs examined implementing a 6-month lifestyle intervention program based on the DPP for primary care patients at risk for T2DM.<sup>15</sup> A convenience sample of 58 adults at risk for T2DM was recruited for the study. Study participants were 45% White, 34% Black, and 21% Hispanic. Participants were randomized to either an enhanced standard care program or the lifestyle program. Motivational interviewing (MI) was an important part of the program and was used to enhance behavior modification. The NPs in the study were trained in MI through reading and workshops. NPs were also trained in providing the lifestyle sessions and met monthly with the primary investigator.<sup>15</sup> The framework for the study was the reach, efficacy, adoption, implementation, and maintenance (RE-AIM) model.<sup>15</sup> A program such as lifestyle intervention must *reach* a diverse sample of people, be effective and adoptable to various settings, able to be implemented as intended, and, finally, results must be maintained by participants and the clinic. The results indicated that, at 6 months, 25% of the lifestyle intervention participants lost 5% of their baseline weight compared with 11% of the standard care participants. For physical activity, 46% of the lifestyle group met the activity goal of 150 minutes per week and 40% of the standard care group met the goal.

The lifestyle intervention focused on several topics.<sup>15</sup> These included:

• Healthy eating with regular meals emphasizing lowfat, culturally relevant recipes

• Benefits of exercise and exercising safely

• Identifying factors that tempted one to deviate from healthy eating and exercise (stimulus control)

• Managing negative thoughts by using positive counterstatements

- Healthy eating out
- Managing stress
- Managing social stress
- Motivation

This study was important because it demonstrated that NPs in a primary care clinic could implement a modified DPP for their patients.

### DPP resources

The DPP Manual and lifestyle intervention participant materials are freely available to the public (see *Resources for NPs caring for AI/ANs with T2DM*). Under the Creative Commons License, the public can freely use the materials if the University of Pittsburgh is appropriately cited for credit.<sup>1-3</sup>

These online DPP program materials can be adapted for use by NPs in primary care. The Diabetes Prevention Program Outcomes Study website includes a downloadable participant notebook with useful information that NPs can adapt and use with their patients.<sup>1-3</sup> Highlights of the notebook include:

- Space for program goals
- Benefits of program
- Blank diet and exercise charts

• Tips for exercising including warm-ups

• Tips for healthy eating including hidden fat in foods and low-fat food alternatives

• Sample menu and space to develop one's own menu make-over

- Managing food cues and desires
- Problem-solving diet and exercise issues

• Eating out and healthy food choices, including healthy fastfood choices

• Managing negative thoughts (I should not have eaten the cake; I will never lose weight)

- Activity suggestions
- Weekly action plans

Unfortunately, much of the nutrition information is based on the outdated food pyramid.<sup>1-3</sup> However, NPs could easily substitute information about the MyPlate system of eating.

MyPlate information is also available as My Native Plate for AI/AN traditional diets (see *My native plate* and *More ideas for my native plate*).

## Interventions for AI/ANs with T2DM

Now let us revisit our AI/AN patient Jim, his wife Amanda, NP Megan, and her friend Jessica. Based on the literature and using a CBPR approach to healthcare for AI/ANs, Megan and Jessica plan several interventions for Jim:

• The most important foundational step for Megan is establishing a trusting relationship with Jim and Amanda. AI/ANs have been abused in the past in both healthcare practices and research studies. During the first few office visits with Jim and Amanda, Megan needs to allow extra time for getting to know her patient, learning about his healthcare history, his work history (if he is experiencing any difficulties accomplishing his job-related duties), and his social history (where he lives, information about his children, finding out if he is able to obtain his medications, his attitude toward healthy eating, what he likes to do outside of work, that is, recreational and physical activities, any stressors such as diabetes distress, and so on).<sup>13,14</sup>

• Discuss Jim's T2DM self-management activities: how often he monitors his BP and weight, foot care regimen, last professional eye exam, last dental exam, immunizations (including COVID-19), and if they are up-to-date. • Review Jim's daily diet and discuss if he incorporates native foods into his meal patterns. Refer to a dietitian for help planning meals that are nutritious and accommodate his food preferences.

• Ask about Jim's consumption of alcohol. If positive for use, assess if this is a problem for him. If alcohol use disorder is suspected, refer Jim for further evaluation to a healthcare professional specializing in alcohol use disorders. Follow up with the patient about carrying through with recommendations.

• Inquire about his physical activity pattern—how much he exercises per week as well as facilitators and barriers to physical activity.<sup>11</sup>

• Inquire about tribal practices that impact his wellbeing such as drumming, incense, sweat lodges, and dancing.

• Inquire about Jim's use of tobacco. Does he use tobacco products, and if yes, how much does he use on a daily or weekly basis? If Jim uses tobacco, discuss the benefits of tobacco cessation, especially regarding his T2DM, as well as available tobacco cessation programs and prescription and nonprescription tobacco cessation aids.

• Screen for depression with an appropriate tool such as the Patient Health Questionnaire-9. Refer to a mental health professional as needed for further evaluation and treatment options.<sup>12</sup>

• Identify small changes Jim can make to his selfcare regimen that may be affecting his adherence to a healthy diet and exercise. Stress that small amounts of weight loss or increased activity can make significant improvements in his T2DM control.<sup>14</sup>

Megan and Jessica discuss other strategies for helping Jim manage his T2DM. The Indian Health Service (IHS) website has culturally appropriate information for managing T2DM. Megan also plans on contacting tribal health services at the reservation where Jim previously lived for culturally appropriate T2DM materials. AI/AN reservations are concerned about T2DM due to the high prevalence in AI/AN populations and likely have culturally appropriate information they can share. Megan is going to use the DPP participant workbook that is freely available as well as handouts from the IHS.<sup>1-3</sup> Using the participant handouts will allow her to help Jim set T2DM goals and record his diet, activity, as well as what happens when he encounters barriers to following his self-management regimen. For patients that prefer an online educational format, the DPP has been successfully translated into an online program.<sup>16</sup>

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Megan will schedule a follow-up appointment with Jim in 8 weeks for further evaluation and to assess the effectiveness of the CBPR lifestyle interventions.

### Conclusion

CBPR indicates that AI/ANs can improve control of T2DM with small changes in weight and physical activity. Culturally appropriate material can make diabetes education more appealing to AI/ANs. This article provides resources the NP can use for T2DM education. The material can be used to provide simple "homework" assignments for their AI/AN patients. All this can occur with the help of a trusting relationship that NPs as premier healthcare coaches can achieve.

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