A good mind. A good heart. A strong fire.

Oneida Helping Oneida (OHO) Family Caregiving Study: Community Report

Utilization and Awareness of Caregiver Resources in the Oneida Nation of Wisconsin

Version Jan 2024. Questions? Please contact Dr. Mary Wyman at mfwyman@wisc.edu

Native American Alzheimer's Disease
Research and Outreach Initiative

Wisconsin Alzheimer's
Disease Research Center
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

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Executive Summary

This Community Report describes the main findings of the Oneida Helping Oneida Family Caregiving Study (OHO) conducted in 2021. The report was reviewed by the Oneida Alzheimer's Community Advisory Board (CAB) and approved for distribution. The project was approved through Oneida Business Committee resolution and sponsored by the Oneida Alzheimer's Disease Community Advisory Board.

Family caregivers (also called "informal caregivers") provide care for family or friends who need assistance. They are not professionals and are typically unpaid. While family caregivers are vital sources of support for older adults in all communities, family caregiving of Elders is more common in Indigenous communities compared to many other racial/ethnic groups. Being a family caregiver can be very time-consuming and demanding, especially for caregivers of Elders with memory loss or dementia. Making use of educational, support, and respite services has been shown to help caregivers by decreasing caregiver stress and improving health and quality of life for the Elder. However, the use of such services by family caregivers tends to be low. This research had the goal of better understanding factors that might impact use of services by family caregivers within the Oneida Nation of Wisconsin.

The OHO Study included a Tribal-wide survey on awareness and use of seven key resources to support family in caring for Elders: 1) caregiver support groups, 2) caregiver training, 3) respite services, 4) financial help, 5) residential or nursing home facilities, 6) transportation services, and 7) household help (e.g., cooking, cleaning, yardwork). A total of 481 Oneida community members, ranging in age from 18 to 87 years old, responded with information on personal characteristics, caregiver status, their awareness of services and how they learned about them, and their attitudes toward use of the seven key resources. They had the option to provide "free-text" open comments at the end of the survey.

Of the 481 people who responded to the survey, slightly less than half (43%, N=207) were currently providing assistance to an adult family member or friend. These Oneida caregivers are diverse geographically and demographically. More than 60% live outside of reservation boundaries, and almost 13% of caregivers are not enrolled Tribal members. Overall, 86% of caregivers were caring for an Elder. The majority (61%) of caregivers provide care for an adult with memory problems. Of the 274 respondents who responded "no" and were classified as non-caregivers, 44.6% reported that they personally knew an enrolled Oneida Tribal member who was providing any kind of assistance to an Elder, and 11.2% personally knew a non-enrolled descendant or family member who was providing assistance to an elder. Taken together, the findings indicate that family caregiving is a common experience within the Oneida

Nation of Wisconsin, regardless of residence or enrollment status, and that many Oneida family caregivers can benefit from supportive resources to help them in their role.

Respondents noted various pathways to learning about resources to support family caregivers. “Word of mouth” (from friends or family) or researching on their own, as well as medical and social service providers, are important sources of information. However, awareness of key resources and how to access them was limited. There was a tendency for more awareness to be reported by respondents who are current caregivers, are older, identify as female, or live within Oneida reservation boundaries. Among current caregivers, many reported being interested in supportive resources. However, past and current use of resources was limited. Use of all resources went down during the COVID-19 pandemic. Notably, a significant group of caregivers (ranging from 30% – 43% across the seven resources), reported no past use and no intention to use resources in the future.

Survey data show that Oneida identity, values, and traditional practices are important factors in influencing perspectives on using a service. Overall, findings from the survey suggest that compared to non-caregivers, current family caregivers perceive the use of caregiver resources as being less consistent with Oneida culture and values. This is concerning, because our analyses show that caregiver perceptions of consistency with cultural values and practices are strongly related to how they think about using supportive resources. Findings from the OHO Study and from previous research with Native caregivers highlight the critical importance of ensuring that caregiver outreach and services are aligned with community culture, traditions, and values.

Finally, personal statements from survey respondents (included toward the end of this report) underline these points and paint a human picture of the Oneida caregiver experience. The OHO Study will help pave the way for future research on family caregiving in Native American communities. The results of this research can help inform decisions of the Oneida Nation of Wisconsin regarding programming, policy, and outreach to the community. Thank you for your interest!

Background and Purpose of the OHO Study

The Oneida Helping Oneida Family Caregiving Study (OHO) was conducted to learn more about the family and friends in the Oneida Nation of Wisconsin who help an adult that needs assistance. We refer to these helpers as family caregivers (also called "informal caregivers") because they are not professionals and are typically unpaid. Most of the adults they are assisting are older adults (Elders, defined as age 55 and older). While family caregivers are vital sources of support in all communities, family caregiving of Elders is more common in Indigenous communities compared to other groups. Native American communities bear an increased risk for dementia and other debilitating diseases, and therefore may have increased need for family caregiving.

This study sought to learn more about the awareness and use of caregiver services and resources in the Oneida Nation of Wisconsin, to help guide future efforts to increase use of these resources by people who need them. Being a family caregiver can be very demanding and time-consuming, especially for caregivers of Elders with memory loss and dementia. Using services and resources (e.g., caregiver education and support, financial help, and respite services) can help caregivers in their role by decreasing caregiver burden and stress and improving the health and quality of life for the Elder. Some evidence-based interventions have even been adapted to be culturally appropriate for Native American communities. It was observed that utilization of caregiver services tends to be low. When caregiver resources that have proven benefit are not utilized, this can negatively impact dementia care access and quality, perpetuating existing disparities. Increasing the use of helpful resources among caregivers is one key strategy to address the caregiving crisis (Administration for Community Living, 2022), especially among caregivers in historically underserved communities such as Native American Tribal Nations. However, we have limited knowledge of the needs and preferences of Native American family caregivers.

The OHO Study was funded by a pilot grant in 2020 to Mary F. Wyman from the University of Wisconsin-Madison Institute of Clinical Translational Research (ICTR) / Collaborative Center for Health Equity (CCHE), under the Advancing Health Equity and Diversity (AHEAD) initiative. Funding concluded December 2021. Dr. Wyman is an affiliate investigator at the Alzheimer's Disease Research Center (ADRC) at the University of Wisconsin. The ADRC works to include groups traditionally underrepresented in Alzheimer's disease research and to prioritize the needs expressed by collaborating communities. The project was sponsored by the Oneida Alzheimer's Community Advisory Board (CAB), which has represented the Oneida Nation as an active participant in research efforts with the University of Wisconsin related to the needs of

Oneida Elders suffering from Alzheimer's disease or other dementias. This research was approved by the Oneida Business Committee on 10/28/2020 (Resolution # 10-28-20-C).

Origins of the Research: Among other things, the goals of the CAB are to help provide targeted outreach and education, and to continue efforts to improve access to culturally appropriate memory care to Tribal Elders and their families. Discussions among members of the Oneida Alzheimer's CAB identified concerns that family caregivers in the Oneida community may be experiencing unmet needs, and at the same time, that services available to Oneida caregivers were underutilized. However, accurate data were not available to address these concerns and possible solutions. The OHO Family Caregiving Study was developed out of these discussions.

Phase 1 – Survey: The OHO Study first involved conducting a community-wide survey of caregivers and non-caregivers in January through March of 2021. The survey was distributed widely in an online format using a web-based link. Upon request, a paper version was made available with a stamped return envelope provided. Participation was open to a) enrolled Tribal members, b) close family of enrolled members (e.g., non-enrolled spouses), and c) non-enrolled descendants of enrolled members. Participants were recruited through social media, the Tribal newspaper, flyers, and word of mouth. The survey was not limited by residence, but outreach efforts did target the reservation and urban Wisconsin (Milwaukee area) communities. Participants could complete the survey anonymously. However, optional entry into a cash raffle and indicating interest in participating in the subsequent interview study required that participants provide name and contact information. In total, 404 respondents entered the raffle. In data processing, identifying information was immediately separated from survey responses. The aims of the community survey were to describe awareness and use of dementia caregiving:

1) related resources in the Oneida Nation, including sources of information on caregiver resources;
2) describe community perspectives on the alignment of traditional values and practices with the use of caregiver resources; and
3) explore associations between demographic characteristics and resource awareness and utilization.

Phase 2 – Interviews: Because our focus was on family caregiving for Elders with dementia, we conducted individual interviews with ten (10) Oneida community members living on or near the Oneida reservation who were current caregivers of Elders with memory loss. Interview questions similarly focused on understanding caregiver decision-making regarding the use of services. *These data are currently being analyzed and are not presented in this report.*

An important goal of the OHO Study was to generate data to help guide efforts to increase use of community services and resources by Oneida family caregivers. The research questions were developed with Oneida community partners (e.g., Aging & Disability Services; Dementia Care Specialist) and Tribal members were employed by the project. Research presentations and publications have and will continue to involve Tribal partners in authorship and acknowledgements.

As stated in the Tribal Resolution, the data belong to the Oneida Nation. No analyses have or will be presented without review by the Oneida Alzheimer's CAB. In all instances, Oneida CAB members are co- or first authors on presentations and publications. The purpose of this report is to communicate the results of the community-wide survey back to Oneida community leaders for their own information and decision making as a Nation to help meet the needs expressed by Oneida Nation community members. The goal of this report is to provide a framework for understanding what is available, what is being used, and what the community may need in terms of support for family caregivers.

Family Caregiving and Service Use: A Brief Background

As noted above, family caregivers perform essential care tasks for loved ones who need help. These tasks are highly varied but could include transportation, shopping or help with financial management, assistance with household tasks (e.g., cleaning, home repair, etc.), dressing, bathing, or toileting, and/or social companionship, meal preparation, or medical care coordination. Most typically, they receive no financial compensation (or only token payment) for their assistance.

Recent efforts by advocacy and research organizations have provided some information on family caregivers in the U.S. National Alliance for Caregiving (NAC) and American Association of Retired Persons (AARP) produced the Caregiving in the U.S. 2020 report based on a nationally representative sample of almost 1,400 caregivers ages 18 and older (AARP and National Alliance for Caregiving, 2020). This survey examined many core areas of caregiving, including the prevalence of caregivers in the U.S., the demographic characteristics of caregivers and care recipients, the context of caregiving, financial impact, the supports provided to working caregivers, and information needs and resources. Based on their estimates, at least 53 million people in the U.S. are providing informal, usually unpaid, care and support to aging family members and people of all ages with disabilities (including mental health conditions).

Although home and community-based services can greatly help caregivers reduce stress and burden, improve care they provide, and sustain their helping role, use of supportive resources among caregivers is generally limited. Data from the 2015 National Study of Caregiving showed that only 27.8% of informal caregivers of older adults (aged 65 years or older) reported using supportive resources (Travers, Rosa, Shenoy, Bergh, & Fabius, 2023). The Caregiving in the U.S. 2020 study found one in four caregivers say it is very difficult to get affordable services in their community to help themselves and the adult they care for – including delivered meals, transportation help, or home health services. Nationally, caregivers report a need for caregiver training and information on keeping the care recipient safe at home, managing emotional/physical stress, and managing recipient's paperwork, e.g., applications determining eligibility for services. According to the recent Report, the most common sources of help or information about caregiving practices and services were doctors or other health care professionals (55%) and friends or family (43%).

In 2014, Dr. Bruce Finke, Elder Health Consultant for the Indian Health Service (IHS), provided testimony to the Special Committee on Aging, U.S. Senate, 113th Congress, as part of a field hearing on Alzheimer's Disease (*Statement of Bruce Finke, MD, Elder Health Consultant, Indian Health Service*, 2014). In his statement, Dr. Finke noted that "Caregiving challenges are amplified by the relative lack of formal long-term services and supports in Indian Country…." (p. 4) and "Increasing awareness and recognition of dementia in Indian Country starts with access to quality care and meaningful support for individuals with dementia and their caregivers in Tribal communities" (p. 9). In 2022, the Administration for Community Living (ACL) released the National Strategy to Support Family Caregivers, which was developed jointly by the Advisory Councils established by the RAISE Family Caregiving Act and the Supporting Grandparents Raising Grandchildren Act, with extensive input from family caregivers, the people they support and other stakeholders. This document contains almost 500 specific "actions" for governments, informal communities, and individuals to consider in order to improve conditions for family caregivers. There are five overarching goals listed:

1) increase awareness of and outreach to caregivers
2) advance partnership and engagement with caregivers
3) strengthen services and supports
4) ensure financial and workplace security for caregivers, and
5) expand data, research, and evidence-based practices to support caregivers.

Importantly, increasing the use of supportive resources by caregivers, especially caregivers from historically marginalized communities, is listed as a key public health strategy to improve outcomes.

Caregiving in Native American Communities

Despite the large numbers and considerable contributions by family caregivers to the care of adults and older adults who need help, they are often invisible within communities. In particular, little is known about family caregiving within Native communities. As an example, the Caregiving in the U.S. 2020 report does not break down information on Native Americans.

The limited existing research on family caregiving in Native communities suggests that Native persons are more likely to be caregivers for an older adult compared to other racial groups (McGuire, Okoro, Goins, & Anderson, 2008). Available data indicate that 17-20% of Native Americans identify as family caregivers (Cordova et al., 2016; Goins et al., 2011). A recent survey of American Indian/Alaska Native communities in the Pacific Northwest found that of the 225 participants (with 45 different Tribal affiliations) who completed the survey, 40% indicated that they had been an unpaid caregiver for a month or more, and 12% were current unpaid caregivers (Strachan & Buchwald, 2023). This study found that informal caregiving disproportionately impacted Native women when compared to other populations.

Native American Caregiver Experience and Service Use

The study of Native caregiving the Pacific Northwest found that 84% of caregivers reported experiencing "increased stress," 40% reported financial strain, and 34% reported decreased health "because of involvement with providing care" (Strachan & Buchwald, 2023). While 46% of caregivers reported receiving "some help" from members of their community, almost as many received "no help" (39%). Similarly, findings from a 2012 survey administered on the Hopi Reservation in northern Arizona (Cordova-Marks et al., 2019) found that caregivers report difficulties with not having enough time for family and or friends (88.6%), financial burdens (75.0%), and not having enough time for themselves (61.4%). That same study found that 77% of the 43 caregivers in the study reported that they do not receive any Hopi Tribal services in their role. However, a study conducted on a rural Northern Plains reservation found that Native caregivers helping Elders reported that providing care was associated with high levels of reward rather than burden (Jervis, Boland, & Fickenscher, 2010). This isolated community had limited formal services, but respondents reported a tendency toward collective caregiving by multiple members of an extended family. Similarly, research on dementia caregivers in Alaska Native communities showed that caregivers experience challenges of providing care – exacerbated by lack of resources and awareness – combined with unexpected blessings of spending time with the Elder (Kim, Asquith-Heinz, & Lewis, 2023). The high cultural value many Native American families hold with regard to providing care to Elders, perhaps explains a buffering from some negative consequences associated with this role.

Factors that impact utilization of resources by Native family caregivers remain unexplored. Native caregivers in the Pacific Northwest study did not believe they needed information on key caregiving topics (e.g., skills for personal care, legal and financial issues, home safety, and self-care). In contrast, almost all (98%) survey respondents in the Hopi Reservation study indicated they wished additional services, including training on patient care, support group, and stress management. Respondents also reported a preference to keep their Elders at home rather than seeking long-term care placement (Cordova-Marks et al., 2019). In the Northern Plains study, caregivers of Elders were not queried about wishes for services, but also did not mention unmet needs in interviews, despite lack of available services (Jervis et al., 2010). Findings from a recent study of Alaska Native dementia caregivers suggests that lack of understanding of dementia, awareness of services, and culturally appropriate resources impact caregivers' experience (Lewis, Manson, Jernigan, & Noonan, 2020).

Cultural factors have a strong impact on both the Native family caregiver experience and decision-making regarding healthcare utilization. For example, a hesitancy to seek services may be related to uncertainty about conventional health care institutions due to differing worldviews, or a preference for traditional healing methods (Hartmann & Gone, 2012; Roh et al., 2017). Culturally sensitive and traditional mental health services were preferred by a sample of Native Americans in Colorado (King, 1999). Thus, it is likely that unique, culture-specific factors also influence resource use by caregivers in different Native American Tribal Nations.

Native American Family Caregiving for Elders with Dementia

Across all communities, family and friends provide the bulk of care for older adults with dementia. This is certainly true for Native American families as well. A recent study from the Pacific Northwest found that out of more than 200 Native caregivers who were surveyed, 23% indicated that the person they were caring for had dementia (Strachan & Buchwald, 2023).

Caring for an Elder with dementia is a common situation in Native communities (K. M. Jacklin, Walker, & Shawande, 2013) and is a focus of the OHO Family Caregiving Study. Many public policymakers view Alzheimer's disease and related dementias as a public health crisis that disproportionately impacts minoritized populations such as Native communities. Combined with the rapid aging of the Native American population as a whole and the fact that Native communities are disproportionately impacted by co-morbid chronic diseases (Cho et al., 2014; Goins & Pilkerton, 2010), risk of dementia is increased (Mayeda, Glymour, Quesenberry, & Whitmer, 2016).

A few studies in Native communities have focused on caregiving for an Elder with dementia. Martindale-Adams and colleagues reported on the adaptation of the Resources for Enhancing

Alzheimer’s Caregivers Health (REACH; Martindale-Adams et al., 2017) caregiver education program within American Indian/Alaska Native communities. While this project was generally successful (and indeed, this program is available within the Oneida Nation of Wisconsin through Oneida’s Dementia Care Specialist), these authors note that in some Native communities, there were barriers to participation for caregivers. They note that due to the language barriers and the dynamics of Elders who were being cared for, there was difficulty in reaching adequate caregiver participation in the REACH program; for many families, an Elder’s wishes were the determining factor on whether caregivers were allowed to participate in the program. Similarly, others have found that respect for Elders was a central cultural value which supported the concept of caregiving within Native communities (Jervis et al., 2010). However, some respondents in this study expressed concern that this cultural tradition had eroded over generations.

Caregiving in International Indigenous Communities

Outside of the U.S., there has been additional research on the role of caregivers for people within Indigenous communities around the world. This research focuses on First Nations in Canada, Aboriginal people in Australia, Māori in New Zealand, and various Pacific Islander communities. Similar to the literature focusing on people Indigenous to the U.S., research on First Nations relationship to caregiving highlights the cultural component to caregiving as being important in supporting the family caregiving model (K. Jacklin, Pace, & Warry, 2015).

In Canada, there is difficulty in accessing services for caregivers of First Nations Elders with dementia due to the current complex policies governing such services (K. Jacklin et al., 2015). A study among the Cree in Canada found that additional barriers experienced by First Nations caregivers include a lack of culturally-grounded healthcare – for example, a lack of culturally appropriate items within assessments and difficulties in communication as a result of language used (Lanting, 2011). Grandmothers who were interviewed within this study emphasized the importance of proper translation services, the use of humor to improve comfort of patients, and culturally relevant testing – for example, the “Pyramids and Palm Trees Test” was modified to “Grasshoppers and Geese Test” so that stimuli were geographically relevant to Cree (Lanting, 2011). Taken together, this literature demonstrates the need for culturally competent healthcare and increased awareness of how cultural identity, practices, and values impacts Indigenous caregivers.

We will now turn our attention to the findings of the Oneida Helping Oneida Family Caregiving Study.

OHO Family Caregiving Study: Who responded to the survey?

> ***"How many caregivers do we have here in Oneida? Some people don't consider themselves a caregiver as they think it's their duty to help their parents...we just automatically take care of them, as that's the cultural belief. They take care of their own."*** —current non-caregiver

Over 500 members of the Oneida Nation community responded to the survey. After data cleaning and removal of incomplete surveys, there were a total of 481 respondents, of which 90% were enrolled Tribal members. Please see **Table 1**. The average age was 53 years (range from 18-87). In terms of gender identity, 75% of respondents were female, 24% male, and 1% two-spirit or other. More than 60% live outside of reservation boundaries; 32% of people reported residing on the Oneida reservation, with 22% residing in nearby counties and 22% residing in a Wisconsin metro area. An additional 10% of respondents lived outside the State of Wisconsin (see **Figure 1**).

We asked all respondents a question in order to identify current family caregivers. The survey question was: ***"A family caregiver is a relative, partner, friend, or neighbor who provides assistance for an adult with disabling health conditions, including Elders who need help. Are you providing any kind of help or assistance to an adult family member or friend?"*** Respondents who responded "yes" were asked specific questions. Slightly less than half of respondents (43%, N=207) reported they were currently providing care to an adult family member or friend. These respondents were diverse geographically and demographically. As can be seen below, more than 60% live outside of reservation boundaries, and almost 13% of caregivers are not enrolled Tribal members. Later in this report, we share additional information specific to respondents who identify as family caregivers.

Of the 274 respondents who responded "no" and were classified as non-caregivers, 44.6% reported that they personally knew an enrolled Oneida Tribal member who was providing any kind of assistance to an Elder, and 11.2% personally knew a non-enrolled descendant or family member who was providing assistance to an elder.

Taken together, the findings indicate that family caregiving is a common experience within the Oneida Nation of Wisconsin, regardless of geographic location or type of affiliation.

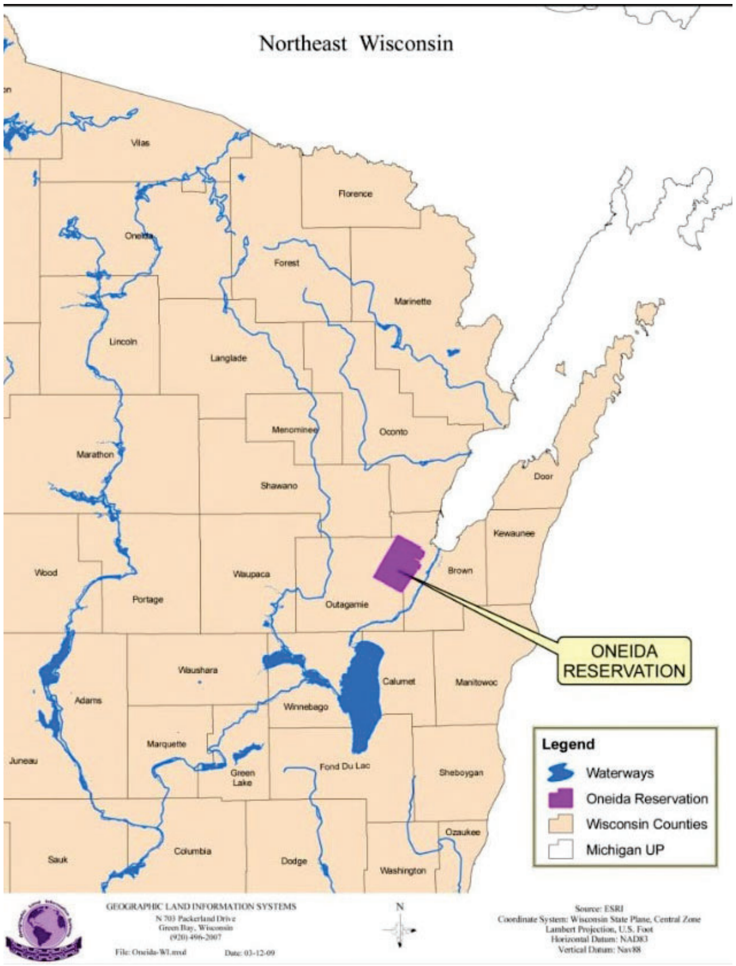
Table 1. Oneida Helping Oneida Family Caregiving Survey respondents, N=481

		Overall sample (N=481)	Currently caregiving for an adult family member or friend (N=207)	Not currently caregiving (N=274)
Gender Identity, N (%)	Female	363 (75.5)	157 (75.8)	68 (75.2)
	Male	115 (23.9)	47 (22.7)	206 (24.8)
	Two-spirit	2 (.4)	2 (1.0)	
	Other	1 (.2)	1 (.5)	
Age in years, Mean (SD) range 18-87		52.78 (16.60)	51.81 (15.33)	53.51 (17.48)
Educational Attainment, N (%)	Less than HS	18 (3.7)	10 (4.8)	8 (2.9)
	HS diploma/GED	160 (33.3)	65 (31.4)	95 (34.7)
	Associate/trade school	137 (28.5)	55 (26.6)	82 (29.9)
	Bachelor's	96 (20.0)	42 (20.3)	54 (19.7)
	Professional degree	67 (13.9)	34 (16.4)	33 (12.0)
	No answer	3 (0.6)	1 (0.5)	2 (0.7)
Marital status, N (%)	Single, never married	113 (23.5)	51 (24.6)	62 (22.6)
	Married or living with partner	234 (48.6)	103 (49.8)	131 (47.8)
	Divorced or separated	90 (18.7)	36 (17.4)	54 (19.7)
	Widowed	39 (8.1)	15 (7.2)	24 (8.8)
	Prefer not to answer	5 (1.0)	2 (1.0)	3 (1.1)
Oneida Affiliation, N (%)	Enrolled Oneida Tribal member	432 (89.8)	181 (87.4)	251 (91.6)
	Non-enrolled descendant	19 (4.0)	12 (5.8)	7 (2.6)
	Non-enrolled family/close friend of enrolled member (e.g., spouse)	30 (6.2)	14 (6.8)	16 (5.8)
Residence	Within reservation boundaries	153 (31.8)	77 (37.2)	76 (27.7)
	Brown or Outagamie counties, outside reservation boundaries	107 (22.2)	41 (19.8)	66 (24.1)
	Milwaukee, WI area	105 (21.8)	41 (19.8)	64 (23.4)
	Elsewhere in WI	63 (13.1)	33 (15.9)	30 (10.9)
	Outside of WI	50 (10.4)	13 (6.3)	37 (13.5)
	Prefer not to answer	2 (.4)	2 (1.0)	1 (.4)
Employment status	Employed	241 (50.1)	112 (54.1)	129 (47.1)
	full-time	192 (39.9)	87 (42.0)	105 (38.3)
	part-time	49 (10.2)	25 (12.1)	24 (8.8)
	Furloughed (full or in part) due to the COVID-19 pandemic	22 (4.6)	9 (4.3)	13 (4.7)
	Unemployed, seeking employment	32 (6.7)	18 (8.7)	14 (5.1)
	Don't work or retired	182 (37.8)	93 (44.9)	116 (42.3)
	Prefer not to answer	4 (.8)	2 (1.0)	2 (.7)
Military Veteran	Yes	36 (7.5)	19 (9.2)	17 (6.2)
	No	443 (92.1)	187 (90.3)	256 (93.4)

Prefer Not to Answer	2 (.4)	1 (.5)	1 (.4)

Notes: All data are self-reported and were collected January to March 2021. N=481 usable responses out of N=507. Survey was generally completed online; N=19 completed the survey on paper, per their request.

Figure 1. Residence of OHO Survey Respondents



Map via https://oneida-nsn.gov/business/development-division/geographic-land-information-systems/#GIS-Maps.

Oneida Helping Oneida Family Caregiving Study respondents resided in communities across the US. N=481 respondents indicated residence as: 1. “Within Oneida Nation of Wisconsin Reservation Boundaries” (31.8%), 2. “In Brown or Outagamie Counties (outside reservation boundaries)” (22.2%), 3. “In the Milwaukee, Wisconsin area” (21.8%), 4. “Elsewhere in Wisconsin” (13.1%), 5. “Outside of the State of Wisconsin” (10.4%), or 6. “Prefer not to answer” (0.4%).

Awareness: What does the Oneida Nation of Wisconsin know about available services?

> ***"I've never even thought about the fact that there would be resources available. I know in the next few years I will step in and take over the majority of the care for my parents. I would definitely utilize resources so that I am able to do the best I can and maintain a positive healthy relationship with my parents and myself."*** — current non-caregiver

We asked survey respondents if they knew about seven specific supportive resources for caregivers and their care recipients. We asked about awareness and use of 1) caregiver support groups, 2) caregiver training, 3) respite services, 4) financial help, 5) residential or nursing home facilities, 6) transportation services, and 7) household help (e.g., cooking, cleaning, yardwork). These services were chosen based on those included in the National Study of Caregiving, a longitudinal, nationally representative survey of informal caregivers linked to the National Health and Aging Trends Study. In addition, we included three resources based on suggestions from our Oneida study team members and their knowledge of offerings within the Oneida community. The survey question was: ***"We want to know how much people who are part of the Oneida Nation know about resources available to family caregivers and know how to access these resources. For each resource listed, please indicate if you are aware of the service in your community and how someone would access it."***

Within the entire sample, respondents were most aware of nursing home services (64% aware) and transportation (59% aware). Caregiver training (39% aware) and support groups (42% aware) were the services with the lowest level of community awareness. The sample included 81 respondents (17%) who were not aware of any of the seven listed services.

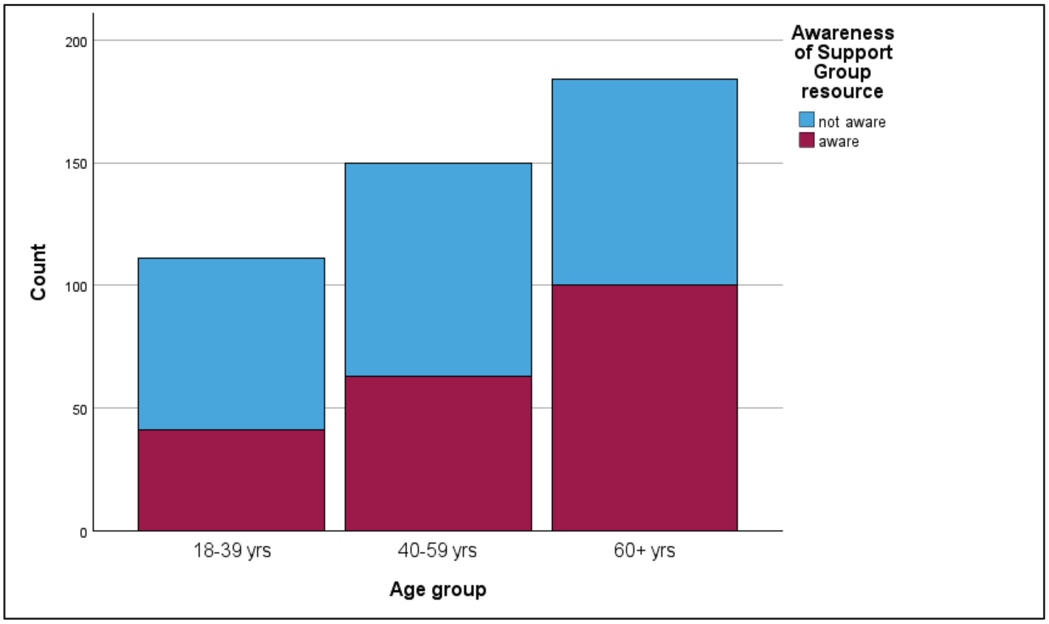
Please see **Table 2** for details on awareness of each service, broken down by self-identified current caregivers and non-caregivers. Among caregivers, awareness was highest for the existence of nursing homes or residential facilities, with 40.6% reporting they knew about this resource and how to access it. Respite services were least known to caregivers, with 23.7% of caregivers reporting knowing about respite and how to access. Non-caregivers showed generally lower levels of awareness of the resources, with nursing homes also being most known (27.4% know about it and how to access) and support groups and respite being least well known (16.1%).

Overall, respondents who were current caregivers and who identified as female reported more awareness. In addition, those who lived within the Oneida reservation boundaries reported more awareness than those living elsewhere.

Interestingly, respondent age was also associated with awareness of certain resources. When we looked at any level of awareness of a service (regardless of whether they knew how to access the service), we found that only 36.9% of respondents aged 18-39 years but 54.3% of older adults (aged ≥60 years) were aware of caregiver support groups. This was a statistically significant difference between the age groups. There were similar trends for differences in awareness of respite services and household help, with younger respondents being less aware than older respondents. There were no differences by age in the other resources queried.

Taken together, these findings show that overall awareness of supportive resources for caregivers and the adult they care for is quite low. Our findings also suggest that information about resources is reaching some members of the Oneida community better than others. Below, **Figure 2** shows how awareness of these two service types increased with the life stage (age group) of the survey respondent.

Figure 2. Respondent age and awareness of support group



Awareness of Support Group services by age group (early adulthood=ages 18-39 years, N=122; middle age=40-59 years, N=159; older adults=60+ years, N=200). Differences among groups were statistically significant (Fischer's exact test, p<.05)

Table 2. Awareness of Resources & Services by Current Caregivers and non-Caregivers in the Oneida Nation

"Do you know about the resource and how someone would access it?"	Yes, I know about it AND how to access		I know about it, but DON'T know how to access *during the COVID-19 pandemic*		I know about it, but NEVER knew how to access (even before the pandemic)		No, I don't know about it		Prefer not to answer	
	N (% of CG or non-CG subgroup)									
	CG	Non-CG	CG	Non-CG	CG	Non-CG	CG	Non-CG	CG	Non-CG
... a support group for people who give care	56 (29.0)	42 (16.1)	18 (9.3)	35 (13.4)	23 (11.9)	30 (11.5)	91 (47.2)	150 (57.5)	5 (2.6)	4 (1.5)
...any service that takes care of an adult family member, so that the caregiver could take some time away from helping	49 (23.7)	44 (16.1)	23 (11.1)	25 (9.1)	35 (16.9)	47 (17.2)	80 (38.6)	140 (51.1)	6 (2.9)	4 (1.5)
... any training to help a caregiver take care of an adult family member	52 (25.1)	32 (11.7)	15 (7.2)	24 (8.8)	26 (12.6)	40 (14.6)	97 (46.9)	160 (58.4)	3 (1.4)	5 (1.8)
... financial help for an adult family member who needs assistance, including helping them apply for Medicaid or other financial programs	67 (32.4)	47 (17.2)	17 (8.2)	25 (9.1)	30 (14.5)	42 (15.3)	73 (35.3)	144 (52.6)	6 (2.9)	3 (1.1)
...nursing home/residential home for the family member	84 (40.6)	75 (27.4)	18 (8.7)	36 (13.1)	32 (15.5)	63 (23.0)	50 (24.2)	82 (29.9)	9 (4.3)	5 (1.8)
...household help (for example, cleaning, cooking, yard work)	72 (34.8)	60 (21.9)	24 (11.6)	33 (12.0)	27 (13.0)	46 (16.8)	68 (32.9)	119 (43.4)	2 (1.0)	3 (1.1)
...transportation for the adult family member you are helping	80 (38.6)	70 (25.5)	22 (10.6)	30 (10.9)	29 (14.0)	51 (18.6)	56 (27.1)	104 (38.0)	6 (2.9)	5 (1.8)

Note. Data are based on self-report. Percentages indicate proportion of caregivers (CG; N=207) or of non-caregivers (non-CG N=274) in the sample. Multiple answers were accepted.

Becoming aware: How did respondents learn about services?

> ***"Information is power, however the power has to be shared. I found out about all the services we use NOT from Oneida, I found out on my own doing research and from friends."***
>
> —current caregiver

If respondents expressed awareness of a resource, we asked how they found out about each of four key resources – support groups, respite care, caregiver training, and financial help – that were taken from the National Study of Caregiving. **Table 2a** shows sources of information for these four resource categories. For caregivers and non-caregivers alike, across the four services, the most common sources of information were from a medical provider/social worker, "on your own" (from a friend, online, etc.), and Oneida Tribal communications. Caregivers were made aware of financial help most frequently on their own via friends, online, the library, etc. (27.1%) Additionally, caregiver respondents had higher awareness of services overall from talking to a medical provider or social worker.

Many respondents provided "free-text" answers, wherein they could type in their own response about how they learned about services. The variety of sources listed revealed that Oneida community members – caregivers and non-caregivers alike – are diligent, curious, and creative in learning information that can support family caregivers and the adults they help. For example, some respondents had gained knowledge through working in the elder care field, or had talked to family with such experience. Some noted they had learned about services through previous caregiving experience or from talking to friends and neighbors who have been caregivers.

Table 2a. Sources of information about four caregiver resources reported by caregivers and non-caregivers.

"If you said you already know about ….., how did you find out about this resource?"	Talking to a medical care provider or social worker		Church or other spiritual community		On your own – e.g., from a friend/family, online, or at the library		From Oneida Tribal communications (e.g., Kalihwisaks or flyer)		From your employer		From Oneida social or health services*		N/A or prefer not to answer	
	N (% of CG or non-CG subgroup)													
	CG	Non-CG	CG	Non-CG	CG	Non-CG	CG	Non-CG	CG	Non-CG	CG	Non-CG	CG	Non-CG
... a support group for people who give care	**41 (19.8)**	**30 (10.9)**	**5 (2.4)**	**9 (3.3)**	**45 (21.7)**	**39 (14.2)**	**40 (19.3)**	**58 (21.2)**	**15 (7.2)**	**12 (4.3)**	**4 (1.9)**	**5 (1.8)**	**2 (1.0)**	**1 (4.0)**
...any service that takes care of an adult family member, so that the caregiver could take some time away from helping	**43 (20.8)**	**23 (8.4)**	**5 (2.4)**	**9 (3.3)**	**58 (28.0)**	**45 (16.4)**	**30 (14.5)**	**52 (19.0)**	**18 (8.7)**	**11 (4.0)**	**2 (1.0)**	**3 (1.1)**	**3 (1.4)**	**5 (1.8)**
... any training to help a caregiver take care of an adult family member	**36 (17.4)**	**21 (7.7)**	**3 (1.4)**	**3 (1.1)**	**44 (21.3)**	**40 (14.6)**	**25 (12.1)**	**42 (15.3)**	**17 (8.2)**	**15 (5.5)**	**2 (1.0)**	**1 (0.4)**	**3 (1.4)**	**3 (1.1)**

"If you said you already know about ….., how did you find out about this resource?"	Talking to a medical care provider or social worker		Church or other spiritual community		On your own – e.g., from a friend/family, online, or at the library		From Oneida Tribal communications (e.g., Kalihwisaks or flyer)		From your employer		From Oneida social or health services*		N/A or prefer not to answer	
... financial help for an adult family member who needs assistance, incl. helping them apply for Medicaid or other financial programs	**36 (17.4)**	**30 (10.9)**	**4 (1.9)**	**3 (1.1)**	**68 (32.9)**	**45 (16.4)**	**29 (14.0)**	**41 (15.0)**	**13 (6.3)**	**12 (4.4)**	**3 (1.4)**	**5 (1.8)**	**3 (1.4)**	**5 (1.8)**

Note. These four resource categories were taken from the National Study of Caregiving, a longitudinal representative survey of informal caregivers linked to the National Health and Aging Trends Study. Percentages indicate proportion of caregivers (CG; N=207) or of non-caregivers (non-CG; N=274) reporting each source. Multiple answers were accepted. Responses listed as "Any other source" with additional free-text information were re-coded to other categories as appropriate. * These responses came from a tally of Oneida services listed in free-text responses and included Oneida Elder Services, Oneida Health Center, and Southeastern Oneida Tribal Services (SEOTS), Milwaukee. These responses almost certainly are an undercount of respondents who received information from these sources, since this category was not included in the survey and some respondents would have counted these sources under "medical care provider or social worker."

Oneida Culture: How do survey respondents perceive that Oneida values and practices align with use of caregiver resources?

"We don't have to be related to help take care of others." —current non-caregiver

Because previous research identified the critical importance of unique cultural values and practices in the experience of caregiving and the use of caregiver resources, the OHO study included questions related to culture. The survey question read: ***"We are interested in your opinion about how much the traditional values and practices of the Oneida Nation support family caregivers in using resources to help them in the caregiving role. In other words, how consistent is Oneida traditional culture with people accepting services to help them take care of family members or friends who need assistance?"*** For each resource, respondents indicated how much they believed traditional Oneida culture supports family caregivers in using each of the seven resources, rated as "Not at all", "A little", "Somewhat", or "Very much" (respondents could also answer "Don't know/prefer not to answer"). With this question, we tried to gain insight into whether or not respondents think service use by caregivers is culturally acceptable – i.e., consistent with social norms in the Oneida community.

Table 3 shows how respondents answered these questions, broken down by caregivers and non-caregivers. It is important to note that there was a high rate (average of 22.6% for caregivers and 23.7% for non-caregivers) of "Don't know or prefer not to answer" responses in this portion of the survey. This should be considered while interpreting these results. Interestingly, overall review of these findings suggests that current family caregivers perceive the use of resources as being *less consistent* with Oneida traditional culture compared to non-caregivers. In other words, caregivers were more likely than non-caregivers to rate use of a service as "not at all" consistent and less likely to rate it as "very much" consistent.

Later in this report, we show additional findings about the importance of culture using data from the caregiver subsample.

Table 3. Respondent perspectives on how much traditional Oneida culture supports family caregivers in using resources to support them in their role

How much do you believe Oneida traditional culture supports….	Not at all		A little		Somewhat		Very much		Don’t know/Prefer not to answer	
	N (% of subgroup)									
	CG	Non-CG	CG	Non-CG	CG	Non-CG	CG	Non-CG	CG	Non-CG
... attending support group for people who give care	**20 (11.2)**	**22 (8.6)**	**24 (13.5)**	**28 (11.0)**	**41 (23.0)**	**54 (21.2)**	**53 (25.6)**	**86 (33.7)**	**40 (19.3)**	**65 (25.5)**
...Using a service that takes care of an adult family member, so that the caregiver could take some time away from helping	**21 (11.8)**	**30 (11.8)**	**24 (13.5)**	**22 (8.6)**	**42 (23.6)**	**53 (20.8)**	**46 (25.8)**	**83 (32.5)**	**45 (25.3)**	**67 (26.3)**
... getting training to help a caregiver take care of an adult family member	**21 (11.9)**	**34 (13.3)**	**25 (14.1)**	**21 (8.2)**	**42 (23.7)**	**51 (20.0)**	**46 (26.0)**	**86 (33.7)**	**43 (24.3)**	**63 (24.7)**
... finding financial help for an adult family member who needs assistance, including helping them apply for Medicaid or other financial programs	**25 (14.0)**	**29 (11.4)**	**19 (10.7)**	**19 (7.5)**	**46 (25.8)**	**45 (17.6)**	**49 (27.5)**	**97 (38.0)**	**39 (21.9)**	**65 (25.5)**
...placing a family member nursing home or residential home	**45 (25.3)**	**27 (10.6)**	**23 (12.9)**	**47 (18.4)**	**37 (20.8)**	**63 (24.7)**	**30 (16.9)**	**59 (23.1)**	**43 (24.2)**	**59 (23.1)**
...receiving household help (for example, cleaning, cooking, or yard work)	**24 (13.5)**	**20 (7.8)**	**26 (14.6)**	**38 (14.9)**	**38 (21.3)**	**52 (20.4)**	**54 (30.3)**	**91 (35.7)**	**36 (20.2)**	**54 (21.2)**
...transportation for the adult family member you are helping	**26 (14.6)**	**24 (9.4)**	**18 (10.1)**	**22 (8.6)**	**41 (23.0)**	**56 (22.0)**	**52 (29.2)**	**103 (40.4)**	**41 (23.0)**	**50 (19.6)**

Note. Percentages indicate proportion of caregivers (CG; N=207) or of non-caregivers (non-CG; N=274)

Who are the current caregivers of adults in the Oneida Nation?

"We were raised to care for our elders and family during illness or any crisis. Keeping them home with our families is our honor and responsibility." —current caregiver

As noted above, all survey respondents indicated whether or not they were currently providing any kind of help or assistance to an adult family member or friend. Out of all respondents, 207 (43%) indicated they were currently providing family caregiving. Together with **Table 1** (demographic information), **Table 4** provides additional information on current Oneida caregivers. Caregivers represent all generations and a wide age range, from 18-82 years. Almost half (41.6%) report caring for more than one person. Overall, 86% of caregivers were caring for an Elder. The majority (61.4%) of caregivers provided care for an adult with memory problems or confusion. However, only 16.3% reported that their Elder had been formally diagnosed with dementia or Alzheimer's disease by a healthcare professional, suggesting that underdiagnosis of a dementia condition may be common.

Most caregivers report having emotional support (85%), practical support (57%), and additional caregivers to rely on (60.5%). However, a significant number of caregivers (15%) are without people to talk to about important things in their life. This may indicate that this group could benefit from caregiver support groups. Likewise, the 39.5% of caregivers without practical support could be potential utilizers of a household help service, and the 33.5% of people without caregiver backup could benefit from respite services. Those caring for more than one care recipient (41.6%) may also be more likely to benefit from support.

"It should not matter where the Elder lives, on or off the reservation, or not in Brown or Outagamie counties, as long as they are enrolled, they should be getting help." —current caregiver

Table 4. OHO Survey: Current caregivers of an adult family member or friend (N=207).

	Caregiver subsample (N=207)	N (%)
Caring for an Elder		173 (85.6)
Care recipient has memory problems or confusion		127 (61.4)
Care recipient has diagnosis of dementia/Alzheimer's disease		33 (16.3)
How many people are you providing care or assistance to, including children?	1	110 (54.5)
	2	56 (27.7)
	3 or more	28 (13.9)
	Prefer not to answer	8 (4.0)
Relationship to care recipient	spouse/partner	32 (16.2)
	adult child/grandchild/niece or nephew	125 (63.1)
	sibling/cousin	20 (10.1)
	friend/neighbor/other	21 (10.6)
Do you have friends or family that you talk to about important things in your life?	Yes	170 (85.0)
	No	18 (9.0)
	Don't know	2 (1.0)
	I used to, but not during the COVID-19 pandemic	10 (5.0)
Do you have friends or family that help you with your daily activities, such as running errands, or helping you with things around the house?	Yes	114 (57.0)
	No	79 (39.5)
	Don't know	1 (0.5)
	I used to, but not during the COVID-19 pandemic	6 (3.0)
Do you have friends or family that help you care for the person you are assisting?	Yes	121 (60.5)
	No	67 (33.5)
	Don't know	3 (1.5)
	I used to, but not during the COVID-19 pandemic	6 (3.0)
	Prefer not to answer	3 (1.5)

Note. Some missing data resulted in total number varying across questions. Others may have resulted from lack of clarity regarding the question.

What services are Oneida family caregivers using?

"I need to take care of myself, physically, spiritually, emotionally because I'm still caring for my mother." —current caregiver

We asked those respondents who self-identified as current family caregivers about past, current, and future intended use of each of the seven resources (see **Table 5**). Reported use of all resources went down during the COVID-19 pandemic. Some caregivers indicated an intent to use a resource in the future, ranging from 23.7% to 30.9% across services. Household help was the service most frequently used before the COVID-19 pandemic and the service with the highest anticipated future demand, with 30.9% of caregivers reporting the intention to use it in the future.

Notably, for each of the seven services, a large group of current caregivers (range 30 – 43%) reported they had not used it and do not intend to use it in the future.

We also conducted some statistical tests to better understand what factors are related to caregivers being open to use these services (see **Table 6** below). We focused on perceptions of alignment of Oneida culture and values – which could be thought about as perceptions of social norms in the Oneida community – with use of services by caregivers. We found that these perceptions were related to how likely a caregiver was to use a service. In general, there was some variability across services in how caregivers rated alignment with Oneida culture. Use of household help was rated to most align with Oneida values (30.3% "very much" consistent), while use of nursing homes was least aligned (16.9% "very much" consistent). As noted previously, there was a high rate of "don't know or prefer not to answer" responses (among current caregivers, range across services 21–26%).

"It's hard to ask for help. And when help arrives it is so appreciated."
—current caregiver

Table 5. Self-reported use of resources by current family caregivers (N=207).

For each resource listed below, current caregivers indicated if they have used the resource (before or during the COVID-19 pandemic) and/or they might use the resource in the future.

	Yes, BEFORE the COVID-19 pandemic	Yes, DURING the COVID-19 pandemic	Intend to use in the future	No, have not used AND do not intend to use in future	Don't know / Prefer not to answer
			N (% of N=207)		
Attended a support group for people who give care	19 (9.2)	1 (0.48)	56 (27.1)	81 (39.1)	31 (14.9)
Used any service that took care of the family member, so that could take some time away from helping	20 (9.7)	5 (2.4)	56 (27.1)	78 (37.7)	28 13.5)
Received any training to help respondent take care of the family member	26 (12.6)	4 (1.9)	50 (24.2)	76 (36.7)	34 (16.4)
Found financial help for the family member, including helping them apply for Medicaid or other financial programs	34 (16.4)	11 (5.3)	53 (25.6)	62 (30.0)	35 (16.9)
Sought a nursing home or residential home for the family member	19 (9.2)	5 (2.4)	49 (23.7)	89 (43.0)	25 (12.1)
Received household help (for example, cleaning, cooking, yard work)	28 (13.5)	10 (4.8)	64 (30.9)	67 (32.4)	22 (10.6)
Used a transportation service for the family member	23 (11.1)	10 (4.8)	54 (26.1)	76 (36.7)	30 (14.5)

Note. Responding to multiple options was allowed. Some missing data results in varying total responses.

Table 6. Correlations of attitudes among current family caregivers toward service use with perceived alignment with traditional Oneida culture for each of seven key resources (N=178).

Resource	Percentage reporting positive attitude toward use of resource (%)	Statistical test (p-value)
Support Group	56.0	.042*
Respite Services	59.0	.051
Caregiver Training	59.7	.011*
Financial Help	71.4	.002*
Nursing Home	61.0	<.001*
Household Help	68.2	.005*
Transportation	62.2	.017*

Notes. Reporting a “positive attitude toward use” is indicated by respondent’s reported past, current or intended future use of a specific service. Test of statistical significance is set at $p \leq .05$. * Denotes a *statistical association* between a positive attitude toward use of a specific type of service and perceptions of how much traditional Oneida culture supports family caregivers in using that service.

Selected comments from survey respondents

All OHO Study respondents had the opportunity to provide anonymous “free-text” open comments at the end of the survey. We asked respondents: ***“What else would you like to tell us about family caregiving in Oneida? We would like to hear from you.”*** Here are just some of the comments, organized in broad themes.

Awareness and Navigating the System

- I feel like there isn't much help or information in this area. There should be information listed everywhere, whether it be around the community or on the website. Usually, the only type of information available is for Elders, and they are not the only ones who could benefit from caregiving.
- As the non-enrolled daughter of a Tribal member, I am unaware of services that might be made available to me to help care for my mother as she ages.
- The bureaucracy is overwhelming, this is definitely NOT traditional.
- Not sure how this all works for an enrolled caregiver caring for a family member not enrolled.
- Those of us who do not live on Tribal land seem to not always know what is going on within the Tribe.

Availability of Services across the Oneida Tribal Nation

- I wish they were not so limited in time or what they offer within the Tribe and not having to go outside of the Tribe to receive services.
- I find the SEOTS [Southeastern Oneida Tribal Services] office very helpful in many regards to the Oneida Nation.
- It would be nice if there was access to caregiving amenities in the entire state of Wisconsin. It is not feasible for me to go to Oneida or Milwaukee for any assistance. There needs to be an expansion of services for those who reside off the reservation.
- These wonderful services need to reach more people.
- I think our community members need more support. Taking care of a homebound elder … is causing burnout across our reservation. Oneida gets millions in grants and help from IHS [Indian Health Service]. I think more funding should go to caregiving or hospice-type situations. I believe we have a “long-term care” option, but I don't think the community is aware of it. If these things are budgeted, they should be advertising more to get help to our Tribal members struggling.
- There are not enough beds at Anna Johns to serve the Oneida people, with people living longer. Sending Natives out in the general public to nursing homes, scary!

Oneida Identity and Community

- …[reflecting on] the concept of 7 generations - If we don't take care of ourselves. Who will?
- We were raised to care for our Elders and family during illness or any crisis. Keeping them home with our families is our honor [and] responsibility.
- Family caregiving is also about reaching other audiences such as those children AND adults under 55 who have physical, mental and developmental disabilities. There is a serious lack of services available to Oneida Tribal caregivers in the means of support groups, training, respite, legal and financial help as they provide a valuable duty to their loved ones with disabilities. Navigating services through county agencies is out of touch and not a part of our traditional ways and means of being understood as unique Native beings. Oneida Nation should prioritize a disability agency where they help Tribal members with all the areas I just mentioned.
- People do not often ask for help, believing families should take care of themselves. A matter of pride, not wanting to be seen as poor, or as "grabby". Slowly changing.
- I know that the Oneida Nation takes pride in their Elders and does help and support them.
- I have seen the different generations taking care of each other…the grandparents helping to raise their grandchildren and then later those roles reversing.

The Oneida Helping Oneida Family Caregiving Survey

- Very grateful for this survey and for it being inclusive of our traditional values as being important to ourselves, our future, and our health. *Yaw^ko!*
- Thank you for this survey. I feel that it will help many families out.
- Thank you for this survey. It opened my eyes to watching out for more information.

Specific suggestions and ideas offered by survey respondents include the following:

- Training for all Tribal members about the benefits for taking care of Elders.
- We would like to see more outreach in the Milwaukee area and more notifications of things offered for Oneida Tribal members. Also presentations at the Milwaukee Office.
- It would be nice to have community outreach and support groups that are as highly communicated as Oneida transportation and other Tribal affiliations such as the golf course and the Oneida health center…

- This is a community program. Program people are familiar with Oneida customs. Would however like to see more employees who work at Anna John Resident Centered Care Community through an outside agency receive cultural training. Weekend staff is often employed through an outside agency and not always culturally sensitive to ways of Oneida and how our Elders are regarded and treated with respect.
- More and continued outreach and awareness in all news media avenues. Kalihwisaks, online, internet access, available tutorials, available online support meetings initiated by the program and offered through zoom or other internet access to caregivers and those being cared for.
- Services like shoveling out mailboxes so that Elderly can receive their mail should be provided! Just visiting an Elder and playing games should be included.
- I think a survey like this should be sent out to the Elders with the ability to let them signify if they feel like they need help. They should also have local resources mailed to them as many of them do not have access to the internet/email.
- Wellness assessments need to be conducted every 6 months to a year for each Elder. More referrals and resources (not just brochures) are vital and need to be more available and accessible. Having caseworker(s) signing the Elders up for assistance.
- I believe in “aging in place” keeping the Elders in their home as long as possible. Between family members and outside help, this can be done. If and when the time comes where it is not possible to stay in the home, we must work with family members to find the most comfortable place to prepare for end-of-life cares. I truly believe that nursing homes should have individual rooms for patients with plenty of room for family members to visit.
- [Disseminate information on] how to detect Elder Abuse and what to do about it. Following up on leads of Elder Abuse.

Impact of the Oneida Helping Oneida Family Caregiving Study

Community Impact

- Hired two Oneida community members for the project.
- Reports and presentations with the Oneida Alzheimer's Community Advisory Board.
- Updates on project activities are provided quarterly to the Oneida Business Committee.
- Community Report approved by the Oneida Alzheimer's Community Advisory Board for distribution in January 2024. Community presentations planned throughout 2024.

Academic/Scientific Impact

- Collaboration with University of Wisconsin medical students and Shapiro research program, encouraging training of doctors with knowledge on caregiving and Alzheimer's disease in Native American communities.
- Results presented at multiple scientific conferences:
  - November 2021: Gerontological Society of America Annual Scientific Meeting (online)
  - April 2023: Alzheimer's Disease Research Day, University of Wisconsin
  - July 2023: Alzheimer's Association International Conference, Amsterdam, The Netherlands
  - November 2023: Gerontological Society of America Conference, Tampa, FL
- In November 2023, findings were presented by Oneida Nation member Sacheen Lawrence at the first annual International Indigenous Dementia Research Network Conference, Hawaii.

Next Steps

In addition to working with the Oneida Alzheimer's Community Advisory Board (CAB) in developing and distributing this Community Report, we will work with the CAB to determine preferences for sharing findings with the Oneida community in other ways. This will likely be community presentations, newsletters, the Kalihwisaks, Facebook posts, and other means. It is also important to share our findings with the larger scientific community. In addition to the conference presentations listed above, we are preparing written papers for submission to scientific journals. There is a lack of solid research on health and health services among Native communities, and it is important to help close this gap. The OHO Study will help pave the way for future research on family caregiving in Native American communities.

Oneida Helping Oneida Family Caregiving Study: Conclusions

The findings contained in this report may lead to more questions than answers. Nevertheless, taken together, our results lead to some important conclusions about family caregiving, use of caregiver resources and services, and the experience of caring for an Elder with dementia in the Oneida Nation of Wisconsin:

1. The experience of being a family caregiver is common in the Oneida Nation. Our survey cannot be considered statistically representative of the Oneida Nation community. However, our data does show that Oneida family caregivers are highly diverse and represent many facets of the Oneida community. Family and friends provide much vital assistance to Oneida adults who need help, particularly Tribal Elders.
    - For consideration: Continued efforts to acknowledge and identify all caregivers in the Oneida Nation (regardless of residence, enrollment status, age or gender identity) are likely to be beneficial to the larger Oneida community.

2. Among Oneida caregivers, there is a desire for caregiver services and resources to support them in their role. While a proportion of current Oneida caregivers indicate they have little interest in using services, many current caregivers perceive potential benefits and either have used or are open to future use of the common services included in the survey.
    - For consideration: Despite concerns about low use, the wide level of interest in caregiver resources suggests that continued availability of services, and even expansion of services, will be helpful to the community. However, barriers to utilization could be identified and addressed to ensure family caregivers can access and benefit from the services offered. Outreach efforts might aim to increase interest and openness to using services in the caregiver role.

3. There is limited awareness of supportive resources and how to access them. A large proportion of respondents indicated they did not know about the services asked about in the survey. Even current family caregivers reported not having awareness about key resources to support themselves and their care recipient. Lack of awareness of services among caregivers is not unique to the Oneida Nation; this is an all-too-common finding. Nevertheless, it is an important potential target for intervention. Increasing awareness of caregiver services among all members of the Oneida community – caregivers and non-caregivers alike – can increase appropriate use of available resources, which is turn can reduce burden and burnout and keep disabled adults and Elders at home.

- For consideration: Increasing community awareness of helpful resources is important and outreach efforts are likely to increase awareness and improve decision-making about service use by family caregivers and care recipients.

4. <u>Oneida community members seek out many sources of information about the existence of and eligibility for resources.</u> Oneida community members are diligent, curious, and creative in locating information that can support caregivers and the adults they help. Nevertheless, themes of challenge and exhaustion were common when respondents talked about “navigating the maze” of service organizations and programs. While some took time to express feeling “fortunate” for the excellent services offered by the Oneida Nation, others used words such as “frustrating” and “disappointed.” Caregivers note that they need to be tireless advocates for themselves as well as the care recipient, creating a double burden. When one member of a care dyad is not an enrolled member or does not live on the reservation, confusion about services and eligibility may increase. Some caregivers found that the Internet or social media platforms (e.g., Facebook) are an effective and timely way to learn about resources. Other respondents reported having trouble accessing these platforms and noted a feeling of being “forgotten” when news of events and services was distributed only over online channels.
    - For consideration: There are multiple pathways which can be leveraged for outreach to current and future caregivers in Oneida, with the goal of increasing awareness and assisting with navigation of eligibility structures. For the time being – in this era of transition across the “digital divide” –it may be important to devote extra attention to disseminating information across internet-based, print-based, and other (e.g., radio broadcast) formats.

5. <u>Oneida identity and community culture – traditional, current, and continuing to evolve and change over time – significantly impacts the caregiving experience</u>. Experiencing connection with and support from the Oneida community is very important to family caregivers. Resources that are considered “aligned” with Oneida community culture are more likely to be viewed positively, and therefore there may be fewer barriers to their use. Respondents reported a preference for receiving services from Oneida-based, familiar sources.
    - For consideration: In public outreach campaigns and other messaging to family caregivers and their Elders, it may be helpful to emphasize how using caregiver resources aligns with Oneida identity and culture through collaboration with culture and heritage services. In addition, general education to the larger Oneida community about dementia and family caregiving could be helpful in increasing the

perception of social norms that support service use. Of note, the team developing and implementing the REACH caregiver intervention in Native communities (Martindale-Adams et al., 2017) noted that one potentially helpful approach to successfully implementing caregiver programs in Tribal communities may be increasing awareness of a) what cognitive decline or early dementia looks like (to increase timely identification) and b) the impact of cognitive decline/dementia on the community.

In conclusion, we hope the OHO Study Community Report will assist the Oneida Nation of Wisconsin to continue to thrive as a strong community and care for each other, as well as those living, helping, or suffering from dementia or other disability and its effects. As one of our participants said, “We don’t have to be related to help take care of others.”

ONEIDA

A good mind. A good heart. A strong fire.

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