



HHS Public Access

Author manuscript

J Aging Health. Author manuscript; available in PMC 2022 August 01.

Published in final edited form as:

J Aging Health. 2021 ; 33(7-8 Suppl): 31S–39S. doi:10.1177/08982643211013232.

Food Insecurity and Associated Challenges to Healthy Eating Among American Indians and Alaska Natives With Type 2 Diabetes: Multiple Stakeholder Perspectives

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Abstract

Objective: To examine stakeholder perspectives on food insecurity and associated challenges to healthy eating among American Indian and Alaska Native (AI/AN) adults with type 2 diabetes (T2D).

Methods: Focus groups and interviews were conducted with purposively selected stakeholders: AI/ANs with T2D, their family members, healthcare administrators, nutrition and diabetes educators, and national content experts on AI/AN health. Two coders analyzed transcripts using the constant-comparison method.

Results: Key themes included (1) rural- and urban-dwelling AI/ANs experience different primary food security and associated challenges; (2) factors contributing to food insecurity extend beyond cost of healthy food; and (3) barriers to consuming fresh, healthy food include cost, preparation time, limited cooking knowledge, and challenges with gardening.

Discussion: Resources for AI/ANs with T2D who experience food insecurity and associated challenges to healthy eating should be tailored based on urban versus rural location and should address cost and other barriers to consumption of fresh fruits and vegetables.

Keywords

American Indian and Alaska Native; qualitative methods; food insecurity; type 2 diabetes; diabetes self-management education and support

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Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Introduction

American Indians and Alaska (AI/AN) Natives have the highest prevalence of type 2 diabetes (T2D) among all racial and ethnic groups in the United States (CDC, 2017). These populations also experience a significant burden of associated comorbidities, including hypertension, cerebrovascular disease, renal failure, depression, and lower-extremity amputations (Goins et al., 2017; Schieb et al., 2014; Zhang et al., 2008).

Healthy eating is central to T2D self-management and glycemic control (Franz & MacLeod, 2018; Wilson et al., 2003). People who experience challenges accessing healthy food have worse glycemic control and diabetes outcomes than do those with reliable access to such foods (Berkowitz et al., 2013; Lyles et al., 2013; Seligman & Schillinger, 2010; Seligman et al., 2009). The U.S. Department of Agriculture (USDA) defines food insecurity as the lack of consistent access to enough food for an active, healthy life (Coleman-Jensen et al., 2019). American Indians and Alaska Natives disproportionately experience both poverty and food insecurity (Bauer et al., 2012; Gundersen, 2008; Jernigan et al., 2017; Pardilla et al., 2014), with food insecurity at twice the rate as non-Hispanic whites (Jernigan et al., 2017).

Contributing to food insecurity, AI/AN are more likely than any other racial/ethnic group to live in food deserts, which are defined as areas that have limited access to affordable and nutritious food (Jernigan et al., 2013; Kaufman et al., 2014; O'Connell et al., 2011). Map the Meal Gap data from 2014 indicate that counties home to American Indian reservations have substantially higher rates of food insecurity than do neighboring counties (Gundersen et al., 2016; Gundersen & Ziliak, 2018). Also complicating healthy food access for AI/AN people is the persistent poverty experienced by many AI/AN communities (Gundersen, 2008). Further, forced removal of AI/AN people from their Native lands (Indian Removal Act, 1830) has disrupted access to healthy indigenous foods that were part of traditional Native diets (Gurney et al., 2015).

Food insecurity is a risk factor for poor glycemic management (Lyles et al., 2013; Mayer et al., 2016; Seligman et al., 2009, 2012). Compromised access to healthy food can force individuals to rely on calorie-dense, carbohydrate-rich, processed foods, which are known to negatively impact glycemic management in the general population (Bawadi et al., 2012; Dyson, 2012; Lyles et al., 2013) and AI/AN populations alike (Daley et al., 2017; Edwards & Patchell, 2009; Teufel-Shone et al., 2015). Individuals with T2D who experience poverty and live in food-insecure households may also experience compromised glycemic control because they may direct resources from management of their diabetes (e.g., prescription medications) to household needs (Berkowitz et al., 2013). Additionally, among older adults more generally, food insecurity is associated with compromised medication adherence (Afulani et al., 2015; Sattler et al., 2014).

The objective of this analysis was to examine stakeholder perspectives regarding food access and food insecurity among AI/AN adults with T2D. We analyzed an existing qualitative data set originally collected as a component of a needs assessment to culturally tailor a diabetes nutrition education curriculum for AI/AN adults with T2D. The analysis presented

in this article takes a deeper dive specifically into food insecurity and associated challenges to healthy eating. Our results provide important insight into related barriers to healthy eating among AI/AN adults with T2D.

Methods

Study Design

The reported analysis used data from a qualitative needs assessment conducted to inform the cultural adaptation of an existing diabetes nutrition education program for AI/AN adults with T2D. The American Diabetes Association's (ADA) *What Can I Eat? Healthy Choices for People with Type 2 Diabetes* program is a classroom-based, diabetes nutrition education program for adults with T2D. Classes focus on diabetes nutrition principles such as portion control, food label reading, healthy cooking, physical activity, and mindful stress-reduction activities. The original program was developed for a general audience and was not specific to any particular cultural group (ADA, 2018).

To inform cultural adaptation of the *What Can I Eat? Healthy Choices for People with Type 2 Diabetes* program for AI/AN adults with T2D, the research team conducted a rigorous qualitative needs assessment in four AI/AN communities across the country. Specifically, we worked with AI/AN communities in New York, Illinois, Oklahoma, and California. To ensure that we would be able to understand important geographic differences in access to healthy food, these sites included two rural and two urban locations.

We solicited perspectives on nutrition and diabetes management from a broad range of stakeholders. Throughout this article, we describe and refer to these stakeholders as (1) focus group participants who are AI/AN adults with T2D and their family members; (2) community-based key informants; and (3) national experts. More specifically, focus group participants included AI/AN adults with T2D ($n = 4$ groups) and separate focus groups with their family members ($n = 4$ groups). Additionally, we conducted individual interviews with community-based key informants having expertise in T2D management or traditional foods in our four collaborating communities ($n = 10$ interviews). Finally, we conducted individual interviews with national experts in diabetes, nutrition, and/or AI/AN health ($n = 9$ interviews). Focus groups and interviews followed semi-structured moderator guides and were conducted by an experienced qualitative researcher and first author of this article. All interviews and focus groups were conducted between August and October 2018. Three moderator guides were developed in order to accommodate different vantage points between the three types of stakeholders. All moderator guides addressed topics such as healthy eating in diabetes, diabetes nutrition education, barriers and facilitators to healthy eating, and preferences/recommendations for diabetes nutrition education and support. An example question for focus group participants with T2D included, "Please tell me what it is like to take care of your diabetes and nutrition." An example question for community-based key informants included, "As someone who is not familiar with your community, it would be helpful if you can tell me how people in your community learn about diabetes and how to stay healthy with diabetes." Finally, an example question for national experts was "Please share your thoughts on access to healthful food as it relates to T2D management for AI/AN

communities.” In this article, we describe the findings of qualitative analyses regarding food insecurity barriers to healthy eating and T2D management in AI/AN communities.

Recruitment

At each of the four collaborating sites, a community-based site coordinator recruited participants for the focus groups and community-based key informant interviews. Coordinators solicited participants for the focus groups through word-of-mouth, posted flyers, and postings on frequently used social media sites such as Facebook. They recruited community-based key informants through purposive selection (Patton, 1980), targeting individuals known for their expertise in the community, nutrition/diabetes education, and/or traditional foods. Coordinators reached out to each individual directly to extend a personal invitation to participate.

The project principal investigator and senior author of this article initiated recruitment of national experts, starting with her professional networks. She reached out to experts in diabetes and nutrition in AI/AN communities via a personalized email invitation. Snowball sampling (Patton, 1980) was then used to identify additional interviewees, whom study staff sought to recruit.

Study Participants and Compensation

Eight focus groups were conducted, four with AI/AN adults with T2D ($n = 29$) and four with their family members ($n = 22$). At each of the four collaborating sites, one focus group was held for each group (i.e., AI/AN adults with T2D and family members). Inclusion criteria for AI/AN adults with T2D were 18 years old, fluent in English, self-identified as AI/AN, and diagnosis of T2D. Each participant in the family focus groups was required to be 18 years of age and a significant support person for a participant in one of the focus groups with adults who had T2D.

Focus groups were held in locations familiar to the participants, such as health centers, community clinics, and community centers. The size of the focus groups ranged from 5 to 11 participants and ranged from 62 to 75 minutes in length. Participants each received a \$25 gift card for their time and a healthy meal during the focus group discussion. Prior to the start of the focus group interviews, each participant completed a demographic survey which included age, sex, race, and ethnicity.

Community-based key informants completed individual interviews at each of the four sites ($n = 10$; 8 of whom were AI/AN). These key informants included tribal elders, elected tribal leaders, registered dietitians, certified diabetes educators, mid-level healthcare providers, health education administrators, and health center support staff. Interviews took place in interviewee homes, clinic offices, clinic conference rooms, and one local café, per the participant’s preference. These interviews ranged from 30 to 65 minutes in length. Participants received a \$40 gift card for their time.

National experts from academic or clinical settings outside of the four collaborating sites participated in one-on-one interviews ($n = 9$; 3 of whom were AI/AN). Their expertise spanned a variety of fields: nutrition/diabetes education for AI/AN adults, health education

program development and evaluation for AI/AN adults, and obesity and food security among AI/AN adults and their families. Interviews were conducted using Zoom technology, which allowed for web-based video and audio recording and screen sharing between the interviewer and the interviewee. These participants did not receive compensation for their time, and these interviews ranged from 45 to 68 minutes in length.

All focus groups and interviews were audio recorded. All transcripts were professionally transcribed and checked for accuracy by the lead qualitative researcher. The lead qualitative researcher collected all qualitative data and was accompanied by a notetaker for all eight focus groups.

Analysis

The project team analyzed qualitative transcripts using a content analysis approach (Hsieh & Shannon, 2005; Stemler, 2000). Two researchers reviewed the transcripts and worked closely to establish a code book that included both deductive a priori codes based on the moderator guides and inductive codes that emerged directly from the data. The research team double coded 25% of the transcripts and met weekly until they achieved >80% concordance (Saldaña, 2012). The constant-comparison coding approach included coding data, categorizing the codes, and reorganization of the categories into thematic representation through a series of assertions and interpretations (Charmaz, 2014). Using this method, researchers compared codes, categories, and themes across transcripts to find similarities and differences.

The research team used Atlas.ti (version 8.0) to organize, sort, code, and store data, which helped to facilitate a transparent analytical process (Paulus et al., 2014). Throughout analysis, the lead qualitative researcher also referenced her field notes kept during data collection, notes from focus groups, subjectivity memos, and analysis process memos (Tracy, 2010).

Human Subjects Research Approvals

The University of Colorado Multiple Institutional Review Board (#19–2269) and National Indian Health Service Institutional Review Board (#N19-N-09) approved all study procedures. Participants provided verbal informed consent prior to participating in any study procedures and received an information sheet about the study in lieu of a signed informed consent document per IRB guidelines to maintain anonymity of the participants.

Results

Findings from the demographic survey among focus group participants indicated participants in both the T2D and family focus groups were 59 years on average (range: 23–80 years of age) across all four sites. Over half (63%) of the participants were female. Family members included parents, significant others, adult children, and close friends of AI/ANs with T2D. Of the 22 family member participants, 16 self-identified as AI/AN.

Three primary themes emerged from qualitative data analysis. First, rural- and urban-dwelling AI/ANs experience different primary food security and associated challenges.

Second, factors contributing to food insecurity extend beyond cost of healthy food for both rural- and urban-dwelling AI/ANs. Third, for both rural- and urban-dwelling AI/ANs, barriers to consuming fresh fruits and vegetables include high cost, preparation time, food waste, lack of cooking knowledge, and challenges with gardening.

Theme 1: Rural- And Urban-Dwelling AI/ANs Experience Different Primary Food Security and Associated Challenges

AI/ANs from both rural and reservation locations identified loss of traditional foods as a major challenge to healthy eating. Participants identified traditional foods as those which their ancestors could hunt, fish, gather, and grow on their Indigenous lands. Examples included fish, wild game, acorns, and walnuts. Access to traditional healthy foods has been impaired as a result of environmental pollution and loss of access to the land where these foods were once found. One AI/AN adult with T2D who lives in a rural area of northern California shared:

I think the biggest problem here in [Name of Community] is that every fish in this lake has mercury. And that was our main diet. We were a fishing society (...) and so we traded it with different villages. So, all of that is gone from us, so we don't really have access to really healthy traditional foods anymore.

An AI/AN community-based key informant who lives in rural upstate New York explained the implications of now vacant manufacturing sites that were adjacent to the reservation. She explained that the manufacturing plants emitted polychlorinated biphenyls (PCBs), fluoride, and other chemicals, which contaminated the ground and water ways:

So, it [manufacturing plant] severely polluted the land there by just open dumping of PCB oil and that sort of thing on the ground, which leaked into the surface water, and into the ground, also, into the [Name] river. (...) Fishing was a way of feeding your families. Then there were people who relied on fish to feed their family, and fish to sell to other families to support their family. (...) We also had farms where people had dairy cattle and beef cattle all through the reservation that were large farms, which you don't see anymore. (...) Farmers were noticing that their cattle weren't able to eat, they were dying because of the fluoride (...) We lost our own cattle, we lost our dairy. People then became afraid of eating their own vegetables, out of their own gardens. It was a cultural change, economically it changed. Nutritionally it changed.

Whereas rural-dwelling AI/ANs considered loss of traditional foods to be a primary barrier to healthy eating, urban-dwelling AI/ANs highlighted the cost of healthy food and limited income as their primary food security challenges. One urban-dwelling AI/AN with T2D responded to the interview question "What's it like to take care of your diabetes?" with this statement:

I think it's costly. You know? The way they want you to eat with diabetes. Some people can't afford it. I know I can't afford it. All I get is social security and... I buy what I can at the store and I get only like \$15 in food stamps a month. And so, once a month, I go to the pantry, and you know, you got to get what they give you.

Likewise, a community-based key informant living in an urban community explained the cost as a challenge to healthy eating among older adults with T2D:

I think it's very common to hear people say it's expensive to eat healthy. People don't have, especially older people, don't have the resources to spend as much money as it costs to feed themselves for a week on (...) So, you stop at McDonalds and you get something cheaper, or KFC [Kentucky Fried Chicken] or something like that. Get something a little bit cheaper. It's all about resources.

Theme 2: For Both Rural- And Urban-Dwelling AI/ANs, Factors Contributing to Food Insecurity Extend Beyond the Cost of Healthy Food

Participants highlighted lack of access to healthy food, easy access to fast and processed food, and lack of time to prepare and cook healthy food as significant factors in food-related decision making. For example, one community-based key informant shared the following about difficulties accessing healthy foods:

We have a lot of insecurity with food. I mean, we have patients that live 10 miles or more from a grocery store and so a lot of them shop at Dollar Store or General Dollar and of course they don't have fresh fruits or vegetables there but that's the closest access that they have to food.

A family member of an AI/AN adult with T2D suggested that many AI/AN people have easy access to unhealthy fast and processed foods:

You know [Name of City], in general, we eat out a lot. And a lot of that fast food [it] is greasy, fattening foods. Yeah, there's a lot of fried stuff down this way. It's just easy.

A nutrition educator identified one particular patient's multiple challenges to healthy eating:

I would say for her, time. Like present day time, work. And transportation. Access to foods. Even though we're an urban area. I remember meeting with this patient and she worked all day and then would go home, and then the supermarket was still [an] hour away. I think she was taking public transportation. So that's just hard.

Theme 3: For Both Rural- And Urban-Dwelling AI/ANs, Barriers to Consuming Fresh Fruits and Vegetables Include High Cost, Preparation Time, Lack of Cooking Knowledge, Food Waste, And Challenges With Gardening

When discussing the high cost of healthy food, participants focused on the cost of fresh fruits and vegetables, rarely discussing the high cost of other healthy foods. Another AI/AN with T2D stated:

I think people's biggest struggle is probably not being able to afford fruits and vegetables, enough fruits, and vegetables. You know maybe leaning more towards a lot of potatoes, corn, pasta type foods.

Though participants indicated interest and understanding of the importance of healthful eating for their T2D and overall wellness, some also highlighted a lack of interest in and

time for cooking fresh foods. Regarding preparation of fresh produce, one AI/AN family member shared:

That's one thing that I have a hard time with, it's I don't like to be in the kitchen very long. I don't want to sit there and chop my veggies. I don't want to sit there ... I did it at first for a long time and then I got rebellious. I just got tired of cooking. So, I try to find things at the store that are pre-made and I know that some of them are over-processed. But who has time for all of that?

Participants suggested the need for more education and resources to learn how to prepare and cook fresh produce with limited time and how to “not make cooking be an all-day thing.” Participants also lamented on issues of food waste specific to purchasing and preparing fresh fruits and vegetables, especially for older adults who live alone. When discussing challenges with cooking and shopping for older AI/ANs with T2D, one nutrition educator suggested:

That, and then the knowledge of, “Well, what should I buy?” You could buy all kinds of vegetables and stuff like that, but if you don't know how to cook them, (...) it's going to go to waste. I mean, I've done that.

In reference to gardening, an elder family member of an AI/AN with T2D shared:

This garden at [Name of Community] is advertised all the time. Come and pick your own garden out here. But, do we do it? I do once in a while, when I want tomatoes. But did anybody participate? No.

Finally, one national content expert shared his thoughts on challenges with gardening in AI/AN communities:

I do think that if you're dealing with a scenario where people are very strapped for time and very limited in money that the idea of gardening can feel very overwhelming to them if they haven't ever had that in their family and that's part of their practice. It tends to, at least initially in most communities that I've been in, be something that feels like an added burden or foreign at first.

Discussion

Together, these findings elucidate the experiences and perspectives of multiple key stakeholders regarding food insecurity and associated challenges to healthy eating among AI/AN adults with T2D. The first theme is well-supported by the literature as research suggests that there are different healthy food access barriers for AI/ANs who live in urban versus rural areas (Bauer et al., 2012; Jernigan et al., 2017; Tomayko et al., 2017). Although the majority of AI/ANs (70%) live in urban areas (US Department of Health and Human Services, 2019), many of the most well-established, evidence-based food insecurity research and resource efforts focus on rural- and reservation-dwelling AI/ANs (Gittelsohn et al., 2013; Jernigan et al., 2012; Ornelas et al., 2017). This represents a gap in the literature and highlights a need for evidence-based food security resources for urban-dwelling AI/ANs. In this analysis, one key difference in perspectives between urban- and rural-dwelling AI/ANs was the emphasis on loss of traditional foods among rural-dwelling AI/ANs. Rural-dwelling

focus group participants and community-based key informants discussed traditional foods in terms of foods their ancestors (and themselves during their childhoods) could hunt, fish, gather, and grow on Indigenous lands. It is possible that urban-dwelling AI/ANs in this study have even less physical access and proximity to the land on which their described traditional foods were fished, hunted, gathered, and grown than their rural counterparts, and therefore, urban-dwelling AI/ANs in this study did not identify loss of traditional foods as a primary contributor to challenges with food access and food insecurity. This finding suggests an opportunity to reframe access to traditional foods found in grocery stores that can be traced back to American Indian origins such as beans, corn, and squash (Jones et al., 2020; Vu et al., 2017).

Themes two and three highlight the commonalities seen between communities who experience socioeconomic challenges such as limited income and persistent poverty. Stakeholders in this study shared their challenges with accessing and eating healthy foods, many of which are mirrored in non-AI/AN communities. This concept related to the social determinants of health is important as it highlights the common lived experiences and human connection among diverse audiences who experience food insecurity. This overarching theme of mutual experience can inform food insecurity resources for AI/AN adults by building on effective food insecurity resources for non-AI/AN communities.

As described in the social determinants of health conceptual model utilized by Healthy People 2020, food security is predicated on economic and environmental factors (Office of Disease Prevention and Health Promotion, 2019). To be food secure, people must have the economic resources to purchase healthy foods and also must live in a neighborhood in which healthy foods are accessible (e.g., access to grocery stores and transportation). Participants in this study highlighted economic factors that contribute to food insecurity in AI/AN communities (e.g., high cost of healthy food and poverty). They also noted issues around the built environment, such as easy access to fast food and processed foods from corner or Dollar stores as well as challenges with accessing full-scale grocery stores. These economic and environmental challenges were identified by both urban- and rural-dwelling AI/ANs in this study and have been addressed through innovative food insecurity interventions for AI/ANs who live in rural areas (Gittelsohn & Trude, 2017; Jernigan et al., 2012; Ornelas et al., 2017). There is also a movement to improve the USDA Food Distribution Program on Indian Reservations program, bringing traditional food items such as salmon, bison, and blue corn meal into the program to increase access to these traditional, healthy foods for reservation-dwelling AI/ANs (USDA, n. d.). Along these lines, there are many grassroots efforts to bring traditional foods back into the everyday diets of AI/ANs through community agriculture, prioritizing food sovereignty efforts, and drawing on cultural practices of “food as medicine.” Food as medicine efforts focus on the inherent healthy and healing properties of food for both disease prevention and treatment, opposed to utilizing pharmaceutical treatment. The majority of these efforts are focused on reservation- and rural-dwelling AI/ANs (Adamson, 2011; Conti, 2006; Hossfeld et al., 2017; Weiler et al., 2015). Our findings suggest that interventions to improve access to healthy foods, both financial and logistic, would also help urban-dwelling AI/ANs with T2D in improving their healthy eating habits.

Participants from both urban and rural areas highlighted the lack of key resources, such as time and cooking skills, as a contributor to unhealthy diets among AI/ANs with T2D. People faced with the challenge of healthy eating often implement suboptimal solutions to deficits in time and cooking skills. They may rely on convenient, processed, fast, or ready-prepared foods, which are unlikely to contribute in a positive way to their health. These practices are also well-supported by the literature in non-AI/AN audiences (Breland et al., 2013). In addition to high cost of fresh produce, scarcity of time and cooking skills also complicates the ability to prepare and consume at least five servings each day of fruit and vegetables, which the American Diabetes Association suggests should fill half of the plate for healthy T2D and weight management diets (Evert et al., 2019).

Our findings suggest that conventional nutrition education classes and community gardening interventions aimed at increasing access to fresh produce may not adequately serve AI/ANs who perceive lack of time and deficits in cooking skills as primary barriers to consuming fresh produce. Yet, the findings suggest that cooking or meal preparation education may help mitigate some of the perceived barriers to healthy eating. As indicated in the literature, interventions that focus on cooking, meal preparation, and food resource management (such as meal planning, developing menus, grocery shopping with a list, and grocery shopping in bulk) can improve diets among participants who experience financial and physical access barriers to healthy eating (Crouch & Dickes, 2017; Kaiser et al, 2013, 2015). An example of an effective cooking education program includes Cooking Matters, a program aimed to end childhood hunger by helping families with young children learn to make affordable, healthy meals on a limited budget (Pooler et al., 2017; Share our Strength, n. d.).

Our findings provide a foundation for developing future T2D nutrition education resources for AI/AN adults who experience food insecurity and associated challenges to healthy eating, with the goal of improving diabetes outcomes in AI/AN communities. Similar qualitative studies have explored barriers to diabetes self-management among non-AI/ANs who experience low income and have served to inform interventions for these groups (Rendle et al., 2013). Solutions to addressing food insecurity for non-AI/AN people with T2D in urban areas include medically tailored meals (Berkowitz et al., 2019), food bank-based education (Seligman et al., 2018), and fruit and vegetable prescription programs (Bryce et al., 2017). However, we do not know of any rigorously evaluated, evidence-based interventions that have specifically addressed urban-dwelling AI/AN adults with T2D who experience food insecurity. Interventions that include partnerships with urban Indian clinics, health centers, and community gathering spaces may be effective ways to serve this audience. Given that tailored interventions are more effective, the lack of food insecurity interventions designed specifically for urban-dwelling AI/AN people, who experience high rates of food insecurity and T2D, is of concern (Conti, 2006; Fleischhacker et al., 2012; Kattelman et al., 2009).

Limitations

As with all qualitative studies, these findings are not intended to generalize beyond this sample (Carter & Little, 2007). Additionally, all four of our collaborating sites had robust diabetes education/care programs with registered dietitians who provide cooking classes and

group education classes. It was from these programs that focus group participants were recruited. Outside of these four sites, some AI/ANs may not have access to comprehensive diabetes education/care programs. Hence, our study participants' experiences with food insecurity and associated challenges to healthy eating may differ from those who have less access to diabetes care services.

Implications and Next Steps

These findings will support future efforts to develop and evaluate resources for urban-dwelling AI/ANs with T2D who experience food security and associated challenges to healthy eating. These findings can be expanded to address other nutrition-related chronic conditions, as well, such as obesity, hypertension, heart failure, and cardiovascular disease, all of which could be negatively impacted by food insecurity (Dinour et al., 2007; Seligman & Schillinger, 2010).

Acknowledgments

We would like to thank the study participants for generously sharing their time and insight. We also are grateful for the efforts of our site-based research coordinators: Nancy O'Banion, Heather Garrow, Gemalli Austin, and Daniella Bellinger.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by the American Diabetes Association [4-18-SMC-01; PI: Moore], the National Institute on Aging-funded Native Elder Research Center [P30 AG15292; PI: Manson], and the National Institute of Diabetes and Digestive and Kidney Diseases-funded Center for American Indian and Alaska Native Diabetes Translation Research [P30 DK092923; PI: Manson].

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