

11-2020

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Recommended Citation

Pollak, Margaret (2020) "Diabetes Care in an Urban Indigenous American Community: Challenges and Suggestions for the Future," *Midwest Social Sciences Journal*. Vol. 23 : Iss. 1 , Article 8.

DOI: 10.22543/0796.231.1029

Available at: <https://scholar.valpo.edu/mssj/vol23/iss1/8>

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***Diabetes Care in an Urban Indigenous American Community:
Challenges and Suggestions for the Future****

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ABSTRACT

Indigenous Americans living with type 2 diabetes in urban areas like Chicago face significant challenges to meeting the care recommendations of their medical providers. Based upon mixed-methods research, including both qualitative and quantitative measures, in Chicago's Indigenous community, I have found that diabetes-care and -prevention challenges faced by individuals in this community include (1) the high financial and time costs of care, (2) lack of recognition of or response to acute symptoms of high glucose levels, (3) prioritization of other life responsibilities, (4) distrust of western medicine, and (5) fatalistic views about diabetes development and prognosis. If we are to reduce rates of type 2 diabetes and its related complications in Indigenous American populations, we need to reframe our view of who Indigenous peoples are and what the type 2 diabetes epidemic means in these communities, and consider how to best develop solutions for care that are feasible in urban settings. This aim can be achieved through a greater awareness of the challenges faced by urban Natives caring for type 2 diabetes and by engaging with these communities to develop collaborative programs to improve care in these settings.

KEY WORDS Native American Health; Anthropology; Chronic Condition Care; Urban

The Indigenous peoples of the Americas face significant disparities in health and in access to health care in the United States of America. Urban Indigenous communities are affected by these disparities while being one of the most understudied and underserved

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I am greatly indebted to members of Chicago's Native community who have shared their diabetes care experiences in this study.

This research was supported by the National Science Foundation Cultural Anthropology Program (award number BCS-1226577), the Robert Wood Johnson Health and Society Scholars Program (award number 053574), the American Philosophical Society, the Mellon Foundation, Northwestern University's Global Health Studies Program, and the University of Wisconsin's Holtz Center for Science and Technology Studies, Anthropology Department, and Graduate School.

ethnic minority populations within the nation. Today, nearly 80 percent of Indigenous peoples in the United States live outside of reservations, with the majority of those living in urban areas (Norris, Vines, and Hoeffel 2012). All data on Indigenous health, however, is skewed toward reservation spaces, where the majority of Indian Health Services facilities can be found and from which the Centers for Disease Control and Prevention gathers its data on Indigenous health. Nationally, Indigenous peoples have the highest rates of diabetes, with 15.1 percent of the population living with the disease (Centers for Disease Control and Prevention 2017). Although there are drastically fewer studies of urban Indigenous health, several studies have identified high rates of diabetes in these populations (Kramer 1992; Rhoades, Roubideaux, and Buchwald 2004). Studies have also found that urban Indigenous peoples face higher rates of diabetes-related mortality (Jacobs-Wingo et al. 2016). In this article, I investigate the challenges to diabetes care in an urban population and offer suggestions for improving care models for the future.

Indigenous peoples living with diabetes in urban areas, like Chicago, Illinois, face significant challenges to meeting the diabetes care recommendations of their medical providers. These populations are overlooked by health communities in city spaces. Although the majority of Indigenous people live in city spaces, they still make up a relatively small proportion of the city populations. For instance, in Chicago, the city with the eighth largest Indigenous population, Indigenous people made up 0.5 percent of the population, according to the 2010 Census (Norris et al. 2012; United States Census Bureau 2012). Despite their relatively small size in terms of total population, urban Indigenous peoples and their health concerns need, and deserve, attention. Based upon 26 months of qualitative and quantitative research, in this article, I describe the challenges to meeting diabetes-care needs in an urban indigenous community, and I suggest some ways to meet the needs of urban Indigenous communities through a collaborative approach.

MATERIALS AND METHODS

This paper is based upon 26 months of research I conducted with Chicago's Indigenous population between 2007 and 2017.¹ I used both qualitative and quantitative methods in this study, including 124 semistructured interviews and the collection of 53 surveys.

I recruited interview participants using the snowball method of sampling. I first met several medical practitioners, diabetes patients, and caregivers through the wellness department of the American Indian Center (a cultural community center). Those first interviewees introduced me to additional research participants. I completed 124 interviews with 97 participants for this study (Table 1). Interviewees identified themselves as citizens of 26 American Indian Nations from across the United States and Canada. The study included 93 interviews about diabetes with individuals living with type 2 diabetes, as well as with family caregivers and medical professionals. These semistructured interviews investigated individual understandings of diabetes and experiences with its daily care. The 31 remaining interviews were oral history interviews conducted with community elders about their experiences relocating to Chicago in the mid-20th century.

Table 1. Interview Participants

	Diabetes Interviews N (%)	Caregiver Interviews N (%)	Biomedical Provider Interviews N (%)	Oral History Interviews N (%)
Gender				
Male	15 (37.5%)	13 (43.3%)	1 (7.7%)	9 (33.3%)
Female	25 (62.5%)	17 (56.7%)	12 (92.3%)	18 (66.7%)
Age				
18–30	4 (10.0%)	7 (23.3%)	3 (23.1%)	0 (0%)
31–45	8 (20.0%)	9 (30.0%)	2 (15.4%)	0 (0%)
46–60	13 (32.5%)	13 (43.3%)	5 (38.5%)	11 (40.7%)
61–75	13 (32.5%)	1 (3.3%)	3 (23.1%)	11 (40.7%)
76+	2 (5.0%)	0 (0%)	0 (0%)	5 (18.5%)
Years with diabetes				
Less than 1	8 (20.0%)	—	—	—
1–2	5 (12.5%)	—	—	—
3–5	10 (25.0%)	—	—	—
6–10	4 (10.0%)	—	—	—
11–15	5 (12.5%)	—	—	—
16–20	1 (2.5%)	—	—	—
21 or more	7 (17.5%)	—	—	—
Has type 2 diabetes				
Yes	40 (100%)	0 (0%)	3 (23.1%)	12 (44.4%)
No	0 (0%)	30 (100%)	10 (76.9%)	15 (55.6%)
Type of care provider				
Physician	—	—	1 (7.7%)	—
Dietician	—	—	1 (7.7%)	—
Nurse	—	—	7 (53.8%)	—
Community health worker	—	—	4 (30.8%)	—
Works primarily with Native population				
Yes	—	—	10 (76.9%)	—
No	—	—	3 (23.1%)	—

Note: Overlap of participants exists across the diabetes interviews and oral history interviews.

Dietary surveys were collected at a community event held in November of 2015 at the American Indian Center; 53 community members completed an 11-page survey about their demographic information, their general health and health care choices, and their typical eating habits.

I analyzed interview data using NVivo coding software. Important themes were identified by analyzing the frequency of mention or occurrence in the data. I analyzed

survey data by entering responses in an Excel workbook and computing data for relevant demographic information. In this article, I focus on the data from interviews, as they provide a rich view of the complicated nature of diabetes care in Chicago's Indigenous community. Survey data provide some basic demographic information about this population to supplement the interview data.

RESULTS

Indigenous Americans living with diabetes in urban areas, like Chicago, face significant challenges to meeting the diabetes care recommendations of their medical providers. I contend this is not an issue of noncompliance with doctors' recommended care routines; rather, these challenges result from the complexity of caring for diabetes within this population in the urban space. Study participants living with diabetes, as well as their family caregivers, understand their doctors' recommended diabetes care guidelines: to monitor blood glucose levels with home testing supplies, and to manage blood glucose levels by taking medications as prescribed, counting and limiting carbohydrates consumed throughout the day and increasing physical activity when possible. The feasibility of meeting their doctors' recommended orders, however, is hindered by other factors in their lives, including financial and time costs of care, not recognizing or responding to acute symptoms of high glucose levels, other life responsibilities, distrust of western medicine, and fatalistic views about diabetes development and prognosis. As I will show below, some of these factors compound with one another to further complicate and hinder care in this situation. Below, I outline these factors before discussing ways to engage with communities to overcome some of the challenges they face.

Riddle and Herman (2018) describe the cost of diabetes care as the elephant in the room for practitioners aiming to improve the daily care of their patients. For patients caring for the disease daily, cost is not the elephant in the room but rather the elephant positioned on their chest and preventing them from meeting the daily diabetes care routines. Joan, a 49-year-old Potawatomi–Puerto Rican woman, explained, for instance, that she understood the basic components of what type of diet she should eat to manage her glucose levels, a diet she developed in consultation with a registered dietician.² She found, however, that the food items recommended by her care team were ultimately more expensive to purchase than the higher-calorie and lower-nutrient foods that better fit into her family budget: “Well I see her [the dietician], but then the stuff she tells you are like impossible. I tell her sometimes when you're on a fixed income it's impossible to buy what you're supposed to have.”

Based on the 2015 survey data collected in this study, 20.4 percent of this population live below the 2015 national poverty line. Additionally, another 38.8 percent live on the border of the poverty line, with incomes just \$1,000–\$5,000 above the poverty threshold for their household size (Table 2). In addition to the higher costs of healthier foods that Joan references are the increasingly high costs for diabetes care supplies: insulin, oral medications, and blood glucose testing supplies. According to self-reported insurance status for the survey participants, 37.0 percent of this population do not have health insurance, 6.5 percent are covered through Medicare, 26.1 percent have health

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insurance through their employers, and 30.4 percent have insurance through their own means (Table 3). Many Indigenous Americans living in Chicago may receive health services and medications at a reduced or minimal rate through American Indian Health Services of Chicago (AIHSC), which is located in Chicago's Uptown neighborhood. Although this neighborhood was once home to a significant portion of Chicago's Indigenous population, most of the Indigenous population no longer live in this neighborhood because of rising housing costs thanks to gentrification, so access to these lower-cost care services and supplies are limited by the location of AIHSC and its nearby partner pharmacy.

Table 2. Participants' Economic Status

	<i>N</i> = 49
Households below the poverty line	10 (20.4%)
Households near the poverty line	19 (38.8%)
Households well above the poverty line	20 (40.8%)

Note: Four of the 53 respondents did not reply to this question.

Table 3. Participants' Insurance Status

	<i>N</i> = 46
Uninsured	17 (37.0%)
Insured through employer	12 (26.1%)
Insured through own means	14 (30.4%)
Medicare	3 (6.5%)

Note: Seven of the 53 respondents did not reply to this question.

Building upon these issues of high financial costs of food and medical care is the issue of distrust in the western medical profession, particularly when run and funded by the government. Individuals in Indigenous communities around the United States base this distrust upon past atrocities committed under the guise of healthcare offered by the U.S. government as part of treaty agreements, and because of this history, urban Indigenous Americans are apprehensive of western medical care. (See Pearson [2003] and Harmon [2010] for examples and discussions of this history.) Financial cost is also a significant issue for urban Natives in completing their diabetes care routines, and seemingly clear-cut avenues for reduced-cost medical services and supplies do not necessarily resolve the issue for them.

Another form of cost that inhibits the capability of Chicago Natives to care for their diabetes in the ways they would like is time cost. Living in Chicago, where commute times are the third longest nationwide, at just under 60 minutes round trip, can limit the time available to prepare wholesome meals, remember to test blood glucose

levels, ensure that medications are taken as prescribed, and find time to be physically active (Robert Half 2017). In this population, people report not just commute times but also work responsibilities, caring for children and grandchildren, and household needs as factors limiting their time available to care for diabetes. Carmen, a 69-year-old Oneida woman living with diabetes, explained in this way:

I don't eat regular like I should I try to, but it's so hard when you gotta go to work and this and that and you just don't have time. . . . I usually forget to take my medicine. . . . So usually when they come, the American Indian Health comes on Wednesdays . . . it [her blood glucose level] is usually pretty high. It's in the two hundreds, you know.

When reading Carmen's statement, one may wonder how she does not recognize prior to testing that her blood glucose is elevated. In interviews with Indigenous individuals living with diabetes, I found that the majority interviewed noted that they do not always feel physically ill when their blood glucose is elevated, so the urgency of caring for diabetes may not be immediately felt, whereas work, family, and other health-care responsibilities can represent more-pressing concerns. In this community, 72.5 percent of individuals living with type 2 diabetes were living with other health conditions (Table 4). Diabetes care is not a priority because for many, the symptoms of high blood glucose levels may not be felt or recognized in the early years after diagnosis.

Table 4. Participants Living with Type 2 Diabetes and One or More Other Diseases

	<i>N</i> = 40
Living with diabetes and one or more other diseases	29 (72.5%)
Living with diabetes alone	11 (27.5%)

If a majority of individuals living with diabetes do not recognize the immediate signs of elevated blood glucose levels and they have limited access to diabetes-management supplies, there is little way for this issue to be resolved as it currently stands. Greater access to glucose-testing supplies would help to increase awareness of the individual signs of high, low, and normal blood glucose levels. When diabetes patients cannot afford blood glucose monitors and test strips, they tend to their diabetes management on their own terms. Some individuals, such as Sylvia, a 67-year-old Chippewa woman, explain that although they cannot measure their glucose levels as often as recommended, they do strive to keep an eye on their diabetes management through resources available in the city, including free glucose screenings at community events and at local pharmacies. In some cases, free glucose monitoring is the only option patients have to test their glucose levels. Although this free testing available at community centers is incredibly valuable to members of this population, it is not a long-term solution. People of all racial and ethnic

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backgrounds who are caring for diabetes need to have access to affordable glucose-testing supplies at home for successful diabetes management.

A final and unique component of diabetes-care challenges in Chicago's Indigenous community is the ubiquity of diabetes in this population. Many of the challenges described above are common across many racial and ethnic populations living with diabetes. One distinctly Native challenge to diabetes care is the commonality of this disease in the population. In the 2009 stage of this research, an informal raise-of-hands survey taken during a community event attested to the high rate of diabetes diagnosis in Chicago's Indigenous population; at this event, when the dietician asked who had a family member with diabetes, nearly every attendee in the crowd of more than 50 people raised a hand. In informal conversations with Indigenous individuals during the years of this study, I spoke with individuals who were not living with diabetes but who insisted that it was only a matter of time before they developed the disease; these people often said that they were "not diabetic yet." This conception of heightened risk for diabetes development is not only based on the ubiquity of diabetes in this local community but also further heightened and shaped by public health campaigns.

Throughout local community and health centers, individuals can find pamphlets from the American Diabetes Association and the National Diabetes Education Project that promote lifestyle changes to prevent and stop diabetes. While each of these pamphlets and posters with hopeful messages supports ideas of control and prevention, these message of hope and support were preceded by descriptions of Indigenous Americans as being at high risk for diabetes. This media states, "Type 2 diabetes is more common than ever in young American Indians and Native Alaskans," and "Diabetes is a growing problem for Native Americans. Many Native Americans have Type II diabetes." This labeling of groups of people as at risk has an unintended lasting effect on the groups identified as such. It leads to fatalistic views, which may inhibit the taking of proactive steps toward diabetes prevention in a group such as Chicago's Indigenous community.

Chicago's Indigenous community has mixed responses to fatalistic conceptions of diabetes. There are people in the community who believe they will develop diabetes and do not take action to change their lives to prevent it. In an interview, Roy, a 35-year-old Oglala Sioux-Navajo man, expressed a concern that he is likely to develop the disease someday. Though he believes he is at risk for developing diabetes, Roy explains that he is not ready to find out if he has diabetes at this point in his life:

I've thought about, but then thinking about it's like, if you really want to know, it's like, going to change your whole life. And right now I don't want that to change. I mean I'm aware of it, and I've always thought about it too every once in a while, like, you know those sweets right there, I want it, you know.

There are also people who believe they will develop diabetes but, unlike Roy, adjust their lifestyles by eating what they consider healthier foods and increasing physical activity to prolong the time before they will develop the disease. Although fatalistic

views are widespread in this community, some participants describe making life adjustments with the expectation that they can and will prevent the development of type 2 diabetes altogether, so while fatalistic views about the disease are prevalent in this population, some members are actively engaging in lifestyle activities that they intend to either prevent the disease entirely or extend the time before its development. Ultimately, the prevalence of the disease in conjunction with public health media fostering the idea of heightened risk of diabetes in this population can lead to fatalistic views about its development, and in some cases, this can inhibit and prohibit steps toward prevention.

The majority of participants in this study described a real desire to care for diabetes and to prevent the development of complications, but obstacles stand in their way. Some of these obstacles are common across multiple populations with diabetes—particularly obstacles related to costs of diabetes care. Other obstacles are unique to this community—notably the distrust of western medicine and the ubiquity of the disease in the community. If we are to effectively reduce rates of diabetes and its complications in Indigenous American populations, we need to reframe our view of who Indigenous Americans are and what the diabetes epidemic means in these communities, and to consider how to best offer solutions for care that are feasible in the urban setting. This aim can be achieved through engagement and collaboration with these communities.

DISCUSSION

Although there is no quick fix for this situation, I see this as an opportunity to open a conversation about how to better ally with marginalized and underserved communities afflicted with high rates of chronic conditions such as type 2 diabetes.

First and foremost, work on diabetes care and prevention needs to be collaborative, engaging with the population in need of care. This is particularly true because the vast majority of diabetes-care and -prevention work is done outside of clinical settings. Local community members know their own needs and capabilities best, and engaging with leaders in local communities will produce better long-term outcomes. There are projects with demonstrated success in preventing diabetes in Indigenous communities, and collaborative work within Indigenous communities in the past has demonstrated real promise in projects relating to diabetes prevention (Jiang et al. 2013; Macaulay et al. 1998; Potvin et al. 2003). This is an area that offers great possibility for future success. Based on interviews and discussions at community events in this study, there are three ways in which progress toward more effective diabetes care can begin: (1) increasing education about healthy living, (2) reframing our views health and care, and (3) returning to traditional practices in the city space to improve care.

In this study, I asked each interviewee what they would like to see happen in the future. The overwhelming majority of community members said they would like to see more education. They would like to see education about diabetes that offers feasible suggestions for preventing diabetes and improving its care. Further, they see diabetes as only one area in a larger health-education need. The development of wellness education programs that focus on how to not only prevent diabetes but also improve health more generally would be of the greatest benefit. Some examples

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include cooking classes on how to make healthier versions of meals that families enjoy and are easy to make, and promotion of increasing physical activity by showing people how to work physical activity into their already busy lives so such activity is both nonthreatening and attainable.

The second area where care can improve for diabetes is the reframing of our ideas of diabetes care into a broader scheme of health care. The majority of participants interviewed in this study who were living with diabetes were also living with other health conditions, including high blood pressure, heart disease, arthritis, cancer, and obesity (Table 4). Recognizing that diabetes rarely occurs on its own and is part of a larger health challenge that needs to be addressed in a new way is the first step in this process. Some of the examples of education that foster improved care of the whole body—promoting physical activity in attainable ways, for instance—would be beneficial not only for diabetes care and prevention but also for heart health and weight control.

The incorporation of traditional Indigenous practices into diabetes prevention and care could be revolutionary in the urban setting. Diabetes treatment programs incorporating traditional cultural practices such as talking circles and Native games as well as traditional foods have been effective in reservation spaces (Bruna 2015; Olson 1999, 2001; Smith-Morris 2006; Venkat Narayan et al. 1998; Wilson et al. 1994). Chicago's Indigenous community has been focused on programming that weaves together traditional activities and city life throughout much of its history—for instance, the American Indian Center planted a traditional medicinal garden outside its building, and American Indian Health Services of Chicago developed diabetes talking circles. Partnering with local community centers that are already engaged in the development of programming based in traditional practices offers great potential for future diabetes prevention and care in this community.

In addition to these three areas that offer some tangible possibilities, we need to see larger societal change for improving the health of not just urban Indigenous populations but the broader U.S. population. Food that is nourishing, filling, and healthy needs to be accessible to everyone, whether they reside in urban or rural spaces. People need better-paying jobs and greater access to health care and medical supplies. Meeting these aims is no small charge, but if health is to be equitable, these larger social issues need to be addressed.

ENDNOTES

1. This study was approved by the Social and Behavioral Sciences Internal Review Board of the University of Wisconsin–Madison under protocol number SE-2009-0188, the Minimal Risk Internal Review Board of the University of Wisconsin–Madison under protocol number 2012-0345, and the Social and Behavioral Sciences Internal Review Board of Northwestern University under protocol number 00201965.
2. All names are pseudonyms.

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