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## Diabetes Self-Care Behaviors and Barriers to Clinical Care During COVID-19 Pandemic for Marshallese Adults

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### Abstract

**Purpose:** The purpose of the study was to explore experiences of Marshallese adults related to diabetes self-care behaviors during the COVID-19 pandemic.

**Methods:** A qualitative descriptive design was utilized to understand participants' diabetes self-care behaviors during the pandemic. Nine focus groups with 53 participants were held via videoconference and conducted in English, Marshallese, or a mixture of both languages. A priori codes based on diabetes self-care behaviors provided a framework for analyzing and summarizing participant experiences.

**Results:** Both increases and decreases in healthy eating and exercise were described, with improvements in health behaviors attributed to health education messaging via social media. Participants reported increased stress and difficulty monitoring and managing glucose. Difficulty obtaining medication and difficulty seeing their health care provider regularly was reported and attributed to health care provider availability and lack of insurance due to job loss.

**Conclusions:** The study provides significant insight into the reach of health education campaigns via social media and provides important information about the reasons for delays in care, which extend beyond fear of contracting COVID-19 to structural issues.

Racial and ethnic minority populations in the United States (US) have been disproportionately affected by COVID-19, with increased infection, hospitalization, and death.<sup>1–6</sup> The available data reporting COVID-19 outcomes for Pacific Islanders shows

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Declaration of Conflicting Interests

The authors declare that there is no conflict of interest.

significantly higher rates of infection, hospitalization, and death compared to other minority populations and white populations in the US.<sup>4,7,8</sup> A July 2020 report from the Centers for Disease Control and Prevention documented the disparate effect of the COVID-19 pandemic on the Marshallese Pacific Islander population in the Northwest region of Arkansas (ie, Benton and Washington counties).<sup>1</sup> Although the Marshallese community is approximately 2.4% of the total population, Marshallese accounted for 19% of all COVID-19 positive cases in Northwest Arkansas.<sup>1</sup> Nationally, 144.1 per 100 000 of COVID-19 cases (<.01%) require hospitalization; however, among Marshallese COVID-19 cases in Arkansas, 9% were hospitalized, and 38% of COVID-19-related deaths in the 2-county region were Marshallese.<sup>1</sup> Although 4% of the population of Hawaii identifies as Pacific Islanders, they represent 21% of all COVID-19 positive cases in the state.<sup>9</sup> Pacific Islanders accounted for 29% of COVID-19 cases requiring hospitalization and 22% of COVID-19-related deaths in Hawaii.<sup>9</sup> These COVID-19 outcomes are much higher than for other racial and ethnic minorities in the US and show the disproportionate effect of the pandemic on the Marshallese community.<sup>1,2</sup>

Cardiometabolic comorbidities (eg, type 2 diabetes) increase the risk of severe infection and mortality from COVID-19.<sup>10,11</sup> Marshallese have extremely high incidence of type 2 diabetes and prediabetes; 38.4% of Marshallese adults have type 2 diabetes, and 32.6% have prediabetes,<sup>12</sup> which is a significant disparity when compared to the general US adult population, of which 10.5% have diabetes and 34.5% have prediabetes.<sup>13</sup> A local needs assessment completed prior to the pandemic showed 49.6% of Marshallese adults reported not accessing care in the past year due to cost.<sup>12</sup> Even after the passage of the Affordable Care Act and Medicaid expansion, the proportion of uninsured Marshallese adults was 48%, more than 5 times the proportion of uninsured adults reported at the national (8.0%) and state (9.1%) levels.<sup>14</sup>

Diabetes self-care behaviors are important for maintaining health. Diabetes self-care behaviors include healthy eating, being active, managing stress, monitoring and managing glucose, medication taking, and seeing a health care provider regularly.<sup>15</sup> In a 2008 comprehensive review of the literature on the effect of disasters and pandemics on diabetes self-care behaviors, patients reported elevated A1C levels postdisasters, even among those without interruptions of their self-management regimens.<sup>16</sup> A 2011 study noted the vulnerability of certain groups, including older adults, rural populations, those with low socioeconomic status and/or without health insurance, and minority racial/ethnic groups, is often magnified by disasters and pandemics, resulting in increased risk of morbidity and mortality.<sup>17</sup> The study presented here explored experiences of Marshallese adults related to self-care behaviors and diabetes care during the COVID-19 pandemic.

## Methods

### Study Aims and Approach

This study aims to describe diabetes self-care behaviors among adult Marshallese during the COVID-19 pandemic using qualitative methods. Study methods and materials were approved by the University of Arkansas for Medical Sciences (UAMS) Institutional Review Board (No. 261131). A community-based participatory research (CBPR) approach was used

in the design and implementation of this study. CBPR has been shown to be an effective approach with vulnerable populations; this approach honors cultural values, norms, and practices and integrates them into every aspect of the research. Community stakeholders provided input on the study aims and design, assisted with participant recruitment, facilitated data collection, and provided feedback on findings during data analysis. The CBPR collaborative is described in several articles.<sup>18–21</sup>

### **Study Design**

A qualitative descriptive design was utilized to understand participants' diabetes self-care behaviors during the COVID-19 pandemic.<sup>22–24</sup> The research team chose this study design because it allowed them to document participants' experiences with diabetes care in the participants' own words. This design allowed the research team to document participants' perspectives regarding barriers to diabetes care during COVID-19.

### **Interview Guide Design**

The semistructured interview guide was developed and revised 3 times with guidance and input from the Marshallese COVID-19 Taskforce, an advisory board of local Marshallese community leaders and health care professionals, and an interprofessional research team of qualitative researchers. Marshallese bilingual study staff provided input to ensure questions were culturally appropriate for Marshallese participants. The interview guide included broad open-ended questions to facilitate discussion while ensuring consistency across focus groups. Participants were asked to describe how COVID-19 had affected their health and quality of life and how they cared for their diabetes. Specifically, participants were asked: (1) How did Marshallese adults experience diabetes care during COVID-19 pandemic? and (2) Did Marshallese adults experience any barriers to diabetes care during the COVID-19 pandemic?

### **Participant Recruitment, Consent, and Remuneration**

A snowball recruitment method was used.<sup>25</sup> Bilingual Marshallese study staff contacted potential participants who were known to have type 2 diabetes or have a family member with type 2 diabetes. Contact was made via phone, social media, and outreach through community health workers and community partners, including local health care clinics, community organizations, and faith-based organizations, in partnership with the Marshallese COVID-19 Taskforce. Initial participants and community partners were asked to identify additional participants who met the inclusion criteria. Inclusion criteria were self-identification as Marshallese, 18 years of age or older, currently living in the continental US or Hawaii, and having type 2 diabetes or a family member with type 2 diabetes. A study staff member read the consent form aloud, and participants provided verbal consent in their preferred language. Participants received a \$40 gift card as remuneration for their participation in the focus group.

### **Data Collection**

Qualitative interviews using focus groups were conducted between September 2020 and November 2020 via videoconference using Zoom. Focus groups took approximately 1.5

hours to complete. Nine focus groups were conducted with 53 total participants. Focus groups varied by the number of participants, with some focus groups having 2 participants and others having up to 7 participants. Interviews were conducted in English, Marshallese, or a mixture of both languages, and participants were encouraged to communicate in the language they found most comfortable. Three bilingual study staff facilitated the focus groups. Focus group facilitators were trained in qualitative research methods and had more than 4 years of experience conducting focus groups. The research team carefully monitored study procedures to protect participant privacy and the quality of the data. No identifiable information was collected. All collected data are kept in password-protected files and stored on secure UAMS servers and/or databases.

### Qualitative Data Analysis

Focus group data were recorded and transcribed verbatim. Any words spoken in Marshallese were translated from Marshallese to English by a medical translator. Three researchers trained in qualitative methods began initial coding using a priori codes based on self-care behaviors: healthy eating, being active, managing stress, monitoring and managing glucose, medication taking, and seeing a health care provider regularly. These initial codes provided a framework for analyzing the data that summarizes and organizes participant experiences and perceptions. Initial codes were used to label data segments with short summations to organize the data for more focused coding. Coding was conducted through and managed with MAXQDA software.<sup>26</sup> Coding discrepancies were discussed, and codes were refined 4 times until consensus among the research team was reached. The most representative quotes are presented. Marshallese have a collectivist culture, and it is common and expected for a family member, most often an adult child, to speak on behalf of the patient. In addition, many Marshallese within 1 family have diabetes, and even when a person with diabetes is speaking, they will use inclusive language such as “we” or speak in the third person to include those in their family and community in the statement.<sup>20,27,28</sup> The quotes were not altered to fit Western language and are presented in participants’ own words and speech patterns.

## Results

There were 53 participants, 36 females and 17 males, who participated in the 9 focus groups. Geographical location of participants was collected, with 25 participants located in Arkansas, 25 participants located in Hawaii, and 3 participants located in Oklahoma.

### Experiences of Diabetes Care

Participants described their experiences with self-care behaviors during COVID-19: healthy eating, being active, managing stress, monitoring and managing glucose, medication taking, and seeing a health care provider regularly.

**Healthy eating.**—Participants’ experiences with healthy eating during the COVID-19 pandemic varied. Some participants described eating a healthier diet due to the increased risk of COVID-19 complications and death for those with diabetes, whereas others explained they were eating too much during quarantine or working from home. Several participants

described how public health messages disseminated in the Marshallese language influenced their family members or other community members to increase their consumption of healthy foods to manage their diabetes during COVID-19. One participant explained her parents were influenced by media reports that “kept saying people with underlying conditions can catch COVID-19 much easier” and “they literally changed their diet; they did a lot of substitutions like substituting [out] white rice for brown rice and a lot of low carbs and low sugar drinks.” Participants also described healthy eating for other community members: “I’m just proud that a lot of people are noticing and they’re changing their diet because of how COVID-19 really does affect persons with underlying conditions.” Another participant described her mother was now “very careful, she eats what she needs, like she eats more fruit, she eats less rice” to eat a healthier diet.

Healthy eating experiences also included limiting consumption of sugar-sweetened beverages. One participant reported his father-in-law made dietary changes “not just in his eating habits but you know drinking so there is a joke that I usually tell him, ‘You’d rather drink Dr Pepper or Dr Sheldon [Riklon, a local physician who is Marshallese]?’ and I can already see that he’s starting to change” his habits. Another participant reported “drinking a lot more water with lemons.”

Approximately half of the participants, however, noted challenges to healthy eating during COVID-19 lock-downs. One participant succinctly explained eating better was not necessarily the experience for everyone. He stated, “I’ve seen that many of them have gone off track in terms of eating healthy food that their doctors talk to them about.” Other participants said, “With being inside our home a lot, we see the food, we’re tempted, and we end up eating them” and “we just eat and eat.”

**Being active.**—Participants’ experiences related to being active during the COVID-19 pandemic also varied; over half of participants reported an increase in exercise to reduce risk, whereas the rest said they were not exercising or were exercising less due to the pandemic. For those who reported more exercise, participants connected their increase in physical activity to public health messages provided in the Marshallese language from social media sources. One participant explained they were “exercising more” and that with other family members, “they were doing a lot of these [Tiktok] challenges like pushup challenges and sit-up challenges.” The participant explained physical activity challenges via social media were a positive experience that had increased exercise for themselves and other community members:

When I was doing the challenges I always tell people to exercise because you know I could really see that the ones who get affected the most [from COVID-19] are the ones with diseases and I was telling myself well if I’m going to tell people to do this maybe I should do it and make an example. I was doing a lot of video, every morning I do my exercises and I tell people, so I did like a 21-day and I did another 19-day and I’m still continuing and that’s one of the positive things

[resulting from COVID-19].

Another participant described her parents' self-care behaviors, explaining that her "dad is very active [and] plays tennis everyday" to manage his diabetes and hypertension. She also reported, "we take my mom to the tennis court and she would walk [and] she walks inside the house ... she's doing more exercise on her own so she's very aware of what's going on in our community because of what we've learned from what Dr Riklon has said" on his Marshallese public health radio show. One participant said his father-in-law had become more active because "he pretty much realizes now how important it is to take care of himself and he walks sometimes during the morning or the evening."

Still, other participants noted a decrease in being active during COVID-19. A participant described the lack of exercise during COVID-19 for Marshallese patients with diabetes who "talked about how they're staying indoors a lot more than they did a couple of months that affects their physical activities." Another participant explained, "we're getting heavier for being inside the house a lot" and not being active.

**Managing stress.**—Participants described increased stress associated with COVID-19 and the pandemic's effect on their emotional well-being and self-care behaviors. A participant stated: "It takes a huge toll on my wife and I because we see loved ones going [dying], and we're like wow that could have been us [and] just to think about what COVID-19 has done to our community takes a toll, just to think about it really drains us out daily." Another participant reported they feared contracting COVID-19 "because my son has a pulmonary condition [and] we really can't go out that much so it takes a toll on us." This participant expressed the stress of COVID-19 on the community, saying, "Seeing community members passing away it's like much every week turning into going to a funeral so it's culturally shocking and we didn't expect to be in this kind of situation so it's a lot." One participant explained, "This pandemic is causing so much anxiety some are forgetting that they need to take medications because they're worried."

**Monitoring and managing glucose.**—Several participants reported experiencing elevated blood glucose levels due to COVID-19. One participant explained she, her husband, and her father have diabetes, stating, "It took a big impact on our diabetes for my dad and my husband because when [my husband] didn't eat, his diabetes went down and then when [my husband] would eat it would go back up again." Another participant explained after recovering from COVID-19, "I went back to see my doctor, my health outcome was out of control, my A1C was way high, so COVID-19 did affect my health." A participant who self-identified as a health care provider during the focus group reported on his patients' experiences, stating, "We're seeing A1Cs climbing back up again."

**Medication taking.**—Participants described encountering barriers to medication taking during COVID-19. Participants provided several examples of challenges they encountered in obtaining their medications, including insulin. One participant whose mother and father-in-law have diabetes explained they "ran out of medicines and insulin to reduce their sugar level, and we couldn't get any refills [from] their doctors [because] we couldn't get a hold of them." Another participant reported "having more problems trying to get their prescriptions" during the pandemic. Participants also described barriers to taking medication because they missed their doctor's appointments while in quarantine with COVID-19. One participant

explained, “I had an appointment to go back, but we had COVID-19 and I didn’t go and later on I ran out of [diabetes] medications. I needed to see my doctor before I can get refills again because I ran out.”

**Seeing a health care provider regularly.**—A majority of participants explained they or their family member delayed or did not seek care for their diabetes over the past year; others stated they tried to seek care but faced barriers to accessing care. One of the reasons reported for delaying care was the fear of contracting COVID-19 during the clinical visit. Participants with diabetes said they were “hesitant to go see my doctor because I was scared to go places where people are present,” and others stated, “I didn’t want to go anywhere because of the virus, I waited until I felt like it was getting better then I made the [doctor’s] appointment.” A participant explained, “we had to [be] really cautious about making sure [not to] get exposed to the virus,” and another participant stated that they delayed seeking care and were “extra careful ... a lot of people are scared [to go] for the doctor because you don’t know who’s going to go in there and if they have that coronavirus.”

Other participants also described the concerns of their family members with diabetes about catching COVID-19, which led them to delay taking their family member to their health care provider. A participant explained a family member had reported “not taking their mother to the doctor because of the virus [and they were] afraid to take her so had been postponing again and again.” Another participant described delaying seeking emergency care for their mother because of fear of contracting COVID-19, stating, “She was feeling sick but we didn’t take her to the ER to see any doctors.”

Some participants stated they had tried to see their health care provider for their diabetes but reported a lack of access to health care providers during COVID-19 due to changes in clinic schedules, policies, and insurance coverage. A participant explained their family member with diabetes had lesions needing immediate attention and reported their family member “needed to go in right away to see a doctor and they have to call and set up an appointment but [their regular] doctor’s not available” due to scheduling conflicts related to COVID-19. Other participants explained that they “couldn’t get a hold of the doctor” and “I haven’t gone to see a doctor for quite a while now” because they were not able to schedule an appointment due to clinic COVID-19 reduced hours of operation.

Some participants noted a lack of insurance related to COVID-19 layoffs, which reduced their access to health care. A participant summarized, “It’s not before [COVID-19], I lost my job and my medical insurance from my job and it really affected me and my family.” One participant provided an example of a family member who lacked access to a health care provider due to the loss of their employee-sponsored insurance. They explained that their family member “had medical insurance but they got laid off because of COVID-19 and then losing his medical insurance was critical to his health and I was really worried about him having diabetes and high blood pressure and having to wait to apply for medical insurance in November during open enrollment.” Another participant said, “when COVID-19 happened and most get laid off and they want to apply for the Affordable Care Act”; however, this causes delays in accessing health care because the patient now needs to wait for the Affordable Care Act open enrollment period, normally in November.

Some participants reported utilizing telemedicine during the pandemic to keep their regular doctor's appointments. Participants' responses to telemedicine technology were mixed. One participant explained patients were "grateful that we have that service [telehealth]." Another participant who had recently recovered from a COVID-19 infection said, "I'm [more] mindful of my health and about seeking health care, which we do from home, we do video appointments with our doctor now." However, a participant said when their family member with diabetes "talks to the doctor they're more comfortable with face to face, whereas now it's telehealth that they're going through and they're not comfortable with that." One participant reported internet access was a barrier to telemedicine: "There's always these gaps with internet connections if someone is living on the south side [less connected area of Hawaii] when they try to talk [to the doctor] so they can't really understand because of internet connection problems." Another participant explained patients were uncomfortable with telemedicine because "there's also the language access issue ... people need interpreters, people need interpretation or translation services and sometimes they're hesitant to express [these] needs or challenges that they are experiencing to their health care providers" over telemedicine.

## Discussion

This study documents the effects of the COVID-19 pandemic on diabetes care among Marshallese adults residing in the US using qualitative methods. Participants described the effects of the COVID-19 pandemic on their individual experiences and their family members' experiences of diabetes care. Participants discussed healthy eating, being active, managing stress, monitoring and managing glucose, medication taking, and seeing a health care provider regularly.

Participants described varied experiences of healthy eating and being active during the pandemic. Approximately half of the participants said they had improved their diet and were exercising more, and half of the participants stated they were less active and were eating too much unhealthy food during the COVID-19 pandemic. The disruption to diet and physical activity regimen participants described is consistent with the literature documenting how COVID-19 has affected the nutrition and exercise behavior of other populations during the pandemic.<sup>29-32</sup> This finding is also consistent with studies of the impact of natural disasters, such as hurricanes, which have affected patients' ability to engage in diabetes self-management activities.<sup>16,17,33</sup> This is the first study to examine healthy eating and physical activity during the COVID-19 pandemic among Marshallese with diabetes using qualitative methods.

A notable finding reported in this study is participants reported connecting positive experiences of healthy eating and being active to the health education messages produced in the Marshallese language, featuring Marshallese leaders, and disseminated via local media sources and social media. These messages were described as emphasizing the importance of staying healthy and the increased risk of infection, hospitalization, and death from COVID-19 for people with chronic conditions such as diabetes. This finding highlights the positive effects of culturally and linguistically appropriate targeted health messaging on the health behaviors of a vulnerable population during COVID-19 pandemic.<sup>34</sup> Future research



should explore additional ways of leveraging culturally tailored messages and social media for health promotion.

Participants discussed an increase in stress due to the pandemic negatively affecting their well-being and their ability to practice healthy coping strategies and to manage their diabetes. This finding is consistent with the emerging literature linking the pandemic with increased stress and negative mental health outcomes.<sup>35–39</sup> Participants also reported elevated blood glucose levels due to the pandemic. This is a consistent finding documented in previous literature on the effects of disasters and pandemics on diabetes self-care behaviors. The results of previous studies have shown patients with diabetes report elevated A1C levels postdisaster, even among those who did not personally experience disruption to their self-management routines.<sup>16</sup> Recent studies have also documented elevated blood glucose levels in patients with diabetes during the COVID-19 pandemic.<sup>40–42</sup> This is the first study to qualitatively document the relationship between COVID-19 and challenges managing blood glucose among Marshallese with diabetes.

Of most concern, participants reported both a lack of access to medication refills and delays in seeing their health care providers. These findings were consistent with the literature documenting the barriers to diabetes care during disasters<sup>16,17,33</sup> and the effects of the COVID-19 pandemic on US adults seeking medical care.<sup>43</sup> Czeisler et al<sup>43</sup> reported 41% of US adults had delayed seeking medical care, including urgent or emergency care and routine care because of concerns about COVID-19. This is the first article to document a more nuanced understanding about the delays in care, which included job loss and a lack of insurance, health care provider scheduling, and fear of contracting COVID-19 among Marshallese with diabetes. Additional research is needed to understand the health insurance and health care access implications of COVID-19-related job loss, which may have created additional health inequalities.

Some participants described using telemedicine to access diabetes care during the COVID-19 pandemic. Although some participants appreciated their experience with telemedicine, others were not as comfortable accessing care through telemedicine, noting language barriers or lack of access to a reliable internet connection. Access issues, including a lack of broadband internet, and limited English proficiency are linked to lower engagement and satisfaction with telehealth.<sup>44–48</sup> Telemedicine has increased during the COVID-19 pandemic.<sup>49–51</sup> Telemedicine has been shown to improve diabetes outcomes and reduce health disparities among minority populations.<sup>52</sup> However, a lack of trust in medical technology, including telemedicine, among minority populations has been shown to impede uptake.<sup>53</sup> Prior research has shown the use of bilingual translators and community health workers can help improve diabetes care,<sup>54–56</sup> and incorporating bilingual community health workers into telemedicine visits may facilitate greater uptake of telehealth among the Marshallese community and other minority populations. Although one study of community health workers and telemedicine has demonstrated readiness,<sup>57</sup> there is a significant gap in the literature regarding the effectiveness of utilizing community health workers in telemedicine. Additional research is needed to increase the uptake of telemedicine among minority communities.

## Limitations

The study is not without limitations. Participants were recruited through a snowball, nonrandom sample. Participants only included Marshallese; therefore, participants' experiences may not be generalizable to other Pacific Islander communities.

## Conclusion

This study makes an important contribution to the literature as the first study with Marshallese participants to document their experiences and barriers related to diabetes care during the COVID-19 pandemic in their own words. The study provides significant insight into the reach of health education campaigns via social media. This study also provides important information about the reasons for delays in care, which extend beyond fear of contracting COVID-19 to structural issues such as health care providers' availability and lack of insurance. The research will inform clinical practice interventions in the Marshallese and other Pacific Islander communities.

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