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Urban American Indian Caregiving during COVID-19

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COVID-19 has infected more than 7.74 million people, with an associated 214,108 deaths in the United States as of October 12, 2020.[1] Infections and deaths are projected to double in 2021, particularly among at-risk communities. In addition, the pandemic has created economic and social challenges, with shutdowns of businesses, stay-at-home orders, and evolving US Centers for Disease Control and Prevention (CDC) guidelines (e.g., masks, physical distancing). As with past pandemics, such as the 1918 influenza pandemic, which saw high mortality rates for American Indians, the American Indian community in particular has been affected during the current COVID-19 pandemic.[2] At various moments during the current pandemic, reservation communities have had the highest per-capita infection rates in the country.[3] With these observations, news outlets have documented the experiences of American Indians living on reservations during COVID-19. However, information on how urban American Indians are being affected is sparse, although they comprise 70 percent of all American Indians and Alaska Natives.[4]

Although the current COVID-19 pandemic has affected every aspect of life, little is known of its effects on caregivers, particularly those people providing care to a family member with a health condition, who may be elderly, and/or differently abled or disabled. According to national reports and surveys, the percentage of caregivers has increased from 18 percent in 2015 to 24 percent in 2020, and 25 percent of all American Indians and Alaska Natives are caregivers.[5] In a national sample of caregivers that did not include American Indians and Alaska Natives, caregivers were

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found to provide care recipients with services that extend beyond the instrumental activities of daily living, such as transportation, grocery shopping, housework, cooking and meals, managing finances, medical treatments (pills, injections) and arranging additional care, while assistance with activities of daily living include bathing/showering, toileting, ambulation and positioning, and dressing.[5] With the many duties that may be required, stress has been found to be a negative consequence associated with caregiving.[6]

With the wide disruptions due to the COVID-19 pandemic, there are likely disruptions and large impacts for caregivers, including urban American Indian and Alaska Native caregivers. The goal of this work is to serve as a starting point for the creation or modification of emergency plans and services for American Indian and Alaska Native caregivers who are living in urban settings. As the United States is still in the midst of the pandemic, it is our hope that based upon our findings, tribes and tribal health organizations (urban and reservation) are able to make changes to assist caregivers almost in real time.

METHODS

Study Design

This is a cross-sectional survey of urban American Indian and Alaska Native caregivers in one region of the US southwest. Prior to the pandemic, we began an urban American Indian and Alaska Native survey of caregiving. Following the pandemic, with disruptions to usual recruitment and interviews, we modified strategies to conduct interviews through Zoom and added questions to address changes in the caregiving process due to COVID-19, given the unique challenges of this pandemic.

Recruitment and Inclusion Criteria

Participants were eligible if they were living in an urban city in the southwest United States, over the age of 18, a self-identified member of an American Indian tribe or an Alaska Native, and providing current care for a family member with a health condition, and/or differently abled (disabled), and/or elderly member. The participant care provider could be either unpaid or paid (e.g., by a tribal program). An "urban city" was defined as having a population over 50,000.[7] Prior to the start of the pandemic, participants were recruited in person at an urban American Indian center. After the pandemic, participants were recruited via electronic means through American Indian-specific listservs, and the social media of American Indian-specific organizations (Facebook and Instagram). Interested participants identified at the urban American Indian center were called to inform them of the study or participants contacted the PI via phone or email after seeing the survey flyers on listservs or social media. These participants were contacted by phone or email, depending on how they contacted the PI.

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Survey Development

The Urban American Indian Adult Caregiver Survey was developed based on the Hopi Adult Caregiver Survey.[8] With the onset of the pandemic, five questions were added to this survey to examine caregiving during the COVID-19 pandemic. In developing these questions, the lead author drafted all questions and edited based on coauthor consultation. Two of the five questions were closed-response, with one asking about perceived change to their personal stress and the second asking about their perceived change to personal resilience. Potential answers for these two questions included (1) increased, (2) decreased, or (3) no change, since the start of the pandemic. Stress was defined as "a physiological and psychological response to perceived threat. . . . it often occurs when an individual perceives the demands of a situation to exceed the resources available to meet these demands."[9] Resilience was defined as "the capacity to maintain stable functioning and to undergo adaptation in the face of significant adversity."[10]

Three open-ended questions focused on various aspects of the caregiving experience: (1) what's been your experience being a caregiver during the coronavirus pandemic? (2) have there been any changes to your health since the coronavirus pandemic started? and (3) as a caregiver, what do you wish you would of known prior to the start of the coronavirus pandemic that would of helped you now?

Interviews

The lead author conducted the interviews through Zoom's virtual meeting technology. To ensure participant privacy, all sessions were password-protected with a waiting room enabled prior to entrance into the meeting. Participants consented to both participate in the study and to be audiorecorded; consents were obtained both verbally and audiorecorded. As compensation, participants were offered a $25 Visa gift card, sent either by email or regular mail. Interviews were audiorecorded, saved on a password-protected device, and then transcribed for analysis.

Analysis

Demographic and quantitative survey information were imported into Stata 14 for analysis. For categorical variables, means, percentages, and sums were calculated. Thematic analysis was derived from the three open-ended interview questions using methods of Felina M. Cordova and colleagues.[11] This process included the creation of a matrix with questions asked, quotations, page numbers locating each quotation, and codings that represented the quotations. A document of summary topics/themes was compiled by grouping similar topics/themes. The final themes emerged from an iterative process of grouping, regrouping and refining themes until the authors reached a consensus. All of these methods are "means of establishing trustworthiness during each phase of thematic analysis."[12] This systematic method of analysis increased rigor in our study.

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Human Research Approvals and Participant/Tribal Protection

This research study (including amendments) was approved by the University of Arizona Human Subjects Protection Program. A local urban American Indian organization and local tribes were consulted. To protect participant and tribal identity, participant information will be presented as group statistics.

RESULTS

Participants

Twenty urban American Indian caregivers were interviewed from May–July 2020. All but three of the caregivers were providing care to their family member without pay. The average time for the interviews was 16.21 minutes. For gender identity, participants were given the choices of female, male, and non-binary, with eighteen identifying as female (90%) and two caregivers identifying as male (10%). The average age of caregivers was 46.5, with an age range of mid-twenties to late sixties. A large portion of caregivers (n=14, 70%) reported that they lived with the care recipient and were the primary caregiver (n=17).

Caregivers were providing care to grandparents (n=4, 20%); parents (n=7, 35%); spouses/partners (n=2, 10%); children (n=3, 15%); and other family members (n=3, 15%). The average age of care recipients was 66.1, with an age range of under eighteen to late nineties. Sixteen care recipients (80%) were differently abled or disabled and fifteen were elderly (75%). Caregivers were providing care to recipients with many different health conditions. On average, care recipients had 2.25 health conditions: cancer, Alzheimer's/dementia, diabetes, cardiovascular, lung, mental health-related, autoimmune disorders, and brain/cognitive disorders.

Urban American Indian caregivers were also directly affected by the COVID-19 virus. None of the caregivers reported they or the care recipient had tested positive for COVID-19. Two caregivers believed that they/their family had contracted the virus prior to implementation of testing, one mentioned having a family member who had tested positive for COVID-19 and was surviving, and four (20%) had family members who had died from the virus.

Themes of the Impact of COVID-19

Although we only had twenty participants, we found a recurrence of responses from participants, with no divergence in responses based on being a paid or unpaid caregiver, displaying saturation and providing confidence in the findings.[13] Outcomes of the thematic analysis revealed five themes, as well as subthemes, of the impact of COVID-19 on the caregiving process (table 1).

THEME 1: CONCERN ABOUT THE CARE RECIPIENT CONTRACTING COVID-19

Concern for the care recipient contracting COVID-19 was an overarching theme of caregiving during a pandemic, with a related subtheme focused on the need for increased health protective behaviors specifically COVID-related. All caregivers

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TABLE 1
THEMES AND SUBTHEMES OF SEMI-STRUCTURED QUALITATIVE INTERVIEWS

Themes	Subthemes
1. Concern about the care recipient contracting COVID-19	• Need for health protective behaviors
2. Increased caregiving intensity	
3. Increased medical care issues	• Difficulties accessing care
	• Increased challenges of in-person care
	• Increased use of telehealth
4. Changes to caregiver health and health behaviors	• Increased stress and other effects on mental health • Increased resilience and coping strategies • Changes to caregiver personal health behaviors—sleeping, eating, exercise
5. Evaluating material and emotional support during the pandemic	

(100%) expressed concern for the care recipient as well as for themselves in regard to how their own health could potentially affect the recipient's health chances of being infected with COVID-19. There was also concern for other non-urban family members: "I think that's the number one thing. You're not in fear for yourself, I'm not even in fear for my kids, it's more I'm in fear for him because he has lived this long and you don't want anything to happen to him."

Concern was also expressed about the limited resources and interactions with family living on the reservation:

> You know we live here in town but people that come in from the reservation, they only have one little store and they were running out.
>
> Also worrying about people back home, my mom lives in [city name redacted] on the reservation right now and I know she has been caregiving too. We have been trying to figure out how to support her in that.

Caregivers also recognized the importance of protecting elders: "I think that it is scary for everyone but our elders are our medicine ways, our people that carry onto, hold onto a lot of knowledge, so making sure that they are safe and cared for is a priority for me."

Subtheme: Need for Health Protective Behaviors. Hand-in-hand with concerned comments about the recipient becoming infected with COVID-19 were caregivers' comments seeking to protect their care recipients. This was accomplished through caregivers' increased health-protective behaviors, defined as "activities by those who believe themselves to be healthy, undertaken for the purpose of preventing disease

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and protecting or promoting their health."[14] Participants discussed numerous times how they keep their recipient and others safe and how they themselves were adhering to CDC recommendations of cleaning/sanitizing, washing hands, wearing masks, and social distancing.[15] Caregivers also discussed the need for others to adhere to guidelines.

> More sanitizing, she doesn't like the hand sanitizer, but I always tell her put your hand out and I make her put hand sanitizer when we are like out in the care and stuff, but so we are doing more hand sanitizer and wiping of the door handles, counters, her wheelchair.

> We have to be more careful than the average person because of my son's condition and it's more stressful knowing that there is risk out there for us to put his health at risk and frustrating because others in public are not abiding by the CDC orders and are increasing the risk of infection.

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Theme 2: Increased Caregiving Intensity

A second theme found was caregiving intensity. "Intensity" typically has been defined as the number of hours of caregiving per week as well as number of caregiving duties.[16] The caregivers in this study reported a wide variety of experiences. Twelve of the caregivers (60%) mentioned that they were providing more caregiving hours during the pandemic, eight (40%) reported doing completely new caregiver duties. These new caregiving duties included disinfecting and cleaning, more trips to shop for the recipient, managing finances, new medical care such as changing catheters and conducting physical therapy. Six caregivers (30%) mentioned that they were working from home in addition to caregiving and several mentioned taking care of children (healthy) while caregiving as well. One person described the intensity of the caregiving as akin to being a medical worker: "The health professional[s] who are doing their best and working, as they say, working on the front lines—we're front line workers as well."

Caregivers frequently mentioned taking the care recipient for car rides among the activities that were adding to caregiver hours: "You know she gets tired staying inside so I take her for a ride." During longer caregiver/care-recipient car rides out of town, a caregiver mentioned the need for others to know that restrooms may be closed due to inconsistent guidelines within the same state or out of state.

Some care recipients have had a difficult time adjusting to the new way that caregivers are required to operate: "I am noticing because of her [health condition] she is really struggling with the new normal on why she can't go in, why she is not able to participate as much with like our grocery shopping with going in for the Walmart, or doing all these things."

Theme 3: Increased Medical Care Issues

A third theme focused on the caregivers' medical care challenges. Medical care issues were defined as: difficulties accessing care, increased challenges, and increased utilization of telehealth.

Subtheme: Difficulties Accessing Care. Of the twenty caregivers, ten (50%) reported that they had had issues receiving medical care or medications. These issues included lack of access to care due to unresponsiveness of healthcare facilities, as well as no access to traditional healers at this time. Interruptions in preventive care was also mentioned for dental care, vision, and cancer screening (colonoscopy). Several caregivers mentioned having to advocate for an in-person appointment for the care recipient.

Subtheme: Increased Challenges of In-Person Care. Three of the caregivers (15%) mentioned they had received in-person medical care during the pandemic, while eight of the recipients (40%) had also received in-person care. During this care, guidelines for temperature checks or COVID-19 screening were not uniform and were reported to be less than optimal. As one caregiver reported of social distancing when in the same room as a medical provider, "I just think it's less personal."

Several caregivers were choosing not to seek care from respite caregivers or at health facilities due to safety concerns over COVID-19: "We don't, we don't go to the hospital as much as we used to for all his clinics, because we are not confident in the safety of going to his clinics."

Subtheme: Increased Use of Telehealth. One of the ways that caregivers tried to access healthcare was via telehealth. Telehealth was accessed during the pandemic by three caregivers for themselves (15%) and for six of the care recipients (30%), with two other unspecified (unknown caregiver or recipient) telehealth mentions, for a total of eleven times that telehealth was accessed by either the caregiver or recipient (55%). Of these appointments, for caregivers accessing telehealth for themselves, only one caregiver received telehealth that included video; the other caregivers mentioned only telehealth appointments by voice telephone. Many caregivers mentioned being on the telehealth phone call or video with the recipient during the recipient's telehealth appointments. Caregivers reported various experiences. Some were negative: "The one telemed appointment we got him had to be cancelled 'cause the doctor was on call and we haven't been able to reschedule that with him since May. We were in the meeting for like ten minutes before we realized the doctor wasn't coming"; and some were positive: "[B]ecause all of the appointments have been over the phone, it's been pretty easy to speak to a health care provider and also to get my medications."

THEME 4: CHANGES TO CAREGIVER HEALTH AND HEALTH BEHAVIORS

Subtheme: Increased Stress and Other Effects on Mental Health. Stress, a major theme of the interviews, was mentioned sixty-five times by the twenty caregivers. When asked how they felt the pandemic has affected their level of stress, all but one caregiver (95%) responded that their stress had increased substantially. Sources of stress included working from home while caregiving, taking care of children while caregiving, and the need for vigilance: "It's constant vigilance I feel [is] the most stressful part of the pandemic."

Stress over safety and health of the participant was echoed numerous times during interviews: "It's the stress of the fear because she is elderly and has underlying health

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conditions that I'm worried more, you know, if she gets the virus." Another source of caregiver stress also came from care recipients not being able to understand guidelines and the state of the world: "It's been really stressful. My grandma doesn't understand what's going on so she kind of thinks she doesn't have to follow the rules, it's very stressful trying to explain and tell her you can't go anywhere or she can't go/come with us, or do things like wear a mask, it's been stressful."

Several caregivers repeated that isolation also increased stress. Mental health was affected from being more isolated at home and the urban environment was not conducive to social distancing: "Well, you know, sometimes the stress because the fact we're at home, inbound, can't go nowhere. Really other than going to the grocery store and that's it, no events, nothing like that because of the pandemic and the ordinance and curfew and so forth. Ceremonial we can't attend either so that's another thing to add to it."

Other mentions of mental health included depression, anxiety, panic attacks, worry, fear for the care recipient, and frustration: "It's just been, having to be on a high level of alert. Which is most of the time, is emotionally draining." With this wide range of emotions being expressed, one caregiver described the ups and downs of caregiving during the pandemic: "It's been an emotional rollercoaster. Some days in the beginning we just upset and sad that everything is going on in the world."

Also affecting the caregivers' mental health were the guidelines for funerals during the pandemic, so that caregivers were not able to grieve the loss of their loved one in a traditional way: "Like my family member passed … and it was more than ten people but they all had to stay in their cars, wear masks you know, it wasn't as traditional as it had been where the grieving process would be a lot easier."

Subtheme: Increased Resilience and Coping Strategies. Although caregivers were facing increased challenges due to the pandemic, seventeen caregivers (85%) perceived their personal resilience as having increased since the start of the pandemic, with the remaining three reporting no change to their resilience. One caregiver expressed the collective resilience of elders, this caregiver herself being one:

> This is not the first pandemic. People, especially the elderly, a lot of elders have been through a lot themselves. They've been through, you know, measles; they've been through the smallpox; they've been through, you know, HIV, you know. So, you know, I believe we will make it. It's just when, and everybody has to work together and do their part.

Many caregivers reported various ways that they have been mindful of their mental health in dealing with the pandemic. "Coping" can be defined as "a multidimensional self-regulation construct that represents the behavioral and cognitive mechanisms to manage ongoing internal and external demands of a stressful episode."[17] Several of the caregivers mentioned faith and prayer as ways of dealing with the pandemic. Virtual activities were also found to be helpful during this time. Such activities included virtual bingo, Social Distance Pow Wow on Facebook, and online workshops such as traditional language classes. Also mentioned were reading and music, as well as

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limiting time spent watching the news. Traditional art was also reported as a way of decreasing negative mental health: "I try to keep busy doing beadwork and sewing and, you know, just keeping myself busy cooking and all that."

With all that caregivers have been facing, nonetheless many expressed gratitude at being a caregiver or being able to be home during the pandemic: "I feel that the coronavirus has allowed me as a caregiver to protect my mother, to be here with her during this challenging time."

Subtheme: Changes to Caregiver Personal Health Behaviors—Sleeping, Eating, Exercise. Caregiving during the pandemic also appeared to influence caregiver personal behaviors such as sleeping, eating, and exercise habits. Seven caregivers (35%) reported a disruption to their sleep (sleeping more or less), eight (40%) mentioned they increased their eating during the pandemic, and four (20%) said their eating had decreased. Several caregivers mentioned their eating habits had become healthier during the pandemic, such as consuming less-processed foods, eating out less often, and returning to traditional foods. A return to exercising outdoors was mentioned by participants, with one mentioning running, a traditional activity. However, fourteen of the caregivers (80%) reported exercising less, due in part to more hours spent caregiving, gyms being closed, and others not adhering to social distancing guidelines in an urban environment: "We have a small apartment and there was a large community and we were really uncomfortable with even walking around near people because there was not a lot of social distancing in our apartment complex."

Theme 5: Evaluating Material and Emotional Support during the Pandemic

Although the majority of study participants were the primary caregivers, all but two of the caregivers (90%) mentioned receiving some form of support from another person or organization. Fifteen caregivers (75%) reported help from family, eight (40%) reported help from an organization, three (15%) received help from Indian Health Services (IHS), and six (30%) received help from their tribe. Help received was for the care recipient and included food delivery from Meals on Wheels, food boxes from their tribe, care packages from urban Indian organizations (some of which contained in-home solo activities such as crossword and coloring books, and personal protective equipment such as a mask), and adult diapers: "The senior center helped a lot. There is a social worker there that will text me and call if we need anything. They bring meals to both of us every day from the senior center and they bring us food boxes, that is very helpful."In addition to support through physical items, caregivers mentioned family as a source of emotional support and respite care:

> I think my family, kids, his grandkids, just sticking together as a family, we're always a family but I mean having like if I have to step out or step away for a few hours, my daughter comes in and watches him. If she has maybe to go out to someplace then her brother, my son stepped in. So we are all, we're all a family unit to take care of him.

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These resources were reported by multiple caregivers as being almost all exclusively for the care recipient and with less support for urban American Indians: "I think for us urban too I mean [name of tribe] on the reservation gave out boxes every other week, foods and meals and [name of tribe] did too. But for urban Indians, there was nothing done, that's always the case."

Although almost all caregivers/their care recipient had received support, caregivers mentioned the need for additional support across a range of needs. Table 2 lists all the needs identified by the caregivers. These needs can be categorized as physical, informational, activities to do during the pandemic, and emotional support for the caregiver.

One of the major needs mentioned was access to respite care. In addition, the non-primary caregivers evidenced self-awareness of their role as respite providers in mentioning the need for the primary caregiver to receive help: "I'm glad that I'm able to offer assistance to the primary caregiver. Which she totally needs some time on her own as well. Not only the care recipient, but the caregiver needs a break."

Support specifically for those that are differently abled or disabled was mentioned, such as the need for reliable specialized transportation to and from medical appointments for those who use wheelchairs and personal protective equipment for this population: "he is constantly moving his tongue and his jaw and trying to find some PPE that he can wear that works with that type of challenge that he has with constantly moving his jaw and his mouth and his tongue. I guess PPE for people who have . . . just cognitive challenges." To help with the pandemic experience, support groups were mentioned as a need: "I think just a group chat would work for caregivers you know. Ideas, sharing ideas and stuff like that. 'Cause you know everybody goes through all this, I would think similar situations and whatnot."

Discussion

Urban American Indian caregivers described a breadth of experiences about how they were providing care during a pandemic. They described the impact of the pandemic on their physical and mental health, as well as their needs and concerns for their care recipient. They also described ways they coped with the events and increasing tasks. The concern that all caregivers expressed for their care recipient's health during the pandemic was justified, given that COVID-19 mortality increased among the elderly, medically at-risk and Native populations that may have comorbid conditions such as diabetes.[18] While non-Native caregivers might also have similar concerns for their recipients, it is notable that Indigenous caregivers' concerns were also expressed for the cultural heritages the care recipients represented as knowledge holders for their tribes. The caregivers acknowledged that the loss of an elder can lead to the loss of cultural ways. The media also reported on the loss of elders as knowledge holders due to COVID-both for Native peoples in the United States as well as Indigenous populations in Brazil.[19]

In addition to concern about the risks of the care recipient contracting COVID-19, increased stress was present among virtually all caregivers. The overall intensity of caregiving appeared to be heightened, with many caregivers expressing that they were

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TABLE 2

LIST OF ITEMS NEEDED DURING THE PANDEMIC IDENTIFIED BY URBAN AMERICAN INDIAN CAREGIVERS BY CATEGORY OF NEED

Physical needs	Information needed	Activities needed for caregiver and care recipient to do together	Emotional support needed
• **Gift cards for food/supplies** • **Food boxes** • **Cleaning supplies and personal supplies:** ○ Adult diapers ○ Bed sheets and bed pads ○ Wipes ○ Toilet paper • **Personal Protective Equipment:** ○ Gloves ○ Masks ○ Masks/PPE for those with cognitive difficulties • **Signage for outside elderly care recipient's homes to notify visitors that they must socially distance and remain outside for protection of the elder**	• **Webinars/training for caregivers focused on:** ○ Care recipient's health condition (i.e. cancer, diabetes, dementia) ○ How to perform medical therapies (such as how to change a catheter) ○ How to perform physical therapy • **How to access the following services:** ○ Medications and how to get multiple months worth at a time ○ Respite care during a pandemic ○ Free COVID Testing ○ Management of the care recipient's finances and other legal aspects ○ How to become a paid caregiver • **Guidance, safety and virus related explaining:** ○ Grocery shopping procedures ○ Social distancing guidelines/policies at group homes ○ COVID-19 seriousness, transmissibility and the transmission from those that are asymptomatic ○ Guidelines for in-person visits at healthcare facilities • **Information specifically for caregivers of those that are differently-abled (disabled) or have cognitive difficulties:** ○ Fact sheet explaining guidelines such as wearing masks, and hand washing in a way they can understand ○ Help with what to do/how to get repairs for disability specific equipment that breaks ○ How to access transportation for those in wheelchairs	• **Activities that incorporate culture/tradition** • **Free or low cost activities** • **Activities to do in the same home, or while socially distancing for those that don't live together**	• **Uplifting resources:** ○ Resources that contain positive imagery and Images of homelands (non-COVID-19 related) ○ A Journal to mark the days in a meaningful way • **Supportive resources:** ○ Access to respite caregiver services ○ Support group for caregivers ○ Emotional validation/support from other Native's either individually or from organizations

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now providing care every minute of every day. The majority of caregivers in our study were also co-residing with additional stresses in their lives (e.g., numerous mentions of working from home, schooling of children, and additional burdens in shopping for groceries). It has been found that caregivers who live with their care recipient, or who provide a high number of caregiving hours per week, report higher stress.[20]

The caregivers reported unmet needs for support and services, a lack of resources, which, as O'Dowd and colleagues have previously noted, could lead to stress.[21] Of importance, these increased mental health changes experienced among caregivers (stress, anxiety, panic attacks, and frustration) may be adding to the impact of historical trauma and/or creating new trauma.[22] A large portion of the support that the caregivers did receive came from family, with less coming from their tribe or IHS. Caregivers may be experiencing difficulties accessing resources due to organizations being closed during the pandemic and social distancing guidelines that are decreasing the in-office workforce. Tribal health organizations and tribes with caregiver programs could strive to meet the increased caregiver needs during this pandemic, including the need for respite care. One potential opportunity for tribes and tribal health organizations might be the development of a preparedness plan specific for their caregivers. The American Association of Retired Persons (AARP) put out a pamphlet on caregiver preparedness during the pandemic.[23] While this source of information was not tailored to any race/ethnicity, many items that our caregivers echoed were similar, such as the need for services, essential items, obtaining medications in bulk supply, and following CDC guidelines.[24]

Our other findings of needs—such as the additional need for personal protective equipment specific for those with disabilities, as well as guideline instructions for those with cognitive difficulties in combination with a plan tailored for American Indians—could benefit Native caregivers. Several caregivers also mentioned they were living in apartments, indicating that preparedness plans, activities, and guidelines should be tailored to built urban environments that likely include size-restricted and high-density living spaces.

Beyond material needs, ways of coping and increasing positive mental health outcomes during the pandemic are also needed. When discussing mental health, cultural tendencies such as American Indians' holistic view of wellness must be considered. Throughout the interviews, participants interwove aspects of tradition and culture in their responses. Culture has been found to be an important piece of resilience that is protective during times of trauma for American Indians.[25] Despite differences in tribal cultures and traditions, cultural activities hold much strategic potential for coping and resiliency. With some caregivers mentioning the return to traditional foods, for instance, urban patio gardens may be a way of extending traditional food-growing into an urban environment. In addition, various urban Native organizations are providing virtual culture activities during the pandemic, such as the Tucson Indian Center.[26]

Caregivers expressed the need for accessing the healthcare system. Prior to the pandemic, urban American Indians and Alaska Natives were already faced with healthcare access difficulties such as lack of insurance, ineligibility for care at IHS facilities that are often located near/on tribal lands, transportation barriers, and receiving

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healthcare at underfunded urban organizations that do not administer comprehensive care.[27] The already-stressed medical system was under even more pressure due to the pandemic. Half of the caregivers reported issues accessing healthcare or medications. Issues included healthcare providers failing to keep scheduled appointments, as well as lack of healthcare staff response. Telehealth has been mentioned as a potential solution to the pandemic-related physician shortage.[28] Nationally, while only 4 percent of caregivers have utilized telehealth for care recipients, 55 percent of our caregivers mentioned accessing telehealth for themselves or the recipients during the pandemic.[29] Although caregivers in our study reported wanting telehealth appointments that included video, access challenges remain.[30]

Limitations and Conclusion

This study of the caregiving process reflects the urban American Indian and Alaska Native experiences in one geographic region at a specific point in time during the pandemic. While the sample size for this study is small, data saturation was achieved for the identified themes. However, there may be caregivers that could not participate due to long hours of caregiving, working away from the home, or caregiving at the time of this survey. In addition, participants were 80 percent female, and thus the results may not adequately capture the experience of male and non-binary caregivers. Because caregivers all lived in urban areas, this study may not represent the different and/or additional difficulties that caregivers living on reservations may face. An additional difficulty for caregivers living on reservations, for example, is access to water for hand-washing. Plumbing and running water is not guaranteed in reservation-based homes and many people have to haul water from wells, or pick up water in large containers at centralized locations miles from their homes.[31]

This study describes issues regarding the urban American Indian caregiving experience and how the COVID-19 pandemic has affected urban American Indian caregivers. Findings from this project can serve as a starting point around which urban and tribal-based health centers and organizations can create pandemic response protocols for their caregivers or make immediate changes to any existing caregiver services to better meet the needs of American Indian urban caregivers.

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NOTES

1. US Centers for Disease Control, *United States COVID-19 Cases and Deaths by State*, October 12, 2020, https://www.cdc.gov/covid-data-tracker/ - cases.

2. Amy V. Groom, Cheyenne Jim, Mic LaRoque, Cheryl Mason, Joe McLaughlin, Lisa Neel, Terry Powell, Thomas Weiser, and Ralph T. Bryan, "Pandemic Influenza Preparedness and Vulnerable Populations in Tribal Communities," *American Journal of Public Health* 99 (2009): S271–78, https://doi.org/10.2105/AJPH.2008.157453.

3. Hollie Silverman, Konstantin Toropin, Sara Sidner, and Leslie Perrot, *CNN*, "Navajo Nation Surpasses New York State for the Highest COVID-19 Infection Rate in the US," May 18, 2020, http://www.cnn.com/2020/05/18/us/navajo-nation-infection-rate-trnd/index.html.

4. US Department of Health and Human Services, Indian Health Service, *Fact Sheets Urban Indian Health Program*, October 2018, http://www.ihs.gov/newsroom/factsheets/uihp/.

5. National Alliance of Caregiving, *Caregiving in the U.S.*, 2020; US Centers for Disease Control, *Caregiving among American Indian/Alaska Native Adults*, April 15, 2020, http://www.cdc.gov/aging/data/infographic/2017/american-indian-adults-caregiving.html.

6. Felina M. Cordova-Marks, Robin B. Harris, Nicolette I. Teufel-Shone, Beatrice Norton, Ann Mastergeorge, and Lynn Gerald, "Characteristics of American Indian Female Caregivers On a Southwest American Indian Reservation, *Journal of Community Health* 44, no. 1: 52–60, https://doi10.1007/s10900-018-0552-7.

7. US Census Bureau, *Urban Rural*, February 24, 2020, http://www.census.gov/programs-surveys/geography/guidance/geo-areas/urban-rural.html.

8. Cordova-Marks, et al., "Characteristics of American Indian Female Caregivers."

9. Emily O'Dowd, Paul O'Connor, Sinéad Lydon, Orla Mongan, Fergal Connolly, Catherine Diskin, Aoibheann McLoughlin, Louise Rabbitt, Lyle McVicker, Bronwyn Reid-McDermott, and Dara Byrne, "Stress, Coping, and Psychological Resilience among Physicians," *BMC Health Services Research* 18, no. 1 (2018): 730, https://doi.org/10.1186/s12913-018-3541-8.

10. Xabel Garcia Secades, Olga Molinero, Alfonso Salguero, Roberto Ruíz Barquín, Ricardo de la Vega, and Sara Márquez, "Relationship between Resilience and Coping Strategies in Competitive Sport," *Perceptual and Motor Skills* 122, no. 1 (2016): 336–49, https://doi.org/10.1177/0031512516631056.

11. Felina M. Cordova, Lori Joshweseoma, Nicolette I. Teufel-Shone, and Kathryn Coe, "Using a Community-Based Participatory Research Approach to Collect Hopi Breast Cancer Survivors' Stories," *American Indian Culture and Research Journal* 39, no. 2 (2015): 97–109, https://doi.org/10.17953/aicrj.39.2.cordova.

12. Lorelli S. Nowell, Jill M. Norris, Deborah E. White, and Nancy J. Moules, "Thematic Analysis: Striving to Meet the Trustworthiness Criteria," *Internal Journal of Qualitative Methods* 16, no. 1 (2017): 1–13, https://doi.org/10.1177/1609406917733847.

13. Egon G. Guba and Yvonna S. Lincoln, *Effective Evaluation* (San Francisco: Jossey-Bass Publishers, 1981).

14. John P. Krick and Jeffery Sobal, "Relationships between Health Protective Behaviors," *Journal of Community Health* 15, no. 1 (1990): 19-34, https://doi.org/10.1007/BF01350183.

15. US Centers for Disease Control, "Corona Virus Disease (COVID-19) How to Protect Yourself and Others," September 11, 2020, http://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html.

16. National Alliance of Caregiving, *Caregiving in the U.S.*; US Centers for Disease Control, *Caregiving among American Indian/Alaska Native Adults*.

Downloaded from http://meridian.allenpress.com/aicrj/article-pdf/44/2/5/2813709/i0161-6463-44-2-5.pdf by University of California user on 20 April 2021

17. Secades, et al., "Relationship between Resilience and Coping Strategies in Competitive Sport."

18. US Centers for Disease Control, "*Corona Virus Disease (COVID-19) People with Certain Medical Conditions*."

19. Terrence McCoy and Heloísa Traiano, "'There Are No Words': Indigenous Elders, Endangered Languages Face Extinction," *The Washington Post*, October 6, 2020, https://www.washingtonpost.com/world/the_americas/coronavirus-brazil-indigenous-endangered-language/2020/10/06/59fa1aa8-f42b-11ea-999c-67ff7bf6a9d2_story.html; Laurel Morales, *National Public Radio* Weekend Edition Sunday, "Navajo Nation Loses Elders and Tradition to COVID-19," May 31, 2020, http://www.npr.org/2020/05/31/865540308/navajo-nation-loses-elders-and-tradition-to-covid-19.

20. National Alliance of Caregiving, *Caregiving in the U.S.*

21. O'Dowd, et al., "Stress, Coping, and Psychological Resilience among Physicians."

22. Urban Indian Commission, *Invisible Tribes: Urban Indians and Their Health in a Changing World*.

23. American Association of Retitred Persons, *Preparedness for Caregivers during COVID19* (nd), https://states.aarp.org/preparedness-for-caregivers-during-covid19.

24. Ibid.

25. Annjeanette Elise Belcourt-Dittloff, "Resiliency and Risk in Native American Communities: A Culturally Informed Investigation," PhD diss., University of Montana, 2007.

26. Tucson Indian Center, Videos, https://www.ticenter.org/video/.

27. Urban Indian Commission, *Invisible Tribes: Urban Indians and Their Health in a Changing World* (Seattle: Urban Indian Health Commission, 2007).

28. Joyce Frieden, "COVID-19 Is Making Physician Shortages Worse, Groups Say," *MedPage Today*, March 27, 2020, https://www.medpagetoday.com/infectiousdisease/covid19/85661.

29. National Alliance of Caregiving, *Caregiving in the U.S.*; US Centers for Disease Control, *Caregiving among American Indian/Alaska Native Adults*.

30. Azure, et al., "Technology Use among American Indians/Alaskan Native Elders."

31. Laurel Morales, National Public Radio *Morning Edition*, "Many Native Americans Can't Get Clean Water, Report Finds," http://www.npr.org/2019/11/18/779821510/many-native-americans-cant-get-clean-water-report-finds; Jones, "10 Steps to Save Native Americans from COVID Catastrophe."

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