Department of Health & Human Services, Centers for Medicare & Medicaid Services

LTSS Research:
Annotated Literature Review

Caregiver Support in Indian Country

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Table of Contents

Glossary

Activities of daily living (ADL)	Basic activities a person must perform during a normal day to remain independent. These include daily actions such as, getting in and out of bed, dressing, bathing, eating, walking, and using the bathroom.
Caregiver	A person who helps care for someone who is ill, has a disability, or is frail due to age.
Caregiver Burden	The weight a caregiver feels while caring for another person due to financial, physical, or emotional stress.
Caregiver Burnout	When a caregiver is physically, emotionally, and mentally exhausted and experiences a change in attitude that leads to frustration, isolation, and/or despair.
Caregiver Support	A set of services for caregivers that provide counseling, peer support, or training to help cope with the stresses of caregiving.
Formal Caregiver	Professionally trained individuals that provide care to another person and receives payment for their help. In some states and service systems, a family member may be paid to receive training and provide care for a loved one.
Informal Caregiver	Typically, family members that provide care to a loved one, friend, or neighbor and does not have professional training or receive payment for their help.
Long-Term Care	Services that help people with personal or health care needs and activities of daily living over an extended period. Long Term Care (LTC) is an older term, which has generally been replaced with Long Term Services and Supports (LTSS).
Long-term Services and Supports (LTSS)	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. These may be provided in a variety of settings or in the person's own home.
Respite Care	Temporary relief of duties for caregivers provided either in the home or in an out-of-home setting, like an adult day care center or skilled nursing facility for overnight stays.

Executive Summary

Background

Providing long-term care for a family member with a chronic illness or disability is an important and challenging endeavor. Caregiving can become overwhelming and place strain on an individual's health and wellbeing. To alleviate these challenges and the accompanying stress, families may choose to utilize caregiver support services. Caregiver support includes a number of services, such as counseling, respite care, transportation, caregiver training, case management, support groups and adult day care.

In Indian Country, family members provide 90% of long-term care to elders or others in need of assistance with activities of daily living—10% more than the general U.S. population (Institute of Medicine, 2008). The majority of these caregivers in Indian Country are female relatives (Goins et al., 2010; Hennessy & John, 1996), with grandparents also often acting as the primary caregiver for grandchildren (Ludtke & McDonald, 2003).

Since these family members typically do not receive training or any payment for their assistance, they are considered informal caregivers (Schure & Goins, 2015). Informal caregivers may assist an elderly, frail relative; an adult; or child who is chronically ill or has a disability. In contrast, formal caregivers receive professional training and payment for their help (National Alliance for Caregiving, 2005). Informal and formal caregivers provide many of the same services; however, informal caregivers typically do so while maintaining a household and outside job without the benefits of additional training and pay.

A number of cultural factors contribute to the prevalence of family caregiving among American Indians and Alaska Natives (AI/ANs). Native cultures emphasize respect for elders and an obligation to provide care (Hennessy & John, 1996; National Indian Council on Aging, 2013). Consequently, AI/AN communities have an overall cultural preference to provide care for family members in their own homes and communities, rather than placement in a formal institution.

Health problems and demographic shifts have led to a sharp increase in the need for caregivers, caregiver support services, and other long-term services and supports (LTSS) in Indian Country. LTSS are a set of health care, personal care, and social services delivered over an extended period to persons unable to perform their activities of daily living independently. These may be provided in a variety of settings or in the person's own home.

Status as an elder is tribally defined, but often a person 55 years and older is considered to be a tribal elder. The elder AI/AN population is one of the fastest growing groups of minority elderly in the United States (Jervis, et al., 2010)**.** Chronic diseases, such as diabetes, cancer, and dementia, are also on the rise in this population (Baldridge & Aldrich, 2009a; Garrett & McGuire, 2008). Further, AI/ANs have the highest rate of disability of any ethnic group in the United States (Nichols & Keltner, 2005). These factors

lead to high rates of chronically ill, frail elderly and individuals with disabilities in need of LTSS. Conversely, the number of available caregivers in Indian Country is declining, as a greater number of young AI/ANs move from reservations to urban areas (Baldridge & Aldrich, 2009a; Garrett & McGuire, 2008). This means a gap exists between those in need of caregiving and other LTSS, and those family or community members available to provide it.

Challenges of Caregiving in AI/AN Communities

To improve support for caregivers in Indian Country, it is important to understand the challenges, cultural concerns, and current supports that exist for AI/AN caregivers.

Poor Access to Health Care and Transportation

Most reservations are located in rural areas with very few or no health and social service providers (Byrd et al., 2011; Jervis et al., 2010). In rural areas, obtaining medical care or caregiver support services can require traveling long distances. Many AI/AN caregivers cannot find or pay for transportation to doctor appointments and support services for themselves or their care recipient (Ludtke & McDonald, 2003; Rose & Garwick, 2003). Lack of transportation can result in missed appointments and delays in critical medical care (Rose & Garwick, 2003). Finding reliable transportation is a significant source of stress for many AI/AN caregivers (Baldridge & Aldrich, 2009a & b).

Cultural Barriers

In several studies, AI/AN caregivers note that non-tribal health care and social service support staff are unwelcoming or disrespectful of their culture (National Indian Council on Aging, 2013; Rose & Garwick, 2003; Sawchuk et al., 2014). Language barriers present a challenge for AI/AN caregivers with limited English proficiency (National Indian Council on Aging, 2013). AI/AN people speak many different tribal languages that may not be understood by medical and social service support staff (National Indian Council on Aging, 2013). In addition, medical and social service support staff may misinterpret traditional values and beliefs as health literacy issues and "speak down" to their AI/AN patients. If health care needs of the care recipient go unaddressed due to these challenges, caregiver demand and burden may increase. Additionally, cultural barriers can discourage AI/AN caregivers from seeking out or accessing needed support services.

Funding and Service Infrastructure Challenges

Currently, caregiver support services are underfunded in Indian Country (Baldridge & Aldrich, 2009). Availability of training, financial support, respite care, and other services for caregivers are often scarce in Indian Country. For available support services, long wait times are problematic (Baldridge & Aldrich, 2009a; Rose & Garwick, 2003). AI/AN caregivers often are not aware of available support services, or that they qualify for any assistance or training (Scharlach et al., 2006).

Though funding sources, such as Medicaid, exist, AI/AN caregivers encounter a number of challenges to receive it. Medicaid reimbursement can be slow and may not keep pace with the cost of services

(Baldridge & Aldrich, 2009b). In addition, many caregivers struggle to understand and meet Medicaid requirements to receive LTSS (Baldridge & Aldrich, 2009a).

Negative Impacts of Caregiving

Caregiving can be incredibly stressful, causing caregivers to feel over-burdened and burned out in this role. The stress of caregiving can lead to a poor quality of life and decline in mental and physical health (Spencer et al., 2013). Since AI/AN communities rely so heavily on family caregivers, caregiver burden and burnout are important issues. The challenges above, lack of transportation and an inability to meet Medicaid requirements, are noted sources of caregiver burden and burnout among AI/ANs (Baldridge & Aldrich, 2009a &b). Other common sources of caregiver burden and burnout among AI/ANs include:

- A lack of caregiver training and knowledge of support services (Baldridge & Aldrich, 2009a),
- Poor support from tribal leaders on the challenges of caregiving, particularly for elder family members (Baldridge & Aldrich, 2009a),
- Challenges communicating and coordinating care with family (Hennessy et al., 1999),
- Feelings of guilt over insufficient care (John et al., 2001),
- Anxiety about providing in-home medical care (Hennessy & John, 1996), and
- Strain on family relations (Hennessy & John, 1996).

While the literature suggests that AI/ANs may have more positive feelings about caregiving than other groups, the stresses of caregiving still pose serious concerns (Hennessy & John, 1996; Jervis et al., 2010).

Support for Caregivers

AI/AN communities rely on a number of formal and informal support services to manage the challenges of caregiving. Formal supports include funding and programs provided by the federal government, state governments and tribes, including:

- *Federal funding through the Title VI, Part C, Native American Caregiver Support Program*: This grant program funds efforts to provide information, assistance, individual counseling, support groups and training, respite, and supplemental services for AI/AN caregivers (Administration on Aging, 2002).
- *Federal and state funding for Medicaid*: Within Medicaid, the home- and community-based services (HCBS) waivers provide in-home care to low-income individuals who are eligible for nursing home care (Baldridge & Aldrich, 2009b).
- *Tribally provided support:* Some tribes provide caregiver support services to their members; however, providing these services depends on the economic climate of a tribe, which may be influenced by factors such as revenue generated by tribal businesses (Baldridge & Aldrich, 2009b).

Recommendations

While caregivers in Indian Country face significant challenges, the AI/AN cultural emphasis on in-home care, respect for elders, and community can be utilized to support caregivers. Many innovative caregiver support strategies have proven successful within Indian Country. Based on the effective and creative interventions identified in the literature, the following recommendations may help programs and communities address the needs of caregivers in Indian Country:

- Increase community-based and in-home caregiver support programs independently or through programs like the Center for Medicare and Medicaid Services' Money Follows the Person Tribal Initiative. Money Follows the Person is a federal initiative to promote community- and home-based care for elderly individuals with chronic diseases or disabilities who have been relocated from institutional settings (Mathematica Policy Research, 2014).
- Improve collaboration among service providers, including federal, state, and tribal governments. (Baldridge & Aldrich, 2009b; Sawchuk et al., 2014).
- Increase funding for and information about caregiver support services, such as transportation services, respite care, and adult day care (Garrett & McGuire, 2008; Goins et al., 2010).
- Provide caregiver education, assistance, and training, including help with paperwork and health or social service care system navigation. (Hennessy, et al., 1999; Riess-Sherwood, et al., 2002).
- Employ professional caregivers from outside the tribal community (Garrett & McGuire, 2008; Goins et al., 2010).
- Educate tribal leaders so they can be more involved with and proactive about their communities' challenges with caregiver support and elder care (Baldridge & Aldrich, 2009a).
- Improve cultural competency trainings for health and social service providers who serve AI/AN caregivers and recipients. Culturally appropriate trainings will make LTSS more widely available in tribal communities (Health Resources and Services Administration, 2001; Rose & Garwick, 2003).
- Incorporate AI/AN culture (such as using native languages and traditional healing practices) into caregiver support interventions (Goins et al., 2010).

Caregiver Support in Indian Country

Administration on Aging. (2002). *The National Family Caregiver Support Program Resource Guide.* **Washington, DC: United States Department of Health and Human Services.**

The Administration on Aging (AoA) created this guide to assist government agencies focused on aging with the implementation of the National Family Caregiver Support Program (NFCSP), created in 2000. The NFCSP is part of the Older Americans Act and provides support services and resources to family members caring for older individuals (p. I-1). The guide provides in-depth information on a number of topics related to the NFCSP and caregiving for elders, including:

- Background information on the NFCSP and the aging network (p. I-2),
- Profiles of family caregivers (p. III-1),
- Overview of aging-related grant programs, including the Native American Caregiver Support Program Grants (Title VI) (p. B-11), and
- The NCFSP in relation to diverse caregiver populations (p. VIII-1).

The guide describes the unique challenges that AI/AN caregivers face in their communities. These challenges are identified as a lack of adult daycare, home health care aides, hospice care, and support groups (p. VIII-9).

Several sections of the guide describe the role of Indian tribal organizations (ITOs) within the aging network. ITOs help identify gaps in key services and ways for tribes to pool regional resources to meet caregiver needs (p. VIII-10)

The guide explains government-funded grant programs that support AI/AN elder caregivers. These grant programs include caregiver support-related grants (Title VI grants) to AI/AN communities, including a list of grantees and dollar amounts received (B-11-B-15). The guide also provides examples of programs that tribes have used to implement the NFCSP (p. VIII-10).

The AoA's guide is a useful tool for individuals and organizations in need of detailed information about the NFCSP and caregiving programs specific to AI/AN communities (Title VI). The examples of tribal programs are particularly useful for gaining a sense of tribal implementation of the NFCSP (p. VIII-10).

Administration on Aging. (2004). *The Older Americans Act National Family Caregiver Support Program: Compassion in Action.* **Washington, DC: United States Department of Health and Human Services.**

This report provides an overview of progress made by the National Family Caregiver Support Program (NFCSP), a program established by the Older Americans Act Amendments of 2000. The Administration on Aging, State Units on Aging, Area Agencies on Aging, and Indian tribal organizations, known as the National Aging Services Network, implement the program. The National Aging Services Network provides caregiver support resources to local communities where tribal members are also eligible for services. The report highlights the number of caregivers served, success stories, best practices, reference resources, and individual state approaches.

One component of the NFCSP is the Native American Caregiver Support Program (NACSP) (Title VI, Part C). The NACSP provides information, assistance, individual counseling, and support groups, and training, respite, and supplemental services (p. 24). The NACSP differs from the NFCSP in three distinct ways to meet the unique needs of tribal communities:

- There is no requirement for matching funds,
- There is no limit on funds for support services to grandparents caring for grandchildren, and
- Tribes decide the age when tribal members become elders (p. 24).

Since the NACSP's establishment in 2000, many tribal programs have created tailored solutions that meet the needs of their communities' caregivers. These solutions include:

- Infrastructure development,
- Public awareness campaigns,
- The development of respite services,
- The coordination of support groups or counseling, and
- The establishment of culturally appropriate caregiver training through caregiver conferences, where caregivers are trained and honored for their work. (pp. 24–25).

Continued barriers for NACSP programs include inadequate staffing, low participation rates, remote locations, and the large number of unmet needs (p. 25). The guide provides overviews of model caregiver support programs in Indian Country and Hawaii (pp. 25–27), highlighting their innovative approaches to caregiver support, which incorporate Native cultural values.

Baldridge, D., & Aldrich, N. (2009a). *Caregiving in Indian Country: Conversations with Family Caregivers.* **Retrieved September 21, 2015, from National Association of Chronic Disease Directors:**
http://www.chronicdisease.org/resource/resmgr/Healthy_Aging_Critical_Issues_Brief/CIB_Carginging_in_Indian_Cou.pdf.

In this paper, the authors provide an overview of the common practices, attitudes, and challenges of elder care and caregiver support in Indian Country. The authors include perspectives of family caregivers and professionals that highlight eldercare issues with quotes obtained through interviews. The paper emphasizes the needs and concerns of family caregivers who make up 90% of eldercare providers in Indian Country (p. 1).

Although the authors stress how elder care is not generally considered a burden among American Indian and Alaskan Native (AI/AN) communities, they highlight the issue of caregiver burnout, and the need for greater caregiver support and some time away (p. 2). Based on responses from interviews with professional and family caregivers, caregiver burnout commonly results from a number of factors, including:

- Absence of caregiver training,
- Lack of knowledge about available support services,
- Inability to meet low-income or Medicaid requirements to receive services,
- The physical strain of caring for elders,
- Insufficient transportation access, and
- Poor support from tribal leaders (pp. 5–7).

The majority of interviewed family caregivers indicated that respite care typically comes from family members; however, few reported receiving it (p. 5). Although the majority of the family caregivers were aware of caregiver support services, they noted a number of barriers that prevent utilization. Common barriers included an inability to qualify for Medicaid and long wait times for services (pp. 7–9).

Interview participants noted a need for increased family caregiver support by tribal leaders. They provided suggestions, such as subsidizing caregiver support, increasing involvement with elders, and providing adult day and respite care services (p. 9). Along with increased tribal leadership support, the authors conclude that AI/AN family caregivers need additional support services, including caregiver training, respite care, transportation, home health care, and adult day care (p. 10).

Baldridge, D., & Aldrich, N. (2009b). *Caregiving in Indian Country: Tribes Supporting Family Traditions.* **National Association of Chronic Disease Directors. Retrieved September 21, 2015, from** http://c.ymcdn.com/sites/www.chronicdisease.org/resource/resmgr/healthy_aging_critical_issues_brief/ha_cib_indiancaregiving.pdf

This article explains the role of families in providing long-term care. The authors also illustrate how changing demographics on reservations affect those in need of long-term services and supports (LTSS). Family members provide 90% of long-term care in Indian Country (p. 1). However, this trend is changing as more young people decide to leave the reservation in search of greater opportunities (p. 1). Unfortunately, the need for LTSS is on the rise in Indian Country due to an increase in chronic health problems among American Indian and Alaskan Native (AI/AN) communities (p. 1).

Although the average life expectancy of the AI/AN population is lower than the national average, it is increasing (p. 4). As the authors point out, this means many AI/ANs will live longer with disabilities (p. 4). The cost for providing care to a population that lives longer with greater challenges is financially and emotionally demanding for families and tribal communities (p. 4).

The authors explain that funding for LTSS programs comes from different sources, such as Medicaid, state or tribal programs, or Older Americans Act programs (p. 6). There is a preference within Indian Country to receive services in the home (p. 6). However, the authors state that, "88% of AI/AN communities surveyed by the U.S. Administration on Aging are not able to meet that demand for home health care" (p. 6). Other barriers that keep many AI/ANs from seeking LTSS include poverty, "a shortage of professional caregivers, and lack of transportation to receive services" (p. 5). Cultural beliefs also prioritize the need of family and spiritual health over the individual and physical wellbeing (p. 5).

With regard to funding for LTSS in Indian Country, there are several resources for individuals, families, and communities. For instance, the Administration on Aging manages the Older Americans Act, which provides for the Title VI Grants for Native Americans Program (p. 11). Beyond the AoA, the Centers for Medicare & Medicaid Services manages the Medicaid Home and Community-Based Services Waiver Program. Waiver programs allow individuals eligible for nursing home care who are at defined income levels to receive services in their homes rather than in facilities. However, the authors note that the Medicaid reimbursement for these services cannot keep pace with the costs of services (p. 13).

Tribes also provide LTSS in their communities. The authors reference a 2004 National Indian Council on Aging study that found that profits from tribal casinos have a profound influence on whether or not tribes provide LTSS to their tribal members (p. 14). Many experts in the field have noted that, given the scarcity of adequate funding to cover the amount of need for LTSS in Indian Country, there is a greater need for collaboration among different service providers and funding sources (p. 14).

Byrd, J., Spencer, S., & Turner Goins, R. (2011). Differences in Caregiving-Does Residence Matter? *Journal of Applied Gerontology, 30*(4), 407-421.

This study describes a telephone survey conducted in 2004 to determine differences in caregiver health based on residence. The authors surveyed 219 metropolitan (population of more than 50,000), 77 micropolitan (population of 10,000 to 50,000), and 104 non-metropolitan (population of 9,999 or fewer) caregivers in West Virginia (p. 410). The study provides background information about the challenges of caregiving in rural areas. These challenges include "poor access to available services including, home-delivered meals, home health aides, adult day care, or respite care" (p. 408).

The majority of survey participants were married women who deliver unpaid care to a parent, which reflects the most common national characteristics for caregivers (p. 416). Participants responded to questions about demographics, challenges with activities of daily living (ADLs), the number of medical conditions, and mental health (p. 414). Key takeaways from the survey were as follows.

- Non-metropolitan caregivers reported more medical conditions than metropolitan or micropolitan (p. 413).
- Residence location did not impact caregiver well-being, including caregiver burden or mental health (p. 414).
- A lower education level was associated with an increased number of medical conditions among caregivers and a subsequently higher level of caregiver burden (p. 414).
- Metropolitan residents reported higher levels of education than did micropolitan or non-metropolitan residents (p. 412).

The authors hypothesize that non-metropolitan caregivers would express more caregiver burden and poorer mental and physical health (p. 409). The authors did discover a higher number of health conditions among the non-metropolitan group (p. 416); however, these respondents did not report higher levels of caregiver burden or poorer mental health than the other groups (p. 416). Overall, the authors hypothesize that nonmetropolitan residents may adapt to a lack of services and rely on informal care networks to cope (p. 416).

Garrett, M. D., & McGuire, L. C. (2008). Family caregivers declining for American Indians, Alaska Natives. *Aging Today, 29*(11), 11.

In this article, the authors discuss the declining levels of family caregiving among American Indian and Alaskan Native (AI/AN) communities. The authors explain that families are the primary providers of long-term services and supports (LTSS) for the elderly in AI/AN communities (p. 11). This dynamic has worked in the past, because "AI/AN providers tend to be younger than those in the broader population" (p. 11). However, the demographics of AI/AN communities are changing since many young AI/AN individuals are moving to urban areas (p. 11).

The authors also briefly describe a study they conducted to determine which communities are facing declines in family caregiving (p. 11). The goal of this research was to identify communities that "have more frail older adults than caregivers" (p. 11). To determine the number of potential caregivers per older adult, the authors used 2000 U.S. Census data and divided the number of potential caregivers by the number of frail older adults (p. 11). Key findings from the study include:

- 13 AI/AN communities do not have any potential caregivers;
- Several large tribes (populations greater than 4,000) have less than 5 potential caregivers per older adult, comprising:

  - United Houma Nation, Kiowa Tribe of Oklahoma, Comanche Nation, Apache Tribe of Oklahoma, Fort Sill Apache Tribe, the Caddo Nation of Oklahoma, and the Sac and Fox Nation of Missouri in Kansas; and

- 92% of the assessed AI/AN communities have 1 to 25 caregivers per frail adult (p. 11).

Overall, the article concludes that a decline in family caregivers for older adults is a problem in many AI/AN communities (p. 11). The authors suggest that communities facing this issue create and improve services like adult day care, respite care, and transportation (p. 11). They should also consider employing formal caregivers from outside the community (p. 11).

Goins, R., Spencer, S., McGuire, L., Goldberg, J., Wen, Y., & Henderson, J. (2010). Adult caregiving among American Indians: The role of cultural factors. *The Gerontologist, 51*(3), 310-320.

This study estimates how common adult caregiving is among American Indian communities and examines cultural factors related to adult caregiving. The study assesses survey data from 5,207 American Indians from the Pine Ridge Indian Reservation and Cheyenne River Sioux Reservation in the Northern Plains and the Gila River Indian Community in the Southwest (p. 310). The study defines an individual as an adult caregiver "if at least one parent relied on them for personal care" (p. 312).

The study finds several factors common among American Indian adult caregivers in all three communities. These factors include:

- Being a woman,
- Being age 35 or under,
- Using traditional healing practices,
- Having a larger household size, and
- Participating in traditional or cultural events (p. 310).

The survey results convey the importance of cultural traditions, families, and the cultural leadership of elders in the roles and lives of American Indian adult caregivers (p. 318). The authors suggest including cultural traditions in future American Indian caregiver research and programs to assure they work well for the communities (p. 318).

The authors also emphasize the need for increased support services for adult caregivers in American Indian communities (p. 318). They suggest increasing caregiver services through Title VI and access to non-tribally managed caregiver programs (p. 318). Overall, the authors stress that more research is needed on the topic of American Indian adult caregivers (p. 318).

Health Resources and Services Administration. (2001). *Cultural Competence Works: Using Cultural Competence To Improve the Quality of Health Care for Diverse Populations and Add Value to Managed Care Arrangements.* **Washington, DC: United States Department of Health and Human Services. Retrieved September 28, 2015, from** http://homeless.samhsa.gov/resource/cultural-competence-works-using-cultural-competence-to-improve-the-quality-of-health-care-for-diverse-populations-and-add-value-to-managed-care-arrangements-20716.aspx

This resource guide, created by the Health Resources and Services Administration (HRSA), explains the need for cultural competency among health care providers. An increasingly culturally diverse population in the United States demands it, particularly in relation to Managed Care Organizations (MCOs) (p. 1). MCOs are contracted companies that work with health care providers to deliver lower cost care and ensure quality (p. 1). States commonly work with MCOs to deliver Medicaid health care services to save money. Due to lower costs and Medicaid delivery, MCOs frequently work with underserved populations, including American Indian and Alaskan Native (AI/AN) communities (p. 1). Therefore, MCOs have a need for increased cultural competency (p. 1).

HRSA provides examples of programs they have funded and recognized for effective cultural competency (p. 7). The most successful programs outlined do the following:

- Broadly define culture,
- Value clients' culture beliefs,
- Recognize complexity in language,
- Facilitate learning between providers and communities,
- Involve the community in defining and addressing service needs,
- Collaborate with other agencies,
- Professionalize staff hiring and training, and
- Institutionalize cultural competence (p. 1).

Although none of the noted programs specifically serve AI/AN populations, they do provide helpful information about successful approaches to providing health care to underserved populations. A few of these approaches include language interpretation services, transportation, and childcare assistance (p. 27). The guide also notes the use of community health workers and case managers to successfully connect underserved groups with health care (p. 29).

Overall, the guide provides in-depth information about the importance of cultural competency in relation to medical care and the particular complexities of managed care related to underserved populations. The guide also provides specific information about successful cultural competency programs and a list of resources and publications addressing cultural competency and managed care (pp. 55–65).

Hennessy, C., & John, R. (1996). American Indian family caregivers' perceptions of burden and needed support services. *Journal of Applied Gerontology, 15*(3), 275-293.

In this study, the authors analyze data collected from focus groups with family caregivers from five different American Indian tribes in the Southwest. The study assesses the participants' feelings about caregiving and needed support services. The authors explain that there is an increasing demand for long-term care among American Indian and Alaskan Native (AI/AN) communities (pp. 275–276). This need stems from a growing elderly population with high levels of chronic illnesses (pp. 275–276). A shortage of professional long-term care services and a cultural preference for family caregiving means that American Indian family members provide the majority of long-term care (p. 276).

The authors asked focus group participants about their perceptions of caregiving and found several cultural views of care, including:

- Respect for elders as an integral aspect of American Indian identity, which translates to a strong sense of obligation for caregiving (p. 279),
- A strong desire to care for elders in the home and keep them out of nursing homes (p. 279), and
- Female relatives as the most common primary caregivers (p. 279).

Although participants expressed positive feelings about caregiving as fulfilling a cultural obligation, the authors also found that the participants experience caregiver burden. Main sources of caregiver burden include:

- Anxiety about providing in-home medical care (pp. 208-281),
- Challenges of providing emotional support to a depressed elder or an elder who will not comply with care (p. 282),
- Strain on family relations (p. 283), and
- Negative impacts on personal health and well-being due to caregiving (p. 283).

The authors also asked participants about needed support services (p. 287). They found several areas with great need, including caregiver training, caregiver and family support groups, case management, respite care, and adult day care (pp. 287–288). The authors emphasize the need for increased and culturally appropriate caregiver support services (p. 289) to help manage the demand for long-term care among American Indian communities (p. 289).

Hennessy, C., John, R., & Anderson, L. (1999). Diabetes education needs of family members caring for American Indian elders. *The Diabetes Educator, 25*(5), 747-784.

This study assesses challenges of diabetes management among American Indians caring for an elder or a family member with diabetes. The authors analyze data collected from five focus groups with six different American Indian tribes (p. 747). Overall, the study illustrates a high need for diabetes education among American Indian family caregivers because diabetes is on the rise among elderly American Indians (pp. 747–748).

Study participants identified the three major challenges they encounter and need more education about related to diabetes care management (p. 747). These challenges are:

- Managing medication, blood sugar, and post-amputation operation care (p. 750);
- Understanding and working with an elder's mental health problems, such as depression and refusal to comply with medical treatment (p. 751); and
- Decision-making and communication problems, including challenges with making care decisions and explaining a diabetes care routine to multiple family members (pp. 750–751).

These challenges illustrate the complexities of caregiving for people with diabetes (p. 753) and display the need for diabetes care education. Study participants also noted the importance of planning and sharing caregiving responsibilities with family members (p. 752). Participants stressed that family coordination is key to preventing the primary family caregiver from becoming overwhelmed (p. 752).

Overall, the authors emphasize the family-focused approach to managing diabetes in care receivers in American Indian communities (p. 753). The authors suggest interventions to improve diabetes caregiver education. These interventions include family-friendly conferences and in-home diabetes education for the patient and caregiver (p. 753). The authors stress the importance of caregiver training that focuses on the care givers' health and wellness, in addition to that of their patients (p. 753).

Jervis, L., Boland, M., & Fickenscher, A. (2010). American Indian family caregivers' experiences with helping elders. *Journal of Cross-Cultural Gerontology, 25*(4), 355-369.

This study assesses the negative and positive aspects of caregiving for an American Indian elders' family members. The authors analyze data from 19 Northern Plains American Indian family members who care for an elder (p. 1). Overall, study participants reported positive caregiving experiences (p. 1).

The authors note that the older American Indian population is "one of the fastest growing groups of nonwhite elderly in the United States" (p. 1). Despite this population growth, there is a lack of research focused on the elderly American Indians (p. 1). In particular, the authors note a lack of information on informal caregiving for this population (p. 1).

Overall, most study participants reported low levels of caregiver burden and positive caregiving experiences (p. 9). Specific positive aspects of caregiving included:

- Emotional rewards of caregiving (p. 7),
- Elders' appreciation for their caregivers (p. 7),
- Enjoyment of spending time with an elder (p. 8), and
- Appreciation for the advice and wisdom of an elder (p. 8).

The authors explain that these positive findings may stem from several unique aspects of AI culture, including:

- Traditional respect for elders (p. 9),
- Emphasis on keeping elderly family members out of nursing homes (p. 9),
- Sharing caregiving responsibilities with several family members (p. 9), and
- Having a sense of "returning the favor" to an elder family member who provided a significant amount of financial and emotional support (p. 9).

The authors note that the caregivers felt that their elder family members did not need high levels of care, which likely contributes to the positive results (p. 9). In addition, 69% of the participants receive caregiving assistance from another individual (mostly family members) (p. 5). Participants only consistently expressed one area of caregiver burden in that many felt they could "do a better job in caring for the elder" (p. 5).

The study participants live on a very rural reservation. However, the authors explain that they reported less caregiver burden than what is typical of rural caregivers (p. 10). The authors suggest that the positive attitude towards caregiving among American Indians is worth further study (p. 10). Based on this study, unique aspects of American Indian culture appear to help lessen other caregiving challenges, such as rural residency (p. 10).

John, R., Hennessy, C., Dyeson, T., & Garrett, M. (2001). Toward the conceptualization and measurement of caregiver burden among Pueblo Indian family caregivers. *The Gerontologist, 41*(2), 210-219.

In this study, the authors evaluate the burden experienced by American Indian family caregivers. The authors surveyed 169 Pueblo primary family caregivers in New Mexico (p. 210). Overall, the Pueblo caregivers reported significant caregiving challenges and burden (p. 214). The participants expressed a number of complex sources of caregiver burden (p. 21).

The authors explain that minority family members more commonly act as long-term care providers for elder family members than non-white Hispanics (p. 210). They also note that, although family caregiving challenges have received a significant amount of attention and research, very little focuses on American Indian populations (p. 210).

The authors asked about different sources of burden in the survey to determine the specific challenges of Pueblo caregivers (p. 212). They found several major areas of stress or burden among the Pueblo caregivers, which include:

- Conflict over a lack of time for self, disruption of other responsibilities, and a changed relationship with the elder (p. 216);
- Negative feelings toward the elder (p. 216);
- Doubt about their caregiving abilities (p. 217); and
- Guilt about not doing more or better (p. 217).

Of these different stressors, feelings of guilt were the most common among the Pueblo Indian family caregivers (p. 217). The authors suggest that service providers assess whether feelings of guilt reflect the actual situation (p. 217). If they do, than providers should intervene with extra caregiver support (p. 217). In summary, the authors explain that identifying types of burden specific to Pueblo caregivers can help provide more efficient support tailored to the communities' needs (p. 218).

Kwak, M., Ingersoll-Dayton, B., & Kim, J. (2012). Family conflict from the perspective of adult child caregivers: The influence of gender. *Journal of Social and Personal Relationships, 29*(4), 470-487.

This study analyzes data from a nationally representative sample of 861 family caregivers caring for a parent. The authors assess how family conflicts and gender impact caregiver stress. The study focuses on gender because daughters are the most common caregiver for a parent (p. 471). The authors also state that daughters receive less support from spouses and experience more conflict with family members over caregiving than sons (p. 471). The study sample was composed of 70% daughters and 30% sons (p. 476).

The authors analyzed several different factors that contribute to caregiver stress, including:

- The severity of the parents' health problems (p. 473),
- Conflicts with other family members (p. 473),
- The division of caregiving responsibilities (p. 475), and
- A lack of caregiver support from siblings or the spouse (p. 478).

The study results show that several factors, regardless of gender, increase family conflicts and stress levels of adult child caregivers. These factors include increased severity of the parent's health condition, lack of caregiver support from a sibling, and lack of support from a spouse (p. 478).

The authors found that sons actually experience more conflict with family than daughters when the health of a parent declines (p. 482). However, although sons appear to experience some unique challenges, overall, the study finds that sons and daughters experience similar levels and types of stress due to caregiving (p. 484). These findings demonstrate the significant stresses associated with caring for an ill parent. They also illustrate the need for family interventions to help alleviate caregiver stress.

Landry-Meyer, L. (1999). Recommended intervention strategies for grandparent caregivers. *Family Relations, 48*(4), 381-389.

This article analyzes data collected from a random survey of 6,307 Ohio households. The authors assess the needs of grandparents caring for their grandchildren. They also propose interventions to improve these needs. The article addresses how caregiving is different for a grandparent and whether support services are available (p. 382).

In the survey, grandparent participants noted their greatest concerns and needs related to caregiving (p. 383). Overall, participants expressed frustration about receiving poor support services (p. 385). Many state programs do not provide an equal amount of support to grandparents compared to what they offer for the biological parents, particularly if the caregiving is informal (that is, not officially a foster care, guardian, or adoption relationship).

Other specific areas of need participants identified include:

- Recreational and social activities for the grandchild (p. 384),
- Physical and emotional health needs of the grandchild (p. 384),
- Child care services (p. 384),
- Physical and emotional health needs of the grandparent (p. 384), and
- Increased parental rights, such as medical authorization (p. 386).

The authors propose a number of interventions to address grandparent caregiver needs, including:

- Encouraging parks and recreation departments and libraries to provide events that include grandparents and grandchildren (p. 384),
- Suggesting schools and community youth agencies offer monthly grandchild support groups that include grandparents and grandchildren (p. 384), and
- Increasing respite care for grandparents to provide a break from caregiving (p. 385).

Overall, this article conveys unique challenges that grandparent caregivers face. The authors explain that grandparents do not have the same legal rights and access to support services as biological parents. These challenges make the role of caregiver very complex for grandparents.

Lehman, D. (2010). *Supporting Caregivers of All Cultural Backgrounds.* **Retrieved October 8, 2015, from Mather Lifeways Institute on Aging:** http://www.matherlifewaysinstituteonaging.com/wp-content/uploads/2012/03/Supporting-Caregivers-of-All-Cultural-Backgrounds.pdf.

This paper discusses cultural diversity among caregivers responsible for elderly family members. The author focuses on diversity education for medical providers, including doctors, nurses, social workers, and community workers (p. 2). The paper emphasizes the growing need for cultural competence in medical care, as the minority, non-white, and over 65 population is growing rapidly in the United States (p. 2).

The author notes a number of basic characteristics to consider when providing support to caregivers. These factors, which can vary across cultures and influence caregivers, include:

- Time,
- Space,
- Communication,
- Family,
- Diet, and
- Health traditions (p. 4).

The author notes several aspects of caregiving that may vary across cultures and determine whether a caregiver needs additional help. These factors include:

- Language barriers,
- Presence of a social support network, and
- Cultural beliefs about a sense of duty or responsibility towards the care recipient (p. 6).

The author suggests that medical and social service providers focus on these factors to determine whether caregivers need extra help (p. 6). The article also lists several resources for family caregivers and a number of studies that explore caregiving among different racial and ethnic groups (pp. 7–10). Overall, the author emphasizes that caregiving varies greatly across different ethnic and racial groups (p. 4).

Ludtke, R., & McDonald, L. (2003). *National Family Caregiver Support Program: North Dakota's American Indian Caregivers.* **Center for Rural Health, University of North Dakota. Retrieved October 8, 2015, from**
https://www.nrcnaa.org/pdf/CaregiverSupportProgram.pdf

The University of North Dakota's Center for Rural Health created this research report to determine the support services needed by American Indian caregivers in North Dakota. The report assesses survey data from American Indian caregivers from five different reservations in North Dakota and compares it to data from the general population (p. 1). The report addresses the needs of American Indians providing care for elder family members and grandparents providing care to grandchildren (p. 3). Topics covered include:

- Difficulties American Indians in North Dakota experience because of caregiving,
- The availability of caregiver support services, and
- Uses of caregiver support services (p. 3).

AIs caring for older family members did not report any significant difficulties, while members of the general population did (p. 15). In terms of availability of caregiver supports, AIs caring for elders reported less access to support services than the general population (p. 17). Access to transportation and home health aides is particularly challenging for American Indians in North Dakota (p. 17). For needed services, AIs caring for elders prioritized visiting nurses and home health aides (p. 18).

American Indian grandparents providing care to grandchildren reported slightly less difficulties due to caregiving than the general population (p. 36). For service availability, levels ranged widely among the general population and American Indians (p. 40). The most needed services among American Indian grandparents providing care include tutoring and mentoring programs for their grandchildren (p. 41).

Overall, this report illustrates the challenges of caregiving among all populations, pointing out how the data indicates American Indian caregivers face more significant and severe challenges in their caregiving than do caregivers in the general population.

Mui, A. (1995). Multidimensional predictors of caregiver strain among older persons caring for frail spouses. *Journal of Marriage and Family, 57*(3), 733-740.

This study assesses the main sources of stress for a husband or wife caring for a frail and elderly spouse. The author analyzed national data gathered by the U.S. Department of Health and Human Services, separating the data from husbands and wives to determine if there are gender differences in caregiver stress. The author analyzes the overall demands of caregiving for an individual, specifically evaluating the emotional, physical, and financial stress that results from caregiving (p. 735).

The results presented several differences in stress and challenges among male and female caregivers. Female caregivers reported significantly higher levels of physical and emotional stress than males (p. 736). Women also reported poorer relationships with their spouses and less respite care services (p. 736). However, both men and women report similar levels of overall caregiver demand (p. 736).

In terms of differences, specific factors that lead to greater levels of stress were identified. For emotional stress, behavioral problems of the care recipient and a lack of respite care appear to contribute to higher stress among female caregivers than for male caregivers (p.737). Behavioral difficulties from care receivers also cause greater physical stress for female caregivers than their male counterparts (p. 737).

Men and women identified poor caregiver health as a significant source of stress (p. 738). Overall, the author emphasizes that the role of a spousal caregiver is complex and presents unique challenges not experienced by other caregivers (p. 739). The study also stresses that husbands and wives may encounter different challenges and needs as caregivers.

Murray, M. (2008). The networked family: Reframing the legal understanding of caregiving and caregivers. *Virginia Law Review, 94*(2), 385-455.

This article reviews how the lack of recognition of informal caregivers by the field of family law affects caregivers. (p. 387). The author argues that the lack of recognition limits caregivers, as family law often refuses to recognize their legal rights (p. 389). The author argues that this lack of recognition "creates a set of extremes that label caregivers as either parents, vested with the rights and duties of that status, or legal strangers, with no rights and duties whatsoever" (p. 389).

The author cites several statutes that validate caregiver networks. One of these statutes is the Indian Child Welfare Act of 1978 (ICWA) (p. 419). The ICWA gave tribal courts control over all child custody cases on Indian reservations (p. 419). Tribal court control is necessary because state welfare agencies were inappropriately removing Indian children from their homes based on invalid abuse charges (p. 419). On Indian reservations, children are frequently cared for outside of the home by family and friends, rather than parents (p. 419). Child welfare agents misunderstood this cultural caregiving tradition as parental neglect (p. 419).

The author explains that the ICWA was a rare legal recognition of tribal caregiving traditions and caregiving networks (p. 422), citing and explaining several other examples of legal triumph for caregiving networks, including open adoption and genetic donors (pp. 415, 424). Overall, the author emphasizes how caregiving networks are essential for many cultural groups for successful child rearing.

National Association of Area Agencies on Aging and Scripps Gerontology Center at Miami University. (2014). *Title VI Survey Results.* **Retrieved November 3, 2015, from http://www.n4a.org/Files/Title%20VI%20research%20record%202014%2010-21-2015.pdf**

This report describes the results from a 2014 survey of 256 Title VI Native American Aging Programs. The survey included questions about how Title VI grantees use funding, where they are located, the types of services that they provide, and the programs' needs. Title VI is a federal grant program administered by the Administration on Aging to support elderly American Indians, Alaskan Natives, and Native Hawaiians (p. 1). The Title VI Native American Caregiver Support Program focuses on support services for caregivers.

Caregiver support is a major part of Title VI. Of all possible services, survey participants noted that elders programs were most likely to manage caregiver support programs (p. 9). The majority of areas served by these Title VI programs are rural (p. 3).

Nearly 75% of Title VI grantees are individual tribes (p. 1). Other grantees include tribal consortiums and intertribal councils (p. 1). Partnerships with other tribal departments are essential to manage effective caregiver support. Seventy-four percent of Title VI caregiver programs work closely with the Indian Health Service, other health care providers, or tribal social service programs (p. 12).

Survey participants noted a number of needs that would improve their programs, which include funding issues and training. Nearly 60% of the surveyed Title VI programs reported a decrease in funding since 2011 (p. 18). The top training needs of Title VI programs included identifying funding sources, strategic planning, and increased knowledge about Medicaid (p. 20).

National Indian Council on Aging. (2013). *The Savvy Caregiver in Indian Country.* **University of Oklahoma. Retrieved October 2, 2015, from** http://nicoa.org/wp-content/uploads/2014/04/Savvy-Caregiver-Part-1.pdf

This training manual was created by the National Indian Council on Aging for American Indian and Alaskan Native (AI/AN) individuals caring for older adult family members with dementia. The manual provides information on effective caregiving (p. 9). It also emphasizes the importance of self-care and well-being for caregivers. The authors outline a "Savvy Caregiver" program, including a suggested syllabus and tips for leading the program (pp. 35–44). The majority of the manual focuses on managing daily life for the care recipient and their caregiver.

The manual addresses the large amount of stress that family caregivers undergo and focuses on a number of activities that can help manage caregiver stress, including:

- Managing the difficult behaviors associated with dementia and creating strategies and set responses when the behaviors occur (p. 20);
- Managing the caregiver's well-being and identifying the emotional impact of caretaking (pp. 20–21), and
- Improving family involvement in caretaking (p. 21).

The manual also identifies cultural aspects of caregiving that are unique to AI/AN communities with case examples (pp. 23–34). Cultural factors include:

- The diversity of AI/AN cultures (p. 11),
- Language differences (p. 23),
- The preference for caregiving for elder family members in the home in AI/AN communities (p. 27), and
- The importance of spirituality (p. 47).

The guide also discusses the cultural importance of elders in AI/AN communities, which may make coping with dementia particularly challenging (p. 47–48). Overall, this manual emphasizes the importance of family and community among AI/AN caregivers. The authors stress that engaging families and communities in caregiving can reduce caregiver burden (p. 46).

Nichols, L., & Keltner, B. (2005). Indian Family Adjustment to Children with Disabilities. Centers for American Indian and Alaska Native Mental Health Research. University of Colorado Anschutz Medical Campus.

This study assesses how American Indian families handle the challenges of raising school-age children with disabilities. The disabilities identified in this study include "learning disabilities, muscular-skeletal disorders, visual and hearing impairments, mental and cognitive disorders, and mental health disorders" (p. 28). The authors interviewed 143 American Indian community members in the Great Plains and Southeast and determined that, although family members provide the majority of care to American Indian children with disabilities (p. 23), they also typically rely heavily on their communities for assistance (p. 23).

The authors describe views of disability held by different American Indian tribes (p. 25). Some of these views do not consider a disability as negative and others are hesitant to label a child as disabled due to stigma (p. 25). Many tribes do not have a word for disability in their language (p. 24). Overall, the authors focus on how American Indian families adjust to life with a disabled child.

Study participants describe successful and unsuccessful family adjustments to a disabled child (pp. 34–43). Successful caregiving families identified:

- Sharing caregiving responsibilities with the whole family,
- Obtaining needed services for the child, such as Medicaid and specialty medical treatments,
- Altering the home environment to accommodate a child's disabilities,
- Maintaining spirituality, and
- Maintaining sobriety to care for the child (p. 43).

Barriers to successful caregiving included:

- An inability to obtain needed services,
- Isolation from the community,
- Disruption of family routines, and
- Using illegal drugs and/or alcohol to cope (p. 43).

The authors conclude that training health care professionals about caregiving in American Indian cultures is essential to effective assistance for the caregiving families. (p. 43).

Riess-Sherwood, P., Given, B., & Given, C. (2002). Who cares for the caregiver: Strategies to provide support. *Home Health Care Management & Practice, 14*(2), 110-121.

This article acknowledges the challenges (mental and physical) of caregiving. It provides strategies that professional home health practitioners, such as nurses, can use to help family caregivers maintain and improve their health. The authors note that providing long-term care for a family member places significant demands on an individual's time, finances, and mental and physical health (p. 111). Once a family caregiver starts to feel burdened, their health and the health of the care recipient may decline (p. 111).

To prevent caregiver burden, the authors suggest that home health nurses engage in a thorough assessment of the caregiver and care situation. The authors suggest assessing a number of factors that affect a caregiver's situation and health (p. 112), including:

- The patient's care needs and number of hours per day required,
- The caregiver's understanding of the patient's diagnosis,
- The caregiver's ability to provide direct care,
- The caregiver's physical and emotional health,
- Caregiving roles within the family and how family roles change for the patient and caregiver, and
- Available resources, which include family support, social support, formal medical support, and respite services (p. 112).

After assessing the caregiver, the authors suggest a number of interventions that may help improve the caregiver's health including:

- Providing education about medical care procedures, equipment, and stress reduction (p. 116);
- Employing coping strategies to deal with caregiving stress (p. 117); and
- Using resources and finding social support (p. 118).

The authors also identified the importance of preventive health care activities for caregivers, including regular vaccinations, dental exams, and cancer screenings (p. 114). Overall, this article acknowledges the challenges of caregiving and provides professional health care providers with tips and tools to help caregivers manage the process.

Rose, D., & Garwick, A. (2003). Urban American Indian family caregivers' perceptions of barriers to management of childhood asthma. *Journal of Pediatric Nursing, 18*(1), 2-11.

This study examines barriers to effective management of childhood asthma, as identified by urban American Indian family caregivers. The authors used data from 16 Ojibwe families with children who have asthma (p. 4). Overall, participants noted many barriers to care, with a particular emphasis on cultural challenges (p. 8).

Participants described challenges with access to care and information to care, including:

- The inability to find and pay for transportation to the hospital or doctor appointment (p. 8),
- Delays in the diagnosis and treatment of asthma (p. 9), and
- The lack of adequate information about childhood asthma (p. 10).

Participants expressed concerns about cultural challenges, including:

- The lack of respect from health care providers, especially in emergency departments (p. 9), and
- Poor support for asthma care at schools (p. 10).

Childhood asthma is a complex issue and the identified barriers make it a greater challenge for American Indian caregivers (p. 10). To reduce these challenges, the author stresses the importance of providing culturally appropriate care (p. 10). In addition, the author suggests culturally appropriate asthma education for families through medical providers (p. 10). Finally, the author suggests that medical providers take part in asthma management programs at schools (p. 10).

Sawchuk C., Van Dyke, E., Omidpanah, A., Russo, J., Tsosie, U., & Buchwald, D. (2014). Caregiving among American Indians and Alaska Natives with cancer. *Support Care Cancer, 23*, 1607-1614.

This study analyzes challenges experienced by American Indian and Alaskan Native (AI/AN) individuals caring for a family member with cancer. The authors conducted interviews with urban AI/AN caregivers and non-AI/AN caregivers. The authors note that cancer is the second leading cause of death among AI/AN populations and AI/AN family members provide significant support (p. 1,607). This support is a crucial aspect of cancer treatment (p. 1,607). The authors also note that AI/AN cancer caregivers face unique challenges, including greater transportation barriers and a tendency to provide higher levels of care than other groups (p. 1,608).

In terms of challenges for caregivers, caregivers answered questions about barriers related to cancer care for their care recipient. Barriers identified by AI/AN caregivers include:

- Finances, family, and work issues;
- Transportation difficulties;
- A lack of trust in health care providers;
- Concerns about confidentiality in health care centers;
- Unwelcoming staff at health care centers (p. 1,611).

Despite barriers and challenges, the AI/AN participants reported relatively low stress related to caregiving (p. 1,611). Participants also reported that they find caregiving "highly meaningful" (p. 1,611). The authors hypothesize that AI/AN cultural values, such as, "upholding family responsibilities and intergenerational support," may contribute to positive caregiving experiences (p. 1,612).

The authors add that, since study participants are urban residents, the noted barriers are likely quite different from those among a group of rural residents (p. 1,613). Overall, the authors recommend screening AI/AN cancer patients and caregivers for barriers to care (p. 1,614). They also recommend culturally appropriate caregiver support services for AI/ANs.

Scarton, L., Bakas, T., Miller, W., Poe, G., & Huber, L. (2014). Needs and concerns of family caregivers of persons with type 2 diabetes – An integrated review of cross-cultural literature with implications for the American Indian population. *The Diabetes Educator, 40*(4), 444-452.

This article identifies needs and concerns of family caregivers of adults with type 2 diabetes in the American Indian population. The authors conducted a literature review and focused on the following five areas of caregiver needs:

- **A lack of Information:** Family caregivers need more general information about dietary restrictions, local services, and long-term effects of type 2 diabetes (p. 450).
- **Dealing with emotions and behaviors of the care recipient:** Family caregivers need more support to handle the emotions and behaviors of individuals with type 2 diabetes (p. 450).
- **Assistance with physical care:** Family caregivers need more training on dietary requirements, particularly in managing blood glucose levels (p. 450).
- **Assistance with finances and transportation:** Family caregivers need increased availability of in-home public health nurses. Caregivers often travel far distances to seek medical care (p. 451).
- **Dealing with personal responses to caregiving:** Family caregivers need more support in maintaining emotional health, due to feelings of guilt and a cultural focus on the "need of the group rather than on the individual" (p. 451).

The authors state that many American Indian caregiver concerns result from a lack of understanding about diabetes and its management, and recommend that health care providers include caregivers in the patient discharge process (p. 451).

Scharlach, A., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. (2006). Cultural attitudes and caregiver service use: Lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work, 47*(1/2), 133-156.

This study evaluates cultural differences in caregiving experiences through the analysis of focus groups conducted with caregivers from eight different racial or ethnic backgrounds, including American Indians. Focus groups were conducted with African American, Chinese, Filipino, Hispanic, Korean, Russian, and Vietnamese caregivers who were asked about their use of caregiver support services and their perceptions of these services (p. 136).

There were a number of similarities among all eight groups. Members from all eight groups consider caregiving to be a family obligation (p. 139). They also emphasize caregiving as a cultural tradition (p. 140). Finally, participants from all groups perceived caregiving as a fulfilling activity, rather than a burden (p. 140). Overall, participants reported a low use of formal caregiver support services (p. 144).

American Indian participants reported positive feelings about caregiving and that caregiving was an important aspect of family tradition (p. 140). However, American Indian participants noted that a long history of discrimination has led to a distrust in the government and a hesitancy to use caregiver support services (p. 141). In addition, American Indian participants reported a lack of knowledge of available caregiver services (p. 145).

American Indian participants also expressed concern that professionally provided caregiver and care recipient support service staff do not understand their culture or special needs (p. 146). Similar concerns were mentioned among several of the other focus groups. Overall, the authors emphasize the need for family-focused and culturally appropriate caregiver support services (p. 153).

Schure, M., & Goins, R. (2015). Association of depressive symptomatology with receipt of informal caregiving among older American Indians: The Native elder care study. *American Journal of Geriatric Psychiatry, 23*(6), 579-588.

This study analyzes levels of depression among older (55 years and older) American Indians and their informal caregiving needs. The study reports that older American Indians experience high rates of physical disability and depression and, therefore, have a high need for assistance with their daily living activities (p. 580). The authors also identify informal caregiving as "unpaid care provided by family members and friends to those in need of assistance with daily activities" (p. 580). Overall, the study finds that 82% of elder study participants receive informal care (p. 584).

The report found that immediate family members—children and spouses, are the most common informal caregivers (p. 584). Other typical informal caregivers include in-laws and neighbors (p. 585). The report indicates that women act as primary informal caregivers more often than men (p. 585).

Older American Indians who reported symptoms of depression with multiple symptoms required more caregiving hours than those without depression or fewer symptoms of depression (p. 585). The authors explain that depression disrupts the bodily process to the point of causing physical symptoms and a diversion from "healthy lifestyle behaviors" (p. 585).

The authors conclude that depression is an important consideration for elder American Indians in need of informal care and their informal caregivers. Recommended intervention programs for caregivers include stress reduction and specialized training (p. 587).

Spencer, S., Goins, R., Henderson, J., Wen, Y., & Goldberg, J. (2013). Influence of caregiving on health-related quality of life among American Indians. *The American Geriatrics Society, 61*(9), 1615-1620.

This study used a survey of American Indian/Alaskan Native (AI/AN) caregivers to analyze health and quality of life. The study was conducted in two regions, the Northern Plains (Lakota Sioux Nation and Cheyenne River Sioux Reservations) and Southwest (Pima and Maricopa Nations from the Gila River Indian Community) (p. 1,616). The authors discuss the increasing need for informal caregivers in the United States due to a growing aging population (p. 1,615). This is particularly true for the AI/AN population, since available information indicates that 17.6% of AI/AN caregivers provided care for persons aged 60 and older, which is 1.2% more than the general U.S. population (p. 1,615). The authors also describe the AI/AN approach to caregiving as a shared responsibility (p. 1,616).

By comparing data from caregivers and non-caregivers, the researchers determined that non-caregivers tended to have better mental and physical health than caregivers (p. 1,619). The authors hypothesize that different types of caregiving require varying levels of intensity, and the intensity of caregiving is what impacts the caregiver's physical and mental health (p. 1,619). Based on these differences, identifying the type and intensity of caregiving may help improve caregiver support services (p. 1,619).

The authors also stress the importance of cultural awareness and sensitivity when working with American Indian caregivers. (p. 1,619). American Indian individuals may be reluctant to discuss the challenges of caregiving (p. 1,619). The term "caregiver" may even have negative connotations among American Indians (p. 1,619).

Steadman, P., Tremont, G., & Duncan Davis, J. (2007). Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology, 20*(2), 115-119.

This report analyzes the relationship between caregivers (primarily spouses and adult children) and care recipients with dementia. The study determined that the caregiver's relationship with the care recipient before the onset of dementia predicts caregiver burden and depression (p. 115). The report describes possible outcomes if a caregiver views a relationship with the care recipient negatively (p. 116). Negative sentiments can lead to abusive behavior or aggression among caregivers (p. 116). It also can result in a preference for institutional care over homecare (p. 116).

The report uses a series of scales to assess the caregiver's relationship with the care recipient (p. 116). It also assesses the caregiver's need for assistance and perceived burden in the environment of the care receiver's problem behaviors (pp. 116–117). The results included the following:

- Caregiver burden is influenced by perception of the relationship with the care recipient before the onset of dementia (p. 117).
- Negative feelings towards the care recipient before the onset of dementia are associated with greater caregiver burden (p. 117).
- Poor relationships with care recipients before dementia onset can result in negative reactions to care recipients' behavior and poor communication and problem-solving skills (p. 118).

The authors conclude that the perceived relationship between the caregiver and care recipient contributes to caregiver burden. Intervention programs that consider this relationship will be more likely to address the attitudes and behaviors that influence caregiver burden and stress (p. 118).

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