

Rural Native Veterans' Perceptions of Care in the Context of Navigator Program Development

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Abstract

Introduction American Indian and Alaska Natives serve in the military at one of the highest rates of all racial and ethnic groups. For Veterans, the already significant healthcare disparities Natives experience are aggravated by barriers to accessing care, care navigation, and coordination of health care within the Veterans Health Administration (VHA) between the VHA and tribal health systems. To mitigate these barriers, the VHA is developing a patient navigation program designed specifically for rural Native Veterans. We describe formative work aimed at understanding and addressing barriers to VHA care from the perspective of rural Native Veterans and those who facilitate their care.

Methods Thirty-four individuals participated in semi-structured interviews (22 Veterans, 6 family members, and 6 Veteran advocates) drawn from 9 tribal communities across the US.

Results Participants described many barriers to using the VHA, including perceptions of care scarcity, long travel distances to the VHA, high travel costs, and bureaucratic barriers including poor customer service, scheduling issues, and long waits for appointments. Many Veterans preferred IHS/tribal health care over the VHA due to its proximity, simplicity, ease of use, and quality.

Conclusion Rural Native Veterans must see a clear benefit to using the VHA given the many obstacles to its use. Veteran recommendations for addressing barriers to VHA care within a navigation program include assistance enrolling in, scheduling, and navigating VHA systems; paperwork assistance; cost reimbursement; and care coordination with the IHS/tribal health care.

Keywords Veterans · Rural · American Indian/Alaska Native · Native American · Barriers · Health care · VA

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Introduction

Motivated by values and tradition, economic need, and/ or the desire to obtain education or job skills, individuals from rural areas serve in the military at higher rates than the overall rural US population and comprise 41% of all Veterans [1]. As the most rural of all Veteran groups [2], American Indians and Alaska Natives (hereafter referred to as "Native") serve in the military at one of the highest rates of all racial and ethnic groups and disproportionately suffer the medical and psychological consequences of military service [3]. The already significant health disparities of Native people [4] are compounded among Native Veterans by barriers related to access, care navigation and coordination, and fragmented health services as users of multiple healthcare systems, including the Veterans Health Administration (VHA), Indian Health Service (IHS), and tribal health programs [5].

Various efforts by the VHA and Department of Veterans Affairs (VA) more broadly have sought to address these barriers to care. One such effort is the IHS-VA memorandum of understanding [6], which promotes interagency coordination, collaboration, and resource sharing. Additionally, the American Indian Vocational Rehabilitations Program [7], telehealth services [8, 9], home-based primary care [10], and the tribal Veteran representative program [11, 12] emerged in response to service gaps experienced by rural Native Veterans. Despite positive localized impact, persistent gaps generally remain with respect to the care of rural Native Veterans [13].

Racial and ethnic disparities in accessing physical and mental health care are well-established in the literature [14–18]. Less is known about specific barriers faced by rural Native Veterans, although an emerging body of research has identified several issues. Rural Veterans generally face challenges obtaining timely and high quality care due to healthcare provider shortages, transportation issues, and long distances to healthcare facilities [19]. Rural Native Veterans experience similar challenges to general tribal populations, including fragmented care across multiple systems [4], the lack of cultural competence in VHA care [20], and distrust of federal agencies rooted in a history of assimilationist policies intended to destroy cultural practices and beliefs as well as rights to ancestral and reservation land [21].

A common barrier to accessing the VA system overall is a lack of understanding of eligibility rules, often compounded by difficulty completing required paperwork for enrollment [20, 22–27]. Perceived inadequacy of care, even absent first-hand experience, is frequently shared via informal peer-to-peer networks and contributes to underutilization as well as negative healthcare experiences [22, 26]. Focus groups with Native Veterans found high levels of distrust and anger at the lack of information provided at discharge from the military about VA benefits as well as perceived obstruction by VA personnel [20]. Rural veterans, including Native Veterans, may believe that they must present with high levels of medical severity to warrant eligibility for care [24, 26].

Perceived unavailability of services by rural Veterans dissuades use, especially of mental health services [26, 28]. Perceived service unavailability or inadequacy add to enrollment issues and dissuade Veterans from navigating complicated help-seeking processes. Native Veterans have additionally experienced cultural barriers to care, including health providers' lack of skill in providing appropriate care, yielding complaints of culturally insensitivity, poor communication, the lack of awareness of Native mental healthcare needs, and incorrect assumptions about Native Veterans and their cultures [20, 29]. Repeated encounters of barriers to care reinforce the belief among these Veterans that the VA system "is not there to serve them" [24].

The lack of coordination across different healthcare systems complicates effective care, especially for those forced to navigate multiple health systems [22-24]. Coordination of care among different locations and across healthcare systems is of particular concern to rural Native Veterans [23, 30]. Individuals who are eligible to receive care from both the IHS and the VA often find that the former's proximity provides greater access than more distant VHA facilities [30]. While transportation is a barrier to healthcare among the general population, it significantly impacts Veterans, Natives, and rural populations [20, 24, 26–28, 30–35]. Vast distances and inadequate transportation amplify the negative experience of poor scheduling (e.g., appointments scattered throughout the week requiring multiple trips or limited office hours) [28, 32]. Long waiting times and the lack of timely appointments also impede healthcare utilization [22, 23, 25, 27, 31].

In late 2019, the VHA Office of Rural Health initiated a project to develop and implement a patient navigation program designed specifically for rural Native Veterans to address these gaps. The goal of this program is to create a state-of-the-art patient navigation program to bridge gaps in access to VHA services for rural Native Veterans. Patient navigation is a model of care that proactively guides patients through the healthcare system by educating them about their health status and care options, coordinating care, and connecting patients with resources. This model, embodying many variations in scope, goals, and personnel, has demonstrably improved patient access, outcomes, and experience [36–38]. A critical challenge is to find the appropriate mix of form and structure to develop a program specifically for rural Native Veterans, which we refer to as the Rural Native Veterans-Health Care Navigation (RNV-HCN) initiative.

As research on barriers to care for rural Native Veterans continues to grow, we deemed the extant research sufficient to inform inquiry into elements critical to the uptake of a culturally tailored version of patient navigation. We sought to elicit views of perceived barriers to VHA care including perceptions of extent and quality of care, transport, cost, scheduling or coordinating care, and preferred platforms for delivery services. The goal was to understand identified barriers to best address and respond to them in the anticipated program.

Methods

Project History and Design

In fall 2019, we initiated the process of partnering with tribal communities to gather input from Veterans, family members, and advocates to inform the development of the RNV-HCN program. While the initial plan was to hold focus groups in person with several communities, COVID-19 pandemic closures forced a revision of methods. Instead of in-person discussions, we developed a virtual data collection plan for individual virtual interviews and expanded the number of communities involved. While this pivot allowed the work to continue, the devastation and toll of the epidemic on many tribal communities was significant, with extremely high levels of COVID-19 related mortality fueled by a lack of access to water for recommended hygiene, over-crowded households due to severe housing shortages, limited transportation, and inadequate and often distant health care [39]. Such conditions indelibly shaped our method, approach, and the tenor of subsequent conversations, both in establishing community participation and working with participants.

Ethical Permissions

The VA Salt Lake City Health Care System reviewed the protocol and assigned the project a determination of non-research status.

Procedures

Eleven communities across the nation were invited to participate; each tribe supported the project and agreed that Veterans in their community could contribute valuable information. Tribal liaisons in each community assisted with securing official tribal support and the recruitment of local participants.

Three categories of participants were interviewed: Veterans, family members, and tribal advocates for Veterans. We developed interview guides for each group, with each including questions designed to elicit the potential utility of a patient navigator program, characteristics best suited for the navigator role, challenges navigators and Veterans may face, experiences with healthcare provision for Veterans, challenges of VHA access to services, the role of spiritual supports, and preferences for virtual visits and communication in navigator-Veteran interaction. Here, we focus specifically on barriers to care as perceived by participants since it is a key component of program development. To frame the conversation in the context of navigator program development, each interview began with a vignette-a story about a hypothetical navigator assisting a Veteran. This vignette provided a concrete example of health care navigation since many Veterans are unfamiliar with this service. The vignette was followed by several questions related to the vignette (Table 1). Interview questions were piloted with Native Veterans, and advocates to ensure content and wording were appropriate and meaningful prior to commencing interviews. Participants were offered the option of Zoom interviews, but all participants opted for a telephone interview. Each interviewee was consented for recording and offered \$60 in direct bank deposit for their time. All interviews were conducted by a Native interviewer.

Participants

Of the 11 tribal communities invited to join the study, participants from 9 sites were interviewed between May 2021 and July 2022. Two sites withdrew because of the logistical and personal challenges posed by the COVID-19 pandemic. The sample disproportionately represented individuals from the Northwest and Southwest (22/34; specific tribes are not named to maintain community confidentiality). Other sites were in the Northern Plains, Southern Plains, Midwest, and Alaska. Thirty-four individuals participated in interviews (22 Veterans, 6 family members, and 6 Veteran advocates). Participants were largely older male Veterans (mean age = 62) (Table 2). Most Veterans served in the Army or Navy for an average of about 8 years. Family members and advocates were primarily women; family members were mostly wives. Advocates held various jobs including Veteran service officer for a state or tribe and patient benefit coordinator for the IHS or a tribe. Advocates were younger than other participants (mean age = 52).

Data Analysis

NVivo 12, a qualitative software program, was used for transcription as well as interview coding [40]. A codebook was developed collaboratively by the first and second authors. Transcribed and deidentified interviews were coded for themes. Interviews were group coded until 80% inter-coder reliability was achieved, with eventual inter-coder reliability reaching 90% agreement. After coding, NVivo was used to

Table 1 Navigator vignette

It might be helpful to start with an example of a situation in which a health care navigator might work with a Veteran. I am going to read a hypothetical story about a Veteran who is enrolled in the VA interacting with a navigator. Afterwards, I would like to hear your thoughts about the story

John was a 54-year old Veteran with severe headaches and back pain. He wasn't sure who to talk to in the VA to get help. Around that time, another Veteran happened to tell him about the Rural Native Veteran Health Care Navigator program. Although John wasn't sure it would help, he decided to give it a try anyway. He called the number, and to his surprise was greeted by a friendly woman named Shanna who asked him what was going on and what she could do to help him. She helped him set up an appointment with a doctor at the VA for his headaches and back pain. John told Shanna about his time in Iraq, that he just couldn't get it out of his mind and that sometimes he felt like he wanted to explode. Shanna suggested that he talk to a doctor about that too. She helped John schedule this appointment at the VA and made sure he had transportation to his appointments. She called a Community Health Representative, who told her about a peer support group in John's community. Shanna suggested he give it a try. She also asked John how he would feel about her checking in with his wife to let her know about the plan of care and see if she needed anything. After John's doctor appointments, Shanna called John to see how they went and what else he might need. She then called him two weeks later to make sure that everything was going ok; John said things were going better. Shanna told him she was glad to hear that and since things were going better, she would not be calling back for now, but that he should feel free to contact them again

- 1) Would it help to have someone acting as a health care navigator like this at the VA? Can you tell me more about that?
- 2) What kind of problems can you see coming up for a Veteran using a health care navigator program like the one in the story?
- 3) What kind of problems can you see coming up for the navigator?
- 4) What type of person would be the best suited for navigator? What characteristics would they need to have?
- 5) Who could most use the navigator program? What type of veteran needs it most?
- 6) What would be some helpful things a navigator could do?

7) What are your thoughts about how well the program would work if the navigator contacted veterans by mainly by phone or computer conferencing rather than in-person? What challenges do you think the navigator might have with this type of contact?

| | Ν | Male | Mean age (in years, range) | Military service | Branch of service | | | Service length |
|-----------|----------|----------|----------------------------|------------------|-------------------|------|---------|-------------------|
| | | | | | Army | Navy | Marines | (in years, range) |
| Veterans | 22 (65%) | 17 (77%) | 62 (36–78) | 22 (100%) | 12 | 7 | 3 | 8 (2-30) |
| Family | 6 (18%) | 1 (17%) | 61 (49–75) | 0 | 1 | 2 | 0 | Not provided |
| Advocates | 6 (18%) | 1 (17%) | 52 (46–58) | 3 (50%) | 1 | 1 | 1 | 5 (2–7) |
| Total | 34 | 19 (56%) | 60 (36–78) | 25 (74%) | 14 | 10 | 4 | 8 (2-30) |

Table 2 Participant demographics (N=34)

examine frequency of codes used and relationships between codes when used congruently with interview text passages. Once all interviews were coded, relationships among themes and codes were examined using NVivo analysis tools.

Results

Barriers to VHA Care for Rural Native Veterans

Participants described many barriers to using the VA, including care preferences, perceptions of care scarcity, travel issues, and bureaucratic obstacles.

Care Preferences

Some Veterans were content to use only IHS and tribal health care; others wanted to use the VHA, as did this

79-year-old male Veteran: "I have some issues that I would like to have [the VA] take a look at, you know, to get a second opinion, because even though IHS looks at it, I'd like the VA doctor to check it out, because you guys actually use doctors. The tribe uses what they call nurse practitioners..." While this Veteran wanted to use the VHA for second opinions, others were interested in specialty care. [Note: As this Veteran's verbiage suggests, most participants used the term "VA" broadly, and did not distinguish the VHA—the arm of VA that provides health care—from other VA arms such as the Veterans Benefits Administration (VBA) or the National Cemetery Administration].

Concerns About Care Scarcity and Relative Need

As found in previous studies [30, 35], some rural Native Veterans had internalized a scarcity model of care, wherein services were viewed as finite and exhaustible, in which one person's use might take care away from others in need. These participants believed that other Veterans were worse off than they were and should therefore have priority for VA services, as illustrated by this 68-year-old male Veteran:

I went down for my initial assessment to [the VHA in the nearby city], talked to a doctor there about my knees, and I felt more ashamed that I saw people with lost limbs, mental health issues, and such, that I didn't want to--I thought that my need was a lot less than what their needs were. I thought I would be just using a number that could be used on a Veteran with more dire need than I was [in]. I was told not to think that way, the VA is there for all those who served.

This passage exemplifies the belief that serving a Veteran with fewer needs would divert care from a Veteran with greater needs, which this Veteran interpreted as shameful. It is possible that care scarcity beliefs are based on experiences with IHS contract care, where chronic underfunding means that some services compete for funding and become largely unavailable at the end of the year [41].

Travel Issues

Travel emerged as one of the most pressing barriers to VHA utilization. Nearly all interviewees experienced travel-related barriers, with long distances to the VHA and cost issues frequently mentioned. These Veterans also cited bad weather and lack of a working vehicle as major barriers to care.

Distance to the VHA Rural Native Veterans often live at considerable distance from VHA facilities. Long distances to the VHA were especially problematic for Alaska Native Veterans, as travel involved a flight on a "bush plane," an expensive and time-consuming endeavor. Consequently, most Veterans living in rural areas of Alaska did not use the VHA at all. IHS or tribal health facilities, on the other hand, were relatively close and easy to reach. A 45-year-old female Alaska Native Veteran her experience traveling to the VHA: "[The VA is] over 400 air miles [away]. We have to do a flight. In the summertime we could use a boat, or a snow machine in the winter, but we [typically] fly in and out in little airplanes."

Travel Costs The cost of travel to appointments was often a barrier to VHA utilization. For example, the Alaska Native Veteran quoted above noted that each trip cost \$400, which she found prohibitively costly. Similarly, a 79-year-old male Veteran described how travel costs limited his use of the VHA: "We try to limit our trips to [the VHA in the nearby city] as much as possible. You know, the 60 miles is not a long ways but when you're talking about gas and wear and tear on my vehicle, it does add up. So, we don't go unless we

have to." Multiple factors were involved in VHA travel costs, including gas (or airfare), overnight stays, meals, and wear and tear on vehicles. This point was illustrated by a 51-year old female advocate:

I think just the lack of good transportation. Like they may have a vehicle at home, and it may just be good enough to travel locally but not to [the VHA in the nearby city]. Reliable transportation or sometimes it's just money. They may not have gas money. It takes money to go to an appointment even though it's just to an appointment and coming back, considering having to pay for gas and food.

Given prohibitively high travel costs, some Veterans expressed a need for the VHA to cover their transportation costs. One 53-year-old male Veteran stated: "If the VA could expand to cover transportation costs, that would be a great thing, especially at the preventative level, before we have to throw [the Veteran] into an ambulance to get specialized care." As alluded here, inability to access care in a timely manner could have dire and costly consequences. While in fact travel costs can be reimbursed in many situations [42], many Veterans did not know if their costs could be covered or how to initiate the process of reimbursement.

Weather Issues Travel plans were often affected by weather. Many participants lived in areas with treacherous roads that were not promptly treated in the winter. Bad roads added to already long travel times, as made clear by this 47-year-old female advocate: "[A road on the route to the VA] doesn't usually get that bad where it's closed, but it's pretty dangerous. And you have to allot like an extra hour for travel time if it's in the wintertime." When weather issues necessitated canceling appointments, Veterans worried that appointments would not be rescheduled in a timely manner. Issues of this nature, especially in hazardous conditions, rendered local IHS/tribal health options more appealing.

Lack of Transportation Access to a reliable working vehicle was necessary for Veterans to be able to attend VHA medical appointments, as the rural areas they lived in did not have public transportation. Some Veterans lacked vehicles that were adequate for long-distance trips, as noted by this 71-year-old male Veteran: "I think the number one challenge is transportation and mobility for some people. Maybe they don't drive for whatever reason. Maybe they don't own a vehicle. But that's going to be key." Given these challenges, family members were often essential for accessing VHA care, providing transportation and attending medical appointments. This 51-year-old male family member described his role in making VHA appointments happen: "I make sure he's up on all his appointments. As far as his health care, mentally and physically, I give him his medicine, take him to his appointments when I can or arrange for somebody [else to do so]. But I usually have to be there with him." Absent familial assistance, many Veterans were unable to access VHA care.

Bureaucratic Obstacles

Participants identified a variety of bureaucratic issues within the VHA system that created difficulty in accessing services, including poor customer service, scheduling issues, and long waits for appointments.

Customer Service Issues Poor customer service was frequently cited as a barrier to using the VHA. A 57-year-old female family member described the VHA this way: "It's like the right hand doesn't know what the left one is doing and everything's an automated system." An example of poor customer service was provided by a 38-year-old female Veteran:

I just filed all the paperwork. I got all my confirmations. I submitted it and then they're like, 'Oh, we don't know what happened. It got lost.' 'Well, I have the confirmation.' 'Well, you've got to do it again.' 'OK, I got it saved, here it is.' You know, I could file it three times and they'd still lose it.

Similarly, a 73-year-old male Veteran described his experience attempting to access a VHA crisis line:

So as far as my disability, I sometimes go through a lot of difficult times, and so they gave me this number for Veteran's services. It's an 800 number and I called a crisis line. And it's not too helpful because they put me on hold for more than fifty minutes. And I tried it several times. But then I just kind of felt disappointed that I was given information about what they do but none of them was able to help me. They just always said that the representatives were busy so I just quit calling them.

This Veteran's story points to the demoralization that occurs when one is unable to traverse the VHA system despite repeated attempts. This is especially concerning given that the service the Veteran could not access was a mental health crisis line.

Appointment Scheduling Problems and Long Waits Challenges with scheduling and rescheduling deter use of the VHA. One 56-year-old male Veteran described his foiled attempt to schedule a VHA appointment:

They do have the software or the website where I can go in and set up my appointment, but I put in a request to schedule an appointment and it didn't work through the website. So I called them directly and three weeks later, I still haven't heard nothing. So bad communication between the Veteran and the VA.

Even when contact was successful, participants such as the following 51-year-old male Veteran often experienced long waits for appointments: "You won't get it scheduled for like, maybe-my next one's in June. Even after I did all the other requirements, blood work, CT scans, all that, the nerve test, I still can't get an appointment until June. So that's the frustrating thing." Should a Veteran need to reschedule an appointment (e.g., for inclement weather), he again faced long waits. One 68-year-old male Veteran tried to reschedule a missed appointment and was told that the soonest he could get in was "two weeks out to two months out."

Given the great difficulties Veterans experienced with VHA systems, family members, like this 57-year-old woman, were crucial to getting Veterans needed care:

I just said, 'He's 40 percent disabled, you know, he's 73. I'm not sure what you guys are expecting of us. What do we need to do to get a CPAP [machine to treat sleep apnea]?' So then the lady called me back like the next day from the pulmonologist and says he should have it by December 22nd. And I said, 'OK.' I said, 'If it's not here by the 22nd, I'll be calling you after Christmas, and I'm going to want your supervisor's supervisor.' I'm tired. I'm scared...

This family member's statement alluded to the emotional toll of dealing with the VHA as well as the importance of family advocacy.

IHS and VHA Services Use and Decision Making

As federally recognized tribal members, all the Veterans we interviewed qualified for care at the IHS and/or tribally supported health clinics. The fact that the IHS or tribal health programs were available was the backdrop to Veterans' decision-making regarding the VHA. Nearly half (9/20) of the Veterans we interviewed never used the VHA; the remainder sought care from the VHA either some of the time or regularly. Reasons for non-utilization of the VHA included satisfaction with IHS/tribal health care, easy access to IHS facilities relative to the VHA, VHA navigation and care continuity issues, and concerns about the coordination of dual use of the VHA and IHS/tribal health systems.

Satisfaction with IHS/Tribal Health Care

Some Veterans were more comfortable utilizing the IHS/ tribal health system than the VHA and felt that all their care

needs could be met there. This 76-year-old male Veteran used the IHS because it worked well for him: "I just go to Indian health, and they take care of my problem. I have no problem with Indian health and Medicare." A 69-year-old male Veteran valued the continuity of care he received at his local tribal health center: "It would be nice if that same doctor was there the next year and the next year, so they become your personal doctor so they can know your symptoms. And that's why I use my medical doctor at [the tribal clinic]. Doctor [name] has been my doctor for the last almost 20 years now, so she knows me from the time I was diagnosed with diabetes to where I am today." These Veterans were satisfied with their care at the IHS/tribal health system and did not feel a need to go elsewhere.

Relative Proximity of IHS and VA Facilities

Many Veterans lived relatively close to IHS/tribal health facilities but far from the VHA. A 56-year-old male Veteran wanted to use the VHA but found the IHS to be closer and more convenient:

I will go to the Indian Health Service primarily because [Natives are] the focus. And if I really need help, that's where I would go. But I would prefer to go to the VA. But it is very difficult because the only nearest Veteran healthcare place is in [nearby city] and it is about a 45-minute drive and it's by appointment only.

In addition to physical proximity, the IHS had the advantage of specializing in the care of Native patients.

VA Navigation Challenges

Many Veterans, such as this 45-year-old woman, found the IHS/tribal health care easier to navigate than the VHA: "I never went to the VA because it's so hard to navigate. 'Call this number.' 'Oh no, you got to call this number.' 'Oh no, you got the wrong office. Call this number.' So, it's not even worth it. I would just rather stick with [tribal health care Center] down in [regional hub]." In this Veteran's view, attempting to work through the complexities involved in accessing VHA services was not worth the hassles incurred by such an attempt.

Lack of VHA Provider Continuity

Quality of care issues, specifically lack of care continuity, were experienced at VHA, as described by this 69-year-old male Veteran:

I have one doctor at the VA that I see once a year or so. And he is the same doctor that I've had for the last three years now. But before that, I was having a doctor every six months at the VA, and that's the hardest thing. You know, you can't have a real personal doctor when they're swapping out every so often.

A 57-year-old family member described a similar experience with the VHA: "I don't know how many of these Veterans go through providers. [My husband], in probably the 17 years that we've been together, he's gone through 11 providers over there, so there's no continuity of care. And I just felt like it was more about volume for them than it was quality of care." Discontinuity of care meant impersonal care, whereas Veterans prized stable and long-lasting relationships with providers.

IHS-VHA Care Coordination and Reimbursement Concerns

Many Veterans did not understand how reimbursement arrangements and/or referrals worked between the VHA and IHS/tribal health. This was especially true of this 62-year-old female Veteran:

See, I really don't know how [things are] coordinated between the VA and in the tribe. You know, who's the primary payer? And this is where I don't know how that works. Because our clinic requires that we have a referral from [the VHA] in order to be eligible for contract health services. That's outside of the clinic. And it's my understanding that the tribe would be a secondary payer on any referred bills, but it sounded like I'd still have to be referred from the clinic. I don't know.

Another Veteran, a 57-year-old man, tried using the VHA but was concerned about inconsistent IHS-VHA care coordination:

So, you know, we go back to the Indian Health Service, which isn't bad. But it was nice having to go to see a primary care provider through the VA so that should anything happen to me, my medical records would be up to date. And, you know, I've had instances where I had to be hospitalized. And often when you don't have a clear medical background history and there's no shared information with the Indian Health Service, then it becomes difficult.

Given the uncertainties related to using both systems, these Veterans preferred the IHS/tribal health for simplicity's sake.

Barriers to VA Enrollment

Many Native Veterans participants were greatly concerned about VA enrollment. Because of the project's focus on healthcare provision, the interview guide did not include specific questions about VA enrollment, but many participants independently introduced the topic. Participants often discussed challenges they or others experienced in trying to enroll in the VA, including lack of knowledge about eligibility, how to get enrolled, lack of experience completing paperwork, and a need for assistance with enrollment and paperwork.

Lack of Knowledge About Enrollment Many Veterans found the complexity of the VHA and VHA benefits unclear and daunting, as made clear by this 62-year-old female Veteran: "I don't really understand the benefits. I just got my benefits handled or whatever, but I didn't have a chance to go through it yet. And I don't know how this whole thing is going to be coordinated or how it's going to work." Some interviewees stated that lack of knowledge (e.g., of benefits available) keeps some Veterans from enrolling in and using VHA services, as made clear by this 47-year-old female Veteran:

As a young Veteran, when I was younger, I didn't even realize I was eligible for services because I thought you had to be a combat Veteran to be eligible for anything. But I didn't know for the longest time until I came across someone at the office that was a Veteran, 'No, you have all these benefits you're not utilizing.'

The belief that combat experience was required for VHA use is just one example of the many knowledge gaps held by Veterans.

Lack of Experience with Paperwork Veterans described not being used to doing their own paperwork as while in the armed services it was done for them by others. Once out, Veterans were then expected to navigate enrollment on their own and many were unprepared to do so. One 45-year-old female Veteran provided her perspective on this: "If we had a navigator to do all the paperwork and all the phone calls for us, I don't think we would have a problem. But if they tried to make us do it ourselves, I think that would be a whole another world of pain." This quote illustrates the great desire expressed by many to have someone help with paperwork.

Need for Assistance with Enrollment Help filling out enrollment paperwork was described as an essential and greatly needed service. Some tribes had local champions—sometimes volunteer, sometimes paid by either the VA or the Tribe—who were described as good models for how to get Veterans connected to VA services. These individuals provided direct VA outreach and enrollment assistance to communities. One 71-year-old man who was both a Veteran and an advocate described the Tribal Rural Veteran Representative Program [12] as very helpful:

....The Tribal Rural Veteran Rep Program....It's a real good program....It's a volunteer program [that] I got

involved with. I got involved with it after I retired from my career. And what it is, it was trained volunteers to work with Veterans with filling out the paperwork.... You know, the paperwork can be daunting, even the simplest forms and the shortest forms for some people. And this was a program that really helped Veterans just to get over that hurdle.

Enrollment was the primary barrier to accessing the VA, and according to participants, the key to overcoming it is direct outreach combined with paperwork assistance.

Discussion

Overall, participants were enthusiastic about the potential for a navigator program designed specifically for rural Native Veterans. However, this enthusiasm was couched in terms of the numerous barriers Veterans currently face; to be successful, a navigator program will need to effectively address these obstacles. One of the most pressing barriers was becoming enrolled in the VA in the first place, related to lack of knowledge about the enrollment process or needing help with paperwork. Some Veterans did not think they had enough need relative to other Veterans to justify use; these Veterans believed that using the VHA would take services away from more needy Veterans. Travel-related barriers were ubiquitous, with long distances to the VHA and travel cost discussed the most, followed by weather issues. Participants wanted the VHA to cover travel-related costs and to help them navigate the travel reimbursement process. Most did not understand VHA systems or how these systems would be coordinated with IHS/tribal health systems. Rescheduling appointments and travel compensation were difficult at the VHA but comparatively easy at the IHS/tribal health systems. VHA bureaucratic issues, including poor customer service and scheduling issues/long waits, also deterred utilization.

When deciding what system to utilize for care, Veterans engaged in a calculus that took into consideration several factors, including satisfaction and familiarity with the IHS/ tribal health care, proximity of IHS/tribal health facilities, ease-of-access/use, concerns about the coordination of dual use of the IHS/tribal health care and the VHA, specialty or primary care, and care continuity. In the end, many Veterans preferred IHS/tribal health care for all or some of their care. IHS/tribal health systems' proximity, simplicity, ease of use, and good quality of care were juxtaposed with the VHA's distance, complexity, access and navigation challenges, and poor customer service. Despite the interest of some Veterans in using the VHA, they found daunting the myriad of issues they encountered and were thus dissuaded from using it. Given the history of inadequate funding for the IHS, resulting in care rationing [43], it is notable that these Veterans found it superior to VA Health.

This study echoed and elaborated earlier findings regarding paperwork, travel, care coordination challenges, and lack of available care [23, 24, 26, 28, 30, 35, 44, 45]. Compared to previous studies [20, 29], this project's participants placed less focus on perceived VA care unavailability or inadequacy and cultural insensitivity, but great emphasis on enrollment, travel, and customer service barriers. The inclusion of Alaska Native Veterans in this sample, many of whom experience travel barriers far beyond their continental US counterparts, may partially explain this, as did the fact that nearly half of Veteran participants did not use the VA. Many customer service and scheduling issues described by the participants' involved frustrated attempts to access care. This picture is consistent with a participant sample comprised of many individuals who were challenged to overcome barriers to VHA use.

Study Strengths and Limitations

This study provides unique insight in rural Native Veteran health care since it draws on three different perspectives (Veterans, family, advocates) from Tribal communities across the nation. The interviews were also completed during the COVID-19 pandemic, laying bare the frail health and wellness infrastructure of many communities, and the devastation of the pandemic across tribes. The interviews, all conducted with a Native interviewer which likely engendered trust among participants, also revealed the commitment and care Native communities had for Veterans-and Veterans for each other. These community ties the VHA facilities would do well to acknowledge and leverage in care plans. While these study strengths provide a robust and insightful view into health care for Native Veterans, the results should be considered with some care. Our findings are based on the views of a relatively small number of Native (largely older male) Veterans, family members, and advocates. While the participating communities represent a broad sample of cultural and regional tribal diversity, the results nonetheless may not generalize to other segments of this population. The requirements for participation in our project likely narrowed the range of types of participants included. All participants needed to accurately fill out paperwork that included personal information and to mail these documents to the VA. They also needed to have bank accounts and mobile phones. Thus, these participants may have been better financially resourced and more trusting of the VA and US Postal Service than non-participants. Veterans with fewer resources and greater distrust of federal systems might have identified even different challenges and unmet needs. Also, our interviews took place during the COVID-19 pandemic. Local

conditions and additional COVID-19-related hardships may have affected who was willing and able to participate.

Recommendations

The barriers identified by participants are not new and have been cited in many previous studies [20, 22–28, 30–32, 32–35, 46]. Their persistence, however, heightens the need for action. A patient navigation program, created with and for rural Native Veterans, would be well-poised to address many of these barriers, and thereby promote appropriate help-seeking, improve access to care, and disrupt longstanding impediments to enhancing the health and wellbeing of this special population.

Given their general satisfaction with the IHS/tribal health systems, rural Native Veterans such as these interviewees must see a clear benefit to using the VHA to attempt to overcome the multiple obstacles to its use. Factors that rural Native Veterans consider essential to address include the relative merits of each health system, travel and cost considerations, ease of scheduling and navigating VHA appointments, availability of paperwork assistance, perceptions of care scarcity, VHA-IHS coordination, and VA eligibility and enrollment processes. Each element, separately and collectively, undergirds both the challenges and potential success of a navigator program.

Participants highlighted key elements of what a navigator program should (and should not) look like. Their concerns and preferences offer a roadmap for how to operationalize specific elements and design features in a navigation program created specifically for rural Native Veterans and those who help with their care (Table 3). Rural Native Veterans need continued assistance navigating VHA systems, including enrollment in specific services, cost reimbursement, and care coordination with the IHS/tribal health, to realize the benefits due them. If expected to tackle these systems on their own, many rural Native Veterans will abandon the search for care and potentially suffer adverse consequences. Navigators must stress that severe injuries and disabilities are not required to use the VHA and that their use of this care will not negatively affect the services available to more severely impaired Veterans.

Resolving travel and travel reimbursement issues is key to service utilization. VHA-provided or supported transportation with convenient schedules would be especially helpful for many Veterans. Criteria for and the process of travel reimbursement are complex; Veterans would benefit from assistance parsing through these details. Since many Veterans cannot access VHA services alone, acknowledging and supporting the important role of families in this process is necessary. Once the Veteran contacts the VHA, it is crucial they receive a timely response, preferably from a human being rather than an automated system. Time and

| Identified barrier | Patient navigator (PN) program strategy | | | | |
|---|---|--|--|--|--|
| Perception of care scarcity and severe disability requirement | PN emphasizes care as an earned benefit regardless of disability severity | | | | |
| Travel distance and travel costs | PN knowledgeable about travel options and local transport resources, reimbursement policies, and required paperwork | | | | |
| VHA customer service: schedul- ing, re-scheduling, paperwork | PN facilitates appointment scheduling; is able to shepherd paperwork through system and troubleshoot problems or delays | | | | |
| Completing paperwork | PN assists with forms, facilitates timely submission, helps to orient Veteran/family to process | | | | |
| Health care provider discontinuity | Each Veteran assigned same PN over time; PN completes detailed computerized documentation to familiar- ize substitute navigators with case | | | | |
| VHA-IHS care coordination | PN program to support IHS coordination/referral as appropriate given IHS-VA MOU status and information sharing agreements | | | | |
| VA eligibility and enrollment | PN facilitates referral to local VA eligibility and enrollment experts | | | | |

Table 3 Identified barriers to VHA care and navigation program mitigation strategies

again participants underscored the importance of meaningful relationships with caring, supportive VHA staff and providers. Continuity of care is critical to utilization. Access to the same navigator and care provider cements therapeutic alliance, feelings of trust, and satisfaction. For many rural Native Veterans, even one encounter with poor customer service or discontinuous care is often dissuade future engagement with the VHA. Such encounters are demoralizing and lead to "giving up" on the VA.

Finally, enrolling eligible Veterans into the VA, including in VHA benefits, was a major concern of the participants. VA eligibility criteria can be complex, confusing, and time consuming, often requiring support from someone with expertise or training in VA enrollment. As a VHA-based project, our intent was to focus on the healthcare experience through *patient* navigation and not *enrollment* navigation which is managed by the VBA. VA enrollment is typically undertaken by trained individuals within the VBA; a state, county, or tribal Veteran Service Office; or a Tribal Veteran Representative [12]. A successful program will need to ensure navigators can facilitate and collaborate on referrals to other organizational components and individuals with expertise in enrollment processes.

Finally, while the focus of the interviews were barriers to care, the implications for clinical care are readily discernible. While accessing care is the first step in care, the experience in the clinic is as important: cultural respect, the ability for clinicians and clinic staff to account for unique care preferences and experiences of Native Veterans, and provider ability to seamlessly connect Native Veterans to resources within the VHA as well as those in the Veterans' community will advance health and wellbeing for that Veteran who, in turn, may then encourage others to access VHA care.

In summary, healthcare navigators, such as those to be envisioned by the VHA patient navigation program for rural Native Veterans, promise to help Veterans anticipate and circumvent many of the barriers identified here, providing essential information (and referral as necessary) on enrollment, travel reimbursement, service availability, and scheduling/rescheduling. Most importantly, navigators serve as guides, imparting personalized attention, affective support, and entry into and through an often impersonal and confusing bureaucracy.

Author Contribution All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Lori Jervis, Keith Klezynski, and Gloria TallBull. Carol Kaufman and Jay Shore were involved in project conceptualization, tribal recruitment, and editing. The first draft of the manuscript was written by Lori Jervis, and all authors commented on subsequent versions of the manuscript. All authors read and approved the final manuscript.

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Data Availability Data cannot be shared publicly because they are owned by the sovereign American Indian and Alaska Native nations of participants and the VA. Data can be requested through the respective governing entities of each tribal nation and the VA. Specific approving tribal entities are not named here to protect community confidentiality, as requested by participating sites. However, we will assist in investigator requests for data via appropriate tribal and VA channels. Please contact Carol Kaufman, Centers for American Indian and Alaska Native Health, Colorado School of Public Health, MS F800, 13,055 E 17th Avenue, Aurora, CO 80045, 303–880-7795 (c), carol.kaufman@ cuanschutz.edu.

Code Availability The project's codebook will be shared upon request.

Declarations

Ethical Approval The VA Salt Lake City Health Care System reviewed the protocol and assigned the project a determination of non-research status.

Consent to Participate Informed consent to be recorded was obtained from all individual participants included in the study. While not a research project, all participants were apprised of the risks and benefits of participating, that they could stop any time and that they were free to decline to answer any question. Tribes agreed to participate on a tribal level and assisted with recruitment.

Consent for Publication Participants consented to having their deidentified data utilized for publication purposes.

Conflict of Interest The authors declare no competing interests.

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