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Glossary

| **Activities of daily living (ADLs)** | Activities of daily living are basic activities a person must perform during a normal day to remain independent. These daily activities can include getting in and out of bed, dressing, bathing, eating, walking, and using the bathroom.¹ |
| **Functional disability** | Functional disability is defined as “personal restrictions in performing fundamental physical and social activities.”² |
| **Type 1 Diabetes** | Type 1 diabetes is a chronic condition caused by an autoimmune reaction that breaks down the cells in the pancreas that generate insulin. With this reaction, the body does not produce insulin, a hormone that allows blood sugar to be broken down and used for energy. Type 1 diabetes is typically diagnosed in children, teens, and young adults; however, it can develop at any age.³ |
| **Type 2 Diabetes** | Type 2 diabetes is a chronic condition in which the body does not respond normally to insulin. Without an adequate response to insulin, the body cannot regulate blood sugar, and blood sugar levels rise. Type 2 diabetes typically develops in adults over 45 years of age.⁴ |
| **Comorbidity** | Comorbidity is the simultaneous presence of two or more chronic conditions (diabetes, heart disease, cancer, etc.,) in the same person.⁵ |
| **Long-term services and supports (LTSS)** | LTSS are a set of health, personal care, and social services delivered over an extended period to persons unable to perform their activities of daily living independently. LTSS may be provided in a variety of settings, including the person’s home.⁶ |


⁵ See footnote 2.

Executive Summary

Introduction and Methodology

American Indians and Alaska Natives (AI/ANs) experience disproportionately high rates of diabetes. In 2017, the Centers for Disease Control and Prevention (CDC) reported that the prevalence of diagnosed diabetes among AI/ANs was more than double the rate found among non-Hispanic Whites. This high prevalence, coupled with increasing lifespans, can result in high disability rates due to complex long-term health and personal care assistance needs among AI/ANs with diabetes.

The care complexities directly related to diabetes in Indian Country emphasize the need for culturally appropriate long-term services and supports (LTSS) for AI/ANs. LTSS are usually provided in an individual’s own home and include a broad set of services—health care, personal care, and social services—for the chronically ill, people with disabilities, or elderly individuals who need assistance with activities of daily living (ADLs). This report provides a brief summary and an annotated literature review of 19 different articles that focus on diabetes and subsequent LTSS needs among AI/ANs. The articles were published in peer-reviewed journals and obtained through several databases, including EBSCOhost, PubMed, and SAGE. The report:

- provides background information about diabetes in Indian Country, including the prevalence of diabetes among AI/ANs, and sociocultural aspects of the disease,
- discusses the heightened LTSS concerns of older AI/ANs with diabetes and comorbidities due to possible increases in functional disability,
- outlines the importance of diabetes self-management and the challenges to successful self-management in Indian Country,
- describes sources of funding and support for diabetes LTSS needs in Indian Country, and
- provides key take-aways for tribes interested in developing LTSS for individuals with diabetes in their communities.

Background Information

Diabetes, specifically type 2 diabetes, is a serious illness in Indian Country that did not exist pre-contact and was rare until the middle of the 20th century. Since World War II, it has become one

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of the most common serious diseases among AI/ANs. Although the etiology of these high rates of type 2 diabetes are unclear and complex, high rates of type 2 diabetes have been observed in other populations of tribal people who have become westernized. It is likely that both a genetic predisposition to type 2 diabetes and environmental factors have contributed to the dramatic increases in the AI/AN population.

According to the CDC’s 2017 National Diabetes Statistics Report, AI/ANs have the highest rate of diagnosed diabetes among all racial/ethnic groups in the United States. The CDC reports that the proportion of AI/AN adults (18 years and older) with diagnosed diabetes is 15.1%. In comparison, the prevalence of diagnosed diabetes among non-Hispanic White adults is 7.4% (CDC, 2017b). Table 1 lists the prevalence of diagnosed diabetes among different racial and ethnic groups in the United States.

Table 1. Prevalence of Diagnosed Diabetes by Race/Ethnicity in the U.S., 2015 (CDC, 2017a)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Prevalence of Diabetes (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Indians &amp; Alaska Natives</td>
<td>15.1</td>
</tr>
<tr>
<td>Non-Hispanic Blacks</td>
<td>12.7</td>
</tr>
<tr>
<td>Hispanics</td>
<td>12.1</td>
</tr>
<tr>
<td>Asians</td>
<td>8.0</td>
</tr>
<tr>
<td>Non-Hispanic Whites</td>
<td>7.4</td>
</tr>
</tbody>
</table>

**Sociocultural Aspects**
AI/AN social experiences with diabetes can manifest itself in a cultural understanding of diabetes, which contributes to complications and severe comorbidities. In a 2008 study, Cavanaugh, et.al. described fatalism, denial, and hopelessness as contributors to late diagnosis, poor management, and the resultant poor outcomes from the disease. Perceived outcomes seen as inevitable results of having diabetes and reviewed in the study included amputations, dialysis, blindness, and cardiovascular disease.

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This social understanding of diabetes can delay diagnosis, limit treatment compliance, and cause additional stress to tribal members. Coupled with limited health care access, food deserts, sedentary lifestyles, and a poor understanding of how to manage the disease, AI/ANs face many more negative outcomes than non-tribal people with diabetes.

**Comorbidities of Diabetes and Disability**

Long-term effects of comorbid conditions make LTSS needs of older AI/ANs with diabetes more complex than those of other groups. The occurrence of two or more chronic conditions in an individual (comorbidity) is common among older adults; however, a 2010 study assessing data from the Native Elder Care Study found that older American Indians experience more comorbidities than other racial and ethnic groups in the U.S.\(^\text{13}\) Specifically, the study found that older American Indians (55+) have higher rates of diabetes, hypertension, back pain, and vision loss.\(^\text{14}\)

A 2005 study that assessed functional disability among older (65 years and older) American Indian and White adults with comorbid diabetes found higher levels of disability among the American Indian study participants (Goins et al., 2005). The authors defined functional disability as “personal restrictions in performing fundamental physical and social activities” (Goins et al., 2005). The study participants had all been diagnosed with both type 2 diabetes and one chronic condition such as arthritis, heart disease, cancer, hypertension, or a respiratory disease. The American Indian study participants reported more severe limitations on their ADLs than did the White participants. Among the American Indian participants, 24% reported having three or more ADL limitations, compared with 3% among the White participants (Goins et al., 2005).

**Diabetes Self-Management and Challenges in Indian Country**

The literature and research suggest that timely diagnosis and self-management are key to successful long-term management of diabetes (Arcury et al., 2012; Jernigan & Lorig, 2011). Self-management elements of diabetes care include proper nutrition, physical activity, medication management, monitoring of blood glucose levels, and foot care (Arcury et al., 2012). Given the complexities of diabetes self-care, the American Diabetes Association recommends that all individuals with diabetes receive diabetes self-management education and support (DSME/S), both upon diagnosis and as needed.\(^\text{15}\)

AI/ANs may receive DSME/S through their health care provider, through their Title VI Elders’ Program, and/or through programs supported by the IHS Special Diabetes Program for Indians.

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\(^\text{14}\) See footnote 12.

(described in greater detail in the “LTSS Support for Diabetes in Indian Country” section on pages 5-6). However, disparities and barriers may hinder diabetes self-management among AI/ANs. These disparities and barriers include the impact of trauma and stress, social assumptions about the results of a diabetes diagnosis, attempts to spare family members from knowledge of the diagnosis, lack of access to and knowledge about healthy foods, and the rural location of many tribal communities. Each of these topics will be discussed in greater detail below.

**Impact of Trauma**
One factor that may hinder the capacity for self-management among AI/ANs with diabetes is the high rates of stress and mental disorders resulting, in part, from the impact of trauma on tribal communities. A 2007 community-based study that assessed epidemiologic data from members of Southwest and Northern Plains tribes found that depressive disorders and alcohol dependence significantly elevated the likelihood of diabetes in the American Indian tribal communities (Jiang et al., 2007). A 2017 study of older (55+) American Indian women with type 2 diabetes reported a significant association between psychological trauma and heightened blood sugar levels, indicative of poorer diabetes control (Goins et al., 2017). Stress and mental disorders then, put AI/ANs at risk of complications of poor control, and may account for the high rate of comorbidities in this population.

**Rural Locations of Tribal Communities**
Rurality is also a factor in AI/ANs’ access to diabetes care. Challenges to diabetes management associated with rural locations of tribal communities include the following factors: long distances to be traveled in order to access care, difficulties with accessing transportation, and long wait times and scheduling processes to obtain care (Nicklett et al., 2017). The use of internet-based diabetes self-management workshops emerged as a potential intervention to help AI/ANs living in rural areas with diabetes self-management. A 2011 study of pilot tests of the Stanford Internet Diabetes Self-Management workshop (IDSMW) among AI/ANs with type 2 diabetes found that the workshop was well received and considered useful (Jernigan & Lorig, 2011). The IDSMW was tailored for use among AI/ANs. Participants reported that the opportunity to interact with other AI/ANs and to discuss issues related to their diabetes care was valuable. Specifically, the opportunity to discuss depression related to diabetes was noted as valuable because participants expressed that they could not have those conversations in their home communities (Jernigan & Lorig, 2011).

**Access to Healthy Food**
Another theme in the literature that may affect self-management among AI/ANs is lack of access to healthy foods and a dearth of knowledge about diet and nutrition (Kelly, 2017; Shaw et al., 2013). A 2017 study that assessed perceptions of healthy eating and diet among American Indian youth in New Mexico reported a lack of knowledge about and access to healthy foods. Participants identified sugary cereal as healthy and assumed that a sugary breakfast served at their school was healthy (Kelly, 2017). The participants also reported a shortage of grocery stores and that most of their food is purchased from fast-food and convenience stores. A 2012 study looked at food access and cost in Indian communities in
Washington State. Reservations which were the furthest from supermarkets had less access to fresh fruits and vegetables and unprocessed meats. Prices in convenience stores were nearly twice those in supermarkets on these items.

The Need to Incorporate Traditional Social Concepts and Food
A discussion about diabetes in Indian Country would not be complete without reviewing the 2006 work of Schulz, et al. In this classic review, two genetically linked populations were compared; one the Pima Indians in Arizona and the other their counterpart in Northern Mexico. The US Pima eat a traditional America diet and live sedentary lifestyles. The Mexican Pima continue to live the agrarian life of their common ancestors and are active about three times as many hours per week. Prevalence of diabetes for the Mexican Pima was 5% and 7% (for men and women respectively) and for the U.S. Pima 32% and 41% (for men and women respectively). The study implies that traditional diets which are lower in fat, lower in calories, and substantially higher in fiber have some benefit for tribal populations.

The literature suggests that incorporating traditional AI/AN behavioral and social concepts and strategies into self-care may be a beneficial approach for diabetes self-management, particularly among older AI/ANs. For example, a 2016 systematic literature review reports that older AI/ANs who identify with traditional AI/AN ways of life are less likely to adhere to self-management recommendations from their health care providers, partially because of distrust of medical providers (Scarton & de Groot, 2016). Other studies recommend incorporating aspects of AI/AN culture, such as spirituality and a broader definition of wellness that includes an individual’s environment and community, into interventions (Mitchell, 2012; Shaw et al., 2013).

LTSS Support for Diabetes in Indian Country
The disparities between the diabetes rates and outcomes in Indian Country and those outside of Indian Country have garnered significant attention from the U.S. government, and funding for diabetes prevention among AI/ANs is available through IHS. However, little funding is available specifically to address LTSS and diabetes. The descriptions of the IHS Special Diabetes Program for Indians (SDPI) and support for diabetes care provided by Medicare offered below describe how these programs may support diabetes-related LTSS in Indian Country.

IHS Special Diabetes Program for Indians
Although diabetes remains a serious problem among AI/ANs, the IHS Special Diabetes Program for Indians (SDPI) is credited with achieving major improvements in diabetes outcomes in Indian Country. The IHS SDPI was established in 1997, to reduce the high rates of diabetes in Indian Country. Through this program, IHS provides $150 million in funding to 301 IHS, tribal,
and urban (I/T/U) Indian Health Programs that deliver community-based diabetes prevention and treatment.\(^{17}\)

Since the program was established, AI/ANs have experienced significant changes in diabetes outcomes. Key improvements include: the most dramatic decline (54%) in kidney failure, or ESRD, related to diabetes among any racial/ethnic group in the U.S.; a 50% decrease in diabetic eye disease rates (which can lead to impaired vision and blindness); and a 10% improvement in blood sugar control. These advances are attributed to the innovative community, population, and team-based approach of SDPI.\(^{18}\)

While SDPI does not explicitly support the LTSS needs of diabetes patients, the grantees implement SDPI diabetes best practices, several of which focus on diabetes self-management, long-term health, and independent care. For example, the SDPI best practices include nutrition and physical activity education, DSME, and foot exams to reduce the risk of foot ulcers and amputations.\(^{19}\) These best practices reduce long-term diabetes risks and help prevent serious complications that can impede performance of ADLs.

**Medicare**

AI/ANs enrolled in Medicare Part B are eligible for 10 hours of outpatient diabetes self-management training/DSME. The training includes information about medication management, nutrition, exercise, and blood sugar management.\(^{20}\) CMS also recently announced the expansion of the Medicare Diabetes Prevention Program (MDPP). The program includes CDC-approved curriculum taught by community health workers and other health professionals during 6 months of group-based classes. It focuses on lifestyle changes that have resulted in a 5% weight loss among diabetic participants.\(^{21}\) Community-based programs may enroll in Medicare to become a MDPP supplier.\(^{22}\) Although this program is still being rolled out and implemented, AI/ANs enrolled in Medicare may be able to participate and benefit from the program as organizations sign up to become MDPP suppliers.

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\(^{18}\) See footnote 11.


Conclusion and Key Take-Aways

Diabetes remains a complex and serious health problem in Indian Country. As the population of AI/ANs over the age of 65 continues to grow, so will the LTSS needs of AI/ANs with diabetes. The literature suggests that type 2 diabetes is most common among older adults and that physical disability may be more severe among older AI/ANs with diabetes, particularly those with comorbidities. Diabetes self-management is an important piece of long-term health and independent living for diabetes patients. However, barriers and disparities may negatively influence AI/ANs’ capacity for diabetes self-management. These disparities include the impact of trauma, lack of knowledge about and access to healthy food, rurality, and a shift to a Westernized diet and sedentary lifestyle. Overall, there is a need for more research that focuses on the LTSS needs of AI/ANs with diabetes. Based on the available literature, the following key take-aways may help inform improved LTSS for AI/ANs with diabetes.

- Address the impact of trauma and stress on AI/ANs when designing diabetes interventions (Jiang et al., 2008; Naqshbandi et al., 2008).
- Understand the sociocultural meaning of diabetes in Native populations and how it can impact timely diagnosis and good self-management (Cavanaugh, et.al., 2008).
- Improve education about healthy diet for AI/ANs with diabetes (Kelly, 2017; Shaw et al., 2013).
- Emphasize the importance of returning to traditional foodways and encourage the use of subsistence foods in public programs (Schulz, et al., 2006).
- Encourage the development of culturally appropriate health management and health promotion programs and materials that support traditional activities (Cavanaugh, et.al., 2008).
- Increase programming and funding that focuses on improved mental health outcomes for diabetes self-management programming among AI/ANs (Jiang et al., 2007, 2008).
- Conduct further research to gain a greater understanding of functional disability among older AI/ANs (Goins et al., 2005).
- Apply a social determinants of health perspective, which addresses the physical and social environments that affect AI/ANs, when designing and implementing diabetes interventions (Mitchell, 2012).
- Implement internet-based diabetes management programs that are tailored for use among AI/ANs, particularly among AI/ANs in rural areas who may not have access to in-person diabetes education (Jernigan & Lorig, 2011).
Diabetes in Indian Country

This section of the report consists of annotations of existing literature about diabetes in Indian Country.

Diabetes and Risk of Physical Disability in Adults: A Systematic Review and Meta-analysis


This article analyzes the risk of disability resulting from diabetes. The authors limited the analysis to physical disability as a useful measure of the overall effect of diabetes on health. The disabilities are measured by ability to perform activities of daily living (ADL) and instrumental activities of daily living (IADL), and mobility. The authors examine the potential moderating factors between diabetes and disability, including gender, duration of diabetes, and blood sugar (glycemic) control. Using protocols published prior to August 2012, researchers based the meta-analysis on 26 articles, which covered 30 populations with the majority from North America. The researchers developed a hierarchy of least to most disabling conditions to accommodate the varying definitions of severity of disabilities in the studies.

Previous research showed a range of results, from no association between diabetes and disability to a doubling of risk. Results of this analysis showed an estimated 50% to 80% increased risk of disability for people with diabetes compared to those without diabetes. The results also showed consistent associations across ADL, IADL, and mobility. For this study, information about the type of diabetes was not recorded; thus, researchers cannot establish whether the association between diabetes and disability differs by type of diabetes.

Many of the studies explored how hyperglycemia may lead to disability. Some studies suggested that elevated concentrations of glucose might lead to systemic, chronic inflammation, resulting in disability. Others suggested that increased risk of disability could stem from links between diabetes and rapid loss of skeletal muscle strength and quality, longer durations of diabetes, and struggles with impaired glucose tolerance.
Emotional and Behavioral Aspects of Diabetes in American Indian/ Alaska Natives: A Systematic Literature Review


This literature review identified 20 studies that examined the emotional and behavioral aspects of diabetes in American Indian and Alaskan Native (AI/AN) populations. Despite the many studies focused on diabetes, few focus on AI/AN populations, though they are 2.2 times more likely to be diagnosed type 2 diabetes than non-Hispanic White populations. With a focus on AI/AN populations, the literature review explored daily challenges for people with diabetes in five categories, as summarized here.

- **Medication adherence:** A person’s attitudes towards self-care recommendations, followed by how they perceived others’ beliefs about self-care (e.g., diet, medication, smoking, and physical activities) were the most predictive factors of medication adherence. Others’ views were especially regarded when they connected cultural identification with traditional AI/AN ways. The limited articles that promote adherence speak to the need for self-management behavior resources.

- **Depression:** Nearly half of the literature in this review focused on depression. Researchers discovered consistent rates of comorbid depression and diabetes among all ethnic and racial groups. Researchers also found that depressive symptoms did not significantly differ across ethnic groups in older rural adults.

- **Physical activity:** Two of the three studies found that most participants did not meet physical activity recommendations at the time of the study. With limited articles in this area, future research could focus on physical activity related to diabetes management for AI/AN populations.

- **Psychosocial needs and social support:** The four studies in this category showed a positive correlation between social support and diabetes outcomes. More research is needed to test the effects of culturally tailored social support interventions.

- **Stress:** Research related to stress for AI/AN populations was limited in identifying factors that contribute to resilience and interventions to mitigate the effects of stress on AI/AN people who have diabetes.
Global Complication Rates of Type 2 Diabetes in Indigenous Peoples: A Comprehensive Review


The unprecedented epidemic of type 2 diabetes led researchers to conduct a systematic review of complications from type 2 diabetes in indigenous populations worldwide. Despite a rich variation in location, language, history, and culture, indigenous populations seem to share increased rates of type 2 diabetes when compared to non-indigenous populations. Researchers found southern American Indian tribes had the highest prevalence at 40%.

The researchers note the following as contributing factors to higher prevalence of type 2 diabetes in indigenous populations:

- traditional lifestyles towards more sedentary living,
- Western diets,
- geographic isolation,
- remoteness, and
- limited health care staff with high staff turnover.

Socio-economic issues also impact capacity for self-care in indigenous communities, such as

- inadequate environmental and social supports for physical activity,
- limited availability of healthy food, and
- high poverty rates.

The researchers reviewed self-reported surveys, audit program results, epidemiologic surveys, and intervention studies using clinical examinations. They included all sample sizes and an age range of 5 to 98 years. The data came from 25 indigenous groups from 5 countries (the United States, Canada, New Zealand, Australia, and the Commonwealth of the Northern Mariana Islands).

Difficulties in obtaining and comparing global reportage resulted in some complications, such as those related to kidney disease and damage and cardiovascular disease, receiving more attention than others. Limited data, especially for remote locations, speaks to the need of nation- and population-specific epidemiologic studies. This research could inform culturally relevant diabetes prevention and management policies and practices, which could improve services and treatment for these high-risk populations.
Reframing Diabetes in American Indian Communities: A Social Determinants of Health Perspective


This study explores how a social determinants of health (SDOH) perspective is highly applicable to other disparate populations that are affected by health inequalities. The majority of health inequalities result from preventable diseases and conditions, including diabetes. American Indians are particularly vulnerable to developing diabetes, and they experience diagnoses nearly twice the rate of non-Hispanic White people in the United States. Numerous complications from diabetes can affect a person’s physical, social, emotional, and financial well-being. However, the full impact of diabetes among American Indian communities is unknown because of preexisting comorbidities and other SDOH experienced across tribal communities, such as illness, quality of life, disability, depression, stigmatization, medical coverage, and premature death.

The author notes that successful, sustainable change is unlikely when efforts to change individual risk behavior do not address the physical and social environments influencing that behavior. Furthermore, those who benefit most from individual approaches are typically from advantaged backgrounds. Individual change initiatives are based on Western medicine, rather than American Indian culture, which is more likely to treat health and wellness as interconnected notions rooted in balance among the body, mind, spirit, and context. Therefore, poor health indicates an imbalance among the body, mind, spirit, and context, while wellness indicates a balanced harmony.

SDOH perspectives look into risk conditions, which include cultural and historical factors for American Indians, such as historical trauma and the health status of the family, community, and tribe. Through SDOH perspectives, the emphasis of intervention moves away from the individual to the living environment to influence more people for longer periods of time. This perspective repositions mainstream medicine beliefs about treatment and healing to influence policy change and structural changes at the community level for American Indian communities.

The author notes that current health inequalities among American Indian communities cannot truly move forward without an honest recognition of the complex environmental contexts that influence their health and social inequalities. The call to action requires practitioners and researchers to further an SDOH agenda. This agenda would reframe diabetes within a culturally relevant context and acknowledge the social, cultural, physical, political, and economic factors that contributed to the current diabetes epidemic in American Indian communities.
Access to Care and Diabetes Management among Older American Indians with Type 2 Diabetes


Across populations, greater distances to health care sites are associated with lower follow through with recommended treatments. Many American Indians (AI) experience greater difficulty accessing specialty care, appointment delays, and longer wait times. Those living in rural areas are also more likely to be poor and less likely to receive care. These barriers to accessing health care could partially explain the drastic differences in diabetes management between non-Hispanic White and American Indian populations.

In this study, the researchers examined associations between health care access and diabetes management among American Indians within Arizona, Oklahoma, and North and South Dakota. The majority of participants considered tribal or Indian Health Service facilities as their usual source of care (91.1%), followed by private practitioners and facilities (4.4%), U.S. Department of Veterans Affairs/medical facilities (2.1%), traditional healers (0.7%), and health maintenance organizations (0.7%). Based on the data collected, the researchers arrived at the following conclusions.

- Clinicians who work with American Indians should partner with patients, providers, or communities to identify potential barriers to and facilitators of diabetes management.
- Improved access to care may be a necessary, but not a sufficient, strategy for diabetes management among American Indians.

The researchers noted several limitations for this study, such as its primary focus on older American Indians residing in rural areas, a lack of inferences that could be made from cross-sectional data, possible bias from self-reported data, and limited sample sizes.
The Prevalence and Correlates of Mental and Emotional Health among American Indian Adults with Type 2 Diabetes


Past research has discovered American Indians and Alaska Natives (AI/ANs) develop diabetes at a higher rate than non-Hispanic Whites, with the majority being diagnosed with type 2 diabetes. This study describes the prevalence and correlations of several mental health factors among a sample of American Indian adults diagnosed with type 2 diabetes. The researchers used data from a community-based participatory research project conducted in two American Indian reservation communities in Minnesota and Wisconsin.

A total of 218 adults diagnosed with diabetes completed in-person interviews and surveys. Participants reported elevated rates of depressive and anxious symptoms compared to prior research findings with other populations. Of the study participants:

- 17.1% met criteria for depression and
- 25% reported moderate to severe anxiety.

The researchers also report that study participants with multiple mental health problems are more likely to report physical health problems. Reported physical health problems include physical limitations, hyperglycemia, and comorbidities. The authors recommend screening diabetes patients for mental health problems, and providing both mental and physical health services. Integrated primary care utilizes this holistic approach and may be an effective model for AI/ANs with type 2 diabetes and mental health concerns.
Resources, Roadblocks and Turning Points: A Qualitative Study of American Indian/Alaska Native Adults with Type 2 Diabetes


Developing effective interventions requires an understanding of the social and psychological factors that impact effective diabetes management. This study examines perceived psychosocial needs and barriers to diabetes management among American Indians and Alaska Natives (AI/AN). Researchers conducted three focus groups and five interviews with 13 AI/AN adults diagnosed with diabetes. Each participant had financial access to comprehensive health care, including those who were actively seeking health care or health education related to their diabetes.

The results showed three emerging themes: resources, roadblocks, and turning points, as summarized here.

- **Resources** include knowledge and education about diabetes, social support from other people with diabetes, spirituality, and self-efficacy. The researchers noted that participants in this study used diabetes education or support groups as resources; however, these resources did not sufficiently meet their psychosocial needs to successfully support their diabetes management.

- **Roadblocks** include self-reported lack of knowledge about nutrition and diet, social difficulties caused by dietary restrictions, and co-morbid medical conditions.

- **Turning points** include experiences described by participants as having transformed roadblocks into resources, facilitating improvement in their diabetes management.

Recommended improvements in these three categories for future programming interventions may result in a greater commitment to achieving positive health outcomes. For example, the researchers recommended focusing efforts on helping newly diagnosed individuals successfully manage their diabetes and providing ongoing support as they adjust. Additionally, because AI/AN patients are likely to use primary care providers as their behavioral health service providers, primary care providers should have tools to help them understand and appropriately address the psychosocial needs of AI/AN patients with diabetes.

The researchers noted several limitations for this study, such as over-representation of individuals with a proactive stance toward diabetes management and health care and limited sample size and generalizability from self-reported data.
The Costs of Treating American Indian Adults with Diabetes within the Indian Health Service


This study is the first to link existing electronic data on American Indians’ health service use from three reporting systems for cost report data. The data provides Indian Health Service (IHS) with detailed treatment cost estimates for a large American Indian adult population. Additional analyses are needed to explore data on medical and pharmacy use and costs. These analyses can help guide federal, IHS, and tribal efforts to reduce and eventually eliminate diabetes-related health disparities for American Indians.

The three reporting systems in this study were the Resource Patient Management System, Contract Health Services, and an IHS facility–specific cost report. The analyses combined data for over 30,000 American Indian adults with and without diabetes. Participants were ages 65 and older, with about 60% female and 40% male. For the 10.9% of American Indian adults with diabetes, IHS accounted for 37.0% of all adult treatment costs. Persons with diabetes accounted for nearly half of all hospital days, and hospital inpatient services costs for those with diabetes accounted for 32.2% of all costs.

It is important to examine how IHS’ diabetes-related expenditures indirectly influence resource availability for treating other conditions. With a significant amount of IHS resources going into treatment costs, IHS would benefit from further efforts to reduce diabetes for American Indians. Challenges impeding efforts to address diabetes-related disparities include shortages of health care professionals, funding limitations, and provider location and transportation costs.
Association between Diabetes and Mental Disorders in Two American Indian Reservation Communities


This American Indian Service Utilization, Psychiatric Epidemiology, Risk and Protective Factors Project (AI-SUPERPFP) examines the association between mental disorders and diabetes. Understanding the relationship between diabetes and mental disorders may help develop effective interventions for diabetes prevention and treatment for American Indian populations. The project focused on associations between diabetes and mental disorders by focusing on the most common disorders among American Indians: depressive disorder, posttraumatic stress disorder, and alcohol dependence.

The researchers used data collected from two American Indian populations for a large community-based psychiatric epidemiologic study. The researchers also compared data collected from members of the Southwest and Northern Plains tribes between 1997-1999 with data from the National Comorbidity Survey. Further, the researchers used multiple logistic regression models to examine the association between diabetes and depressive disorder, posttraumatic stress disorder, and alcohol dependence for American Indian populations.

Results of AI-SUPERPFP showed:

- an overall diabetes prevalence of 7.7%,
- a significant association between diabetes and former diagnoses of all three mental disorders,
- a significant association between former depressive disorder and alcohol dependence and increased likelihood of diabetes,
- a significant elevation in the prevalence of depressive disorder and alcohol dependence and the likelihood of diabetes in the American Indian tribal communities.

The researchers noted several limitations for this study, such as a lack of information about the onset of diabetes and mental disorders, variations between diagnosis, self-reporting, and the severity of the illness. Additionally, this study also did not reflect older generations. The mean age for the sample was 34 years, and 53% were women.
Differences in Functional Disability of Rural American Indian and White Older Adults with Comorbid Diabetes


The article examines the differences in functional disability between American Indian older adults with comorbid diabetes compared to their White counterparts. Functional disability is defined as personal restrictions in performing fundamental physical and social activities. Aside from functional disability, the results showed that American Indians experience comparatively more limitations with activities of daily living (ADL) and instrumental activities of daily living (IADL).

The researchers looked at data collected from 62 rural American Indian and 64 White community members aged 65 years or older. Adjusted prevalence rates indicated that, compared with the White participants, a significantly higher percentage of American Indians reported limitations with dressing, walking, bathing, and shopping. The results also showed higher concentrations of disabilities among the American Indian participants than the White participants. Further results of this study are summarized below.

- Of all racial/ethnic groups, American Indians and Alaska Natives (AI/ANs) have the highest levels of impairment and length of time living with disabilities.
- Approximately 50% to 60% of older AI/ANs have disabilities.
- White populations experience a lower prevalence of functional disability than other races and ethnicities.
- Mounting evidence suggests that chronic and degenerative diseases are increasing, with diabetes being one of the most prevalent among older American Indians.

The researchers noted several limitations for this study, such as limitations within self-reporting measures and an inability to generalize cross-sectional data. However, this study offers a foundation to inform health care practitioners and policy makers in the development of effective interventions for American Indian health.
Management of Diabetes in Long-Term Care and Skilled Nursing Facilities: A Position Statement of the American Diabetes Association


This article addresses diabetes management at end of life and for patients receiving palliative and hospice care. In these care settings, challenges and self-care responsibilities change with each environment, requiring unique recommendations for individual patients’ diabetes management. The American Diabetes Association acknowledges the need to identify challenges to care in order to develop individualized approaches to care. They note that challenges to standardized intervention strategies stem from the diversity of the population and a lack of clinical trial data for all older adults with diabetes.

Previous research has shown that diabetes among older adults contributes to the unsustainable growth of health care costs in the United States. Further, diabetes diagnoses often correlate with age-related physiologic changes, such as increased weight gain, sarcopenia, and chronic low-grade inflammation. Additionally, patients’ risk for experiencing adverse events tends to increase as they transition from one provider to another. Once specific challenges are identified, individualized approaches can be designed to improve diabetes management and ultimately improve patients’ quality of life.
Home visits have emerged as an educational health care strategy to teach patients with diabetes how to achieve lifestyle changes and monitor their signs and symptoms, such as how to record and interpret their blood glucose levels, blood sugar, and blood lipid levels. Chronic complications of type 2 diabetes mellitus progression reduce quality of life and increase mortality for the patient, which results in a heavy burden on health care systems. Home visits are considered an economical and effective method for preventing and controlling chronic disease, and they have also been shown to improve the quality of life for the patients and their families.

Previous research revealed uncertainty regarding the effectiveness of home visit interventions for managing diabetes. For this analysis, the researchers reviewed seven studies to determine the effect of home visits on diabetes management. Despite promising results for other conditions, there is no clear international evidence supporting the effectiveness of home visits in diabetes management. The results are as follows.

- Home visit interventions did not result in significant physical changes for the patients, nor did they increase patients’ likelihood of success in managing lifestyle changes or monitoring symptoms. The researchers noted this finding may be limited by the relatively brief duration of the home visits.

- Weight loss in obese patients with type 2 diabetes mellitus decreased hepatic glucose production and improved insulin secretion and sensitivity. A 5% reduction in weight significantly improved glycemic control in obese patients with type 2 diabetes mellitus.

The researchers suggested that future trials of biological and behavioral interventions include longer follow-up visits to improve their effectiveness. The findings from this research have important implications for public health providers, clinical practice, and research, as glycemic control is an important predictor of the chronic complications associated with diabetes.
National Trends in Treatment Initiation for Nursing Home Residents with Diabetes Mellitus, 2008-2010


The high prevalence of nursing home patients with diabetes can potentially inform process quality measures to assess the quality of prescriber and facility care. This study looked at national trends for glucose-lowering medications to manage diabetes in nursing home residents from 2008 to 2010. More in depth, this study examined the use of insulin by type and product. The study consisted of a random, national sample of Medicare fee-for-service beneficiaries and information about beneficiaries’ nursing homes from Certification and Reporting (OSCAR) Survey data.

Data from this sample were linked to Medicare Parts A and D claims from 2007 to 2010. This study consisted of 11,531 long-stay nursing home residents, age 65 or older, with diabetes. Residents chosen had received glucose-lowering medication between 2008 and 2010, but had not taken it in 4 months.

The researchers noted several strengths in this study, such as access to a large data set of patient-specific information and the use of combination glucose-lowering medication products, which had not previously been described for the nursing home population. On average, they found that facilities provided 3.5 hours of direct nursing care daily. Additionally, more than half of the residents in more than half of the facilities had Medicaid. The researchers observed dramatic changes in insulin prescribing, with rapid-acting insulin driving much of the new uptake and substantial decreases in the prescribing of oral glucose-lowering agents.

The researchers advocated for future studies aimed at documenting the use of glyburide in the wake of the 2012 and 2015 Beers Criteria list, which recommended against the use of glyburide, noting its absence from the American Medical Directors Association guidelines. They also suggested future studies examine pattern changes with adopting current clinical guidelines that recommend less stringent glycemic targets in nursing home residents, especially for those who are frail or have limited life expectancies. These studies could inform cost-effectiveness analyses and prescribing-related quality of care measures, such as the proportion of residents with diabetes who are prescribed glyburide.
Social Integration and Diabetes Management among Rural Older Adults


This study aimed to describe and define associations between diabetes management behaviors and social integration among older adults. For this study, diabetes management included practices such as glucose monitoring, foot care, diet and exercise, and monitoring hemoglobin A1c (HbA1c). Studies have shown that older adults with greater social integration have higher levels of cognitive functioning. Additionally, according to the Disablement Process Model, people with higher social integration should be able to accomplish diabetes management behaviors based on their access to greater help and support.

Barriers for diabetes care range from being able to afford glucose monitoring strips and monitoring and interpreting results to maintaining a proper diet and exercise regimen. Older adults in rural areas face significant barriers to optimal social integration. Past research has shown correlations between proper diabetes management and social integration mainly for people living in metropolitan areas. Furthermore, a person’s culture may affect social integration in how people access their social networks. Social integration variances may account for differences in a person’s diabetes management and control, complications, and disability.

The researchers recruited participants in eight central North Carolina counties with dense minority populations. Using interview data from 563 African American, American Indian, and White participants ages 60 and older, the researchers noted a relationship between high levels of social integration and a large adherence to diabetes management behavior. The researchers also discovered associations between the size of a person’s social network, particularly with family members, and provider HbA1c monitoring and foot examinations. Although social integration had a small, but significant, association with diabetes management behavior, further research could examine the role that older relatives may play in a patient’s adherence to their health management.

The researchers noted several limitations with this study, such as being able to only infer causality due to the study’s cross-sectional design and limitations based on participants’ willingness and ability to self-report and participate in this research.
National Diabetes Statistics Report, 2017


This periodic publication from the Centers for Disease Control and Prevention (CDC) provides updated statistics about diabetes in the United States for a scientific audience. The data may help focus efforts to prevent and control diabetes across the United States. The report covers numbers and rates for acute and long-term complications of diabetes. CDC derived the data, summarized here, from the National Inpatient Sample, National Emergency Department Sample, and the National Health Interview Survey.

CDC noted the following information for the prevalence of diabetes.

- An estimated 30.3 million people of all ages (9.4%) of the U.S. population had diabetes in 2015.
- An estimated 23.1 million people had been diagnosed with diabetes.
- An estimated 5% of people with diabetes had type 1 diabetes.
- The percentage of adults with diabetes increased with age, reaching a high of 25.2% among those aged 65 years or older.
- Diagnosed and undiagnosed diabetes was higher among Asians, non-Hispanic Blacks, and Hispanics from 2011 to 2014.
- Among U.S. adults aged 18 years or older, data for 2013 through 2015 indicated those with diagnosed diabetes comprised:
  - 15.1% of American Indians and Alaska Native populations,
  - 12.7% of Non-Hispanic Black populations,
  - 12.1% of Hispanic populations,
  - 7.4% of Non-Hispanic White populations, and
  - 8.0% of Asian populations.
- **Risk factors** for complications included smoking, overweight and obesity, physical inactivity, high blood pressure, high cholesterol, and high blood glucose.
- **For deaths in the United States in 2015**, diabetes was the seventh-leading cause, and it was listed under “any cause of death” on 252,806 death certificates.
- **The total cost in 2012**, direct and indirect, was $245 billion.
  - Average medical expenditure for people with diabetes was $13,700 per year, with about $7,900 attributed to diabetes.
  - People diagnosed with diabetes had about 2.3 times higher expenditures than people without diabetes.
Racial/Ethnic Differences in Use of Health Care Services for Diabetes Management


This study evaluated racial and ethnic differences in dementia among older patients with diabetes. Previous research has shown patients with type 2 diabetes have double the risk of dementia; however, it was unclear whether the risk of dementia for people with type 2 diabetes varied across racial or ethnic groups.

This study gathered data from 22,171 patients with diabetes who did not have preexisting dementia. The patient sample consisted of non-Hispanic Whites, African Americans, Latinos, Asians, and American Indians and Alaska Natives (AI/ANs), age 60 and older. The researchers pulled prevalent medical histories and dementia incidences from medical records. For example, the researchers noted prevalent medical incidences could include cerebral microvascular and macrovascular diseases, which are recognized as potential links between diabetes and dementia.

Results showed dementia diagnoses among 17.1% of the patients, with the highest incidences among AI/ANs, followed by African Americans. Asians experienced the lowest rates of dementia diagnoses. After 10 years, among the patients with type 2 diabetes, African Americans and Native American had a 40% to 60% greater risk of dementia compared with Asians. Non-Hispanic Whites and Latinos were at intermediate risk. The researchers recommended future studies to investigate why these differences exist and identify ways of reducing them. Although the prevalence of microvascular and macrovascular complications varied by race and ethnicity in this study, generally speaking, the burden of complications did not appear to be especially greater for any particular race or ethnicity.
The Internet Diabetes Self-Management Workshop for American Indians and Alaska Natives


This study assesses the effectiveness of the Stanford Internet Diabetes Self-Management Workshop (IDSMW) for type 2 diabetes self-management among American Indians and Alaska Natives (AI/ANs). The authors noted that AI/ANs experience disproportionate rates of type 2 diabetes compared to other races and ethnicities. They also noted that self-management programs, though increasing in popularity for diabetes care, have not yet been assessed among AI/ANs.

The Stanford IDSMW is a 6-week, internet-based workshop for approximately 25 participants with type 2 diabetes. Stanford designed the IDSMW to provide broad access, with competency at a seventh-to eighth-grade reading level, for use by anyone with an internet connection. Two peer-trained moderators lead the IDSMW and cover the following topics: diet, exercise, causes of diabetes, foot and eye care, hypoglycemia prevention and management, emotional wellness, improving family relationships, and improving patient-provider communication.

The researchers analyzed pilot tests among a group of 27 AI/ANs and a group of 27 non-AI/ANs. For the tests, Stanford recruited AI/AN participants through AI/AN-specific listservs, tailoring the website to an AI/AN audience, and sending personal email invitations from an AI/AN researcher. The researchers assessed the effectiveness of the IDSMW through a questionnaire, home blood test measurements, discussion analyses from the IDSMW’s online bulletin board, focus group feedback, and an assessment of the differences between the AI/AN and non-AI/AN workshops.

The results indicated that participation among the AI/ANs in the study group was slightly higher than that among members of the non-AI/AN group. The researchers noted that the AI/AN participants also had a higher average weight, more symptoms of high glucose levels, and more depression. The AI/AN participants reported that the ability to interact with other AI/ANs and discuss issues related to their diabetes was particularly valuable and made the IDSMW culturally relevant for them (pg. 267). Specifically, they noted the ability to discuss depression related to diabetes as valuable because they felt they could not discuss depression in their communities (pg. 269). The authors concluded that the IDSMW was a valuable tool for the AI/AN study participants. They also concluded that online workshops may benefit AI/ANs and other racial and ethnic groups that experience health disparities.
Photovoice: Capturing American Indian Youths’ Dietary Perceptions and Sharing Behavior-Changing Implications


For this study, the researchers used a participatory research method called photovoice to assess American Indian youth’s perceptions of their diets and nutrition. With this method, researchers asked study participants to photograph images of healthy eating habits in their communities, with the goal of sharing their perspective on the topic. The researchers sought to better understand barriers to healthy eating among American Indian youth to help prevent childhood obesity and lower diabetes rates for American Indians. This study is part of Cooking with Kids, a larger initiative that focuses on healthy eating habits for kids by improving their understanding of nutrition and their cooking skills.

This study included 14 American Indian youths (ages 11 through 14) from several tribes in New Mexico. To provide the youths with context, the researchers shared key findings from a literature review that they had previously conducted for their study. Based on the literature review, the authors explained that childhood obesity is a serious problem among American Indian youths, and it is on the rise. They explained that childhood obesity contributes to diabetes, which is also a serious problem among American Indians.

The researchers provided the youths with three disposable cameras: one to capture opportunities for healthy eating, one to capture challenges to healthy eating, and one to capture traditional foods and customs. The researchers then interviewed each participant about their photos and conducted a group discussion about the photos. They found that the participants had trouble categorizing foods as healthy or unhealthy. For example, some participants assumed the meals provided at school were healthy since the school provided them. They reported challenges with having junk food in their homes, being tempted by fast food, and lacking access to grocery stores. They reported opportunities in their willingness to eat healthy foods and ask their parents to buy healthy foods. They noted traditional foods associated with their tribes, such as fry bread, Navajo tacos, and squash stew.

Based on the photovoice project results, the researchers concluded that there are opportunities to improve the eating habits of American Indian youth. They noted that interventions need to include family members, schools, and the wider community. They also noted that, given its story-telling approach, Photovoice is a good fit for American Indian communities.
Effects of Traditional and Western Environments on Prevalence of Type 2 Diabetes in Pima Indians in Mexico and the U.S.


This study compared the prevalence of type 2 diabetes and obesity among Pima Indians in the U.S. and in Mexico. The two populations of Pima Indians share genetic similarities, and the U.S. Pima Indians have a well-documented, high prevalence of diabetes. Therefore, the researchers assessed the impact of genetics and environment on obesity and type 2 diabetes.

Pima Indians in Mexico continue to live the subsistence, agrarian life of their common ancestors and report significantly higher levels of physical activity and lower levels of obesity than U.S. Pima-Indians. U.S. Pima-Indians typically do not engage in farming and report a higher fat intake and a more sedentary lifestyle, which has become typical of American rural life.

The prevalence of diabetes among U.S. Pima-Indians was significantly higher than among Mexican Pima Indians. The researchers reported the following prevalence rates of diabetes for men and women among the two groups:

- Mexican Pima-Indians: women (8.5%), men (5.6%)
- U.S. Pima-Indians: women (40.8%), men (34.2%)

The difference in prevalence of diabetes among the two groups mirrored that of obesity. The researchers reported the following percentages of men and women in the two groups that were considered obese, based on body mass index and waist-to-hip ratio:

- Mexican Pima-Indians: women (19.8%), men (6.5%)
- U.S. Pima-Indians: women (74.8%), men (63.8%)

The researchers conclude that despite genetic predispositions, type 2 diabetes is impacted largely by environmental factors that promote or prohibit physical activity and low-fat diet. Study results indicate that the loss of a traditional, agrarian lifestyle among U.S. Pima-Indians and the shift to a more sedentary, Western lifestyle may impact obesity and diabetes among this population.
This article analyzes a qualitative investigation of the Family Education Diabetes Series (FEDS). FEDS is a 6-month program based in Minnesota that was established in 2003. It brings together American Indians with diabetes, their family members, and medical providers for diabetes-related education and support.

This study assessed a FEDS program operated by American Indian staff. This program included education on how to check blood sugar, weight, and body mass index (BMI); proper foot care; and how to prepare culturally appropriate meals. Staff provided educational activities on topics, including basic diabetes education, diabetes in the American Indian community, exercise, and healthy eating. Cultural activities including traditional dancing, drumming, music, and talking circles.

The researchers of this study conducted six group interviews with six participants each. They asked participants what aspects of FEDS they found most and least helpful and what parts of the program they learned the most from. Interviewees reported the following.

- The diversity of topics and how they complement each other were highly beneficial.
- The interactive nature of FEDS kept the program engaging.
- Discussing topics in the group, particularly food and diet, led to healthier diet decisions. For example, participants reported that they now review food labels and have a better understanding of appropriate portion sizes.
- The practical exercise and stress management information provided in the program led to improved competency in these areas. For example, one participant stated, “The exercises that we do, they’re very simple and they’re ones that you can easily do at home and...You can even be at work doing some of them.” (pg. 1528).

Overall, the researchers found that the most important elements of the FEDS program are the social and group activities. They suggest that individuals interested in starting a group-based diabetes intervention among a Native population tailor the FEDS program to the needs of the diabetic population in their community.
Cultural Perceptions of Health and Diabetes among Native American Men


This article reports the results of a study assessing perceptions of diabetes among Native American men. The study included qualitative interviews with 20 men served by two different tribal health clinics in Northeastern Oklahoma. The researchers acknowledge the impact of both Native and Western culture on Native Americans and considered how it would impact study participant’s perceptions of diabetes.

During the interviews, study participants discussed either their own experiences with diabetes, or the experiences of family or community members with diabetes. In terms of cultural definitions of diabetes, the disease was mainly defined by long-term complications, including blindness, kidney disease, dialysis treatments, transplants, and amputations. Amputations were discussed with especially fearful and gruesome language.

Several of the participants expressed fear about diabetes, and the authors report that fatalism was a common attitude towards the disease. The men in the study described diabetes as inevitable and deadly for Native Americans. Participants stated, “Yeah, you’re going to get it anyway”, “It’s an ailment that most Indians got, not all, but most”, and “[Diabetes is] just one death sentence as far as I’m concerned” (pg. 1037).

Overall, participants expressed a sense of inevitability towards developing diabetes. The authors explained that this outlook may hinder active management and prevention of diabetes among Native Americans. Given the high prevalence of diabetes in Indian Country, the authors suggest that more research needs to focus on cultural perceptions of the disease among Native Americans in order to tailor effective prevention and management interventions.
LTSS Research: Diabetes in Indian Country
Annotated Literature Review

Sources


