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Producing insecurity: Healthcare access, health insurance, and wellbeing among American Indian elders

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Abstract

Although health care is a treaty-guaranteed right for members of federally recognized tribes, decades of research describe persistent disparities in health and access to health services for American Indians. Despite gains in insurance enrollment after the passage of the 2010 Affordable Care Act, underfunding of the Indian Health Service and national debate over the new health law contributes to insecurity, especially among the majority of American Indians aged 55 and older who rely on public insurance. We consider the production of insecurity surrounding health care for American Indian elders, analyzing its pragmatic and affective consequences. Between June 2016 and March 2017, we conducted 96 quantitative surveys and in-depth qualitative interviews with American Indian elders aged 55 and older in two states in the U.S. Southwest. Interviews were recorded, professionally transcribed, and analyzed iteratively using open and focused coding. We found that elders consistently shared discourses of doubt, fear, and uncertainty that centered on: 1) interactions with healthcare providers and facilities, especially the IHS; 2) calculations regarding health insurance and the potential costs of healthcare services; and 3) dynamics at the national level around health policy, particularly for American Indians. We argue that persistent perceptions of healthcare insecurity present a major barrier to wellbeing that remains unaddressed by existing health policy interventions for this population, which focus predominately on individual-level knowledge and behavior.

Keywords

American Indians; Health bureaucracy; Medicaid; Affordable care act; Health policy

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Author contribution

Elise Trott Jaramillo: Formal analysis, Investigation, Data curation, Writing - original draft, Project administration
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Availability of data and materials

The data that support the findings of this study are available from the principal investigator upon permission from the Southwest Tribal Institutional Review Board and the tribal nations participating in this research.

Declarations of competing interest

None.

1. Introduction

Throughout the fraught national debate over the 2010 Patient Protection and Affordable Care Act (ACA), relatively little popular or scholarly attention has been paid to the law's effects on American Indian people in the United States (U.S.). Despite a common misconception that the health needs of American Indians are entirely met by the Indian Health Service (IHS), research documents persistent disparities in access to health care and health insurance for this population that the ACA purported to address (Warne and Frizzell, 2014). Among elements intended to close longstanding racial gaps in insurance coverage (and consequently, healthcare access), the ACA offered specific provisions for American Indians that opened up the possibility of long-awaited improvements to the chronically underfunded and under-resourced healthcare system on which American Indians rely (Artiga et al., 2017). At the same time, the passage and implementation of the law took place in a pervasive national atmosphere of strife over social safety net programs in general, and health care in particular. As the 2016 presidential election loomed, the future of the ACA, as well as Medicaid, appeared increasingly precarious.

In the summer and fall of 2016 and spring of 2017, as the national discussion about public health insurance programs was near its peak, we engaged in lengthy conversations with American Indian elders about their experiences with health care and health insurance. Although these elders reported rates of insurance coverage and access to healthcare services that met or exceeded the national average, they also expressed a common set of fears about their ability to get the care they needed. For example, when asked whether she had been affected by the passage of the ACA, one elderly woman reflected, "Not really, but in the back of my conscious[ness], I'm thinking about: What if it [the ACA] gets taken away and we do need it?" She then noted that she was considering enrolling in a Medicaid managed care plan, but that state- and national-level discussions about introducing co-pays for Medicaid enrollees gave her pause:

I've been wanting to get on it but I've been hesitant about it, so if they [benefits enrollment counselors] can help me go through it then I think I can. But it's the copay I think I'm afraid of. Then I guess in our traditional ways... why go through all of that when everything is alright?... [I]n our mind, we still got to take care of ourselves.

As she thought about the ACA, this woman expressed a number of interconnected fears about the future: Would she need health care? Would the care she needed be available when she needed it? Should she enroll in a health insurance plan and if she decided to do so, would she be able to figure out the enrollment process? What would it cost? The urgency of these questions was heightened by her awareness of public debates that threatened to eliminate options and introduce new costs. These fears, in turn, were followed by twin sentiments that would become familiar over the course of our conversations with elders: That the effort involved in navigating healthcare and insurance systems was both difficult and potentially futile ("Why go through all of that?"), and that ultimately, elders were left in the dark and on their own ("We still got to take care of ourselves").

This article explores the nearly ubiquitous circulation of such expressions of doubt, fear, and abandonment that characterize American Indian elders' interactions with healthcare and insurance systems. Drawing on anthropological theories of bureaucracy and insecurity, we argue that despite some apparent advances in healthcare access for American Indian elders, the prospect of navigating the healthcare system creates a pervasive atmosphere of instability and exhaustion that deepens and perpetuates health disparities for this rapidly growing and already underserved population, an effect that is only aggravated by the ongoing national debate over the ACA and public insurance programs in general. Although the majority of existing health policy interventions for this population focus predominantly on individual-level knowledge and behavior, we contend that the health system in fact produces the lack of knowledge that we call "health illiterate." Consequently, addressing health and healthcare inequities for American Indian elders will require long-term provider- and system-level changes to secure the collective right to health care for American Indians and transform the experience of help-seeking and care for this population.

1.1. Health care for American Indian elders after the ACA

In exchange for land and natural resources ceded to the U.S. government, members of federally-recognized tribes have a treaty-guaranteed right to receive available healthcare services at IHS and tribally-run facilities at no cost and without health insurance (Skinner, 2016). Yet, decades of research describe major disparities in health outcomes and access to health care and insurance for American Indian people. American Indians are affected by higher rates of illness and mortality compared to their White counterparts. This includes disproportionate incidences of stroke, heart disease, hypertension, diabetes, obesity, and mental health problems, as well as higher rates of cancer mortality and suicide (Herne et al., 2014; IndianHealth Service, 2015; Schieb et al., 2014; White et al., 2014). Like other indigenous populations, American Indian elders are second only to African Americans in prevalence of dementia (Mayeda et al., 2016), and have a lower life expectancy than all other aging populations in the U.S. (Espey et al., 2014).

These disparities are due in part to the severe and chronic underfunding of the IHS, which provides services to 2.56 million American Indians and Alaska Natives (Indian Health Service, 2020). The IHS is not an entitlement program, like Medicaid or Medicare; rather it depends entirely on direct funding appropriated from year to year by Congress, which has never been adequate to meet the needs of American Indian people. In 2017 for example, the per capita healthcare expenditure for the general U.S. population was \$9,726, compared to only \$4,078 for IHS patients (Indian Health Service, 2020). Indeed, IHS patients receive less healthcare funding than users of Medicaid, Medicare, and the Veterans Administration, as well as federal prisoners (Skinner, 2016). Consequently, IHS facilities are unable to provide comprehensive healthcare services. Although referrals for services not available at the IHS are made through its Purchased/Referred Care (PRC) program, coverage through PRC is regularly limited to those medical treatments necessary to preserve "life and limb," so that American Indian people are accustomed to going without recommended treatments to avoid facing major medical bills (Fox, 2011; Skinner, 2016).

These limits particularly impact the rapidly growing population of older American Indians who are likely to need more frequent, complex, and expensive care as they age (Goins et al., 2007). Elders make up an increasingly large proportion of American Indian communities, with the percentage of American Indians and Alaska Natives aged 65 and older projected to increase from 5.6% in 2000 to 13.4% in 2030, compared to an increase from 12.4% to 20.3% in the overall U.S. population (a relative increase of 139.3%; U.S. Census Bureau, 2000; U.S. Census Bureau, 2012). Yet, inequities in physical and mental health persist for elders, even among those with access to Medicare. Moreover, although the ACA re-authorized the 1976 Indian Health Care Improvement Act (IHCIA), which included language authorizing hospice, assisted living, long-term, and home- and community-based services that elders need, Congress has never funded the IHS to provide such services. Instead, American Indian elders must rely on a “patchwork” of funding sources and state and federal programs that provide health and social services to older people (Bylander, 2018).

The ACA included major provisions intended in part to improve access to health care for American Indian people. In addition to the establishment of unlimited enrollment periods for American Indians to purchase health insurance, the law’s re-authorization of the IHCIA also protects the ability of the IHS to first bill Medicaid, Medicare, and other private health insurance providers for patients’ care before acting as the payor of last resort. Perhaps most importantly, the law expanded Medicaid eligibility to adults at or below 138% of the Federal Poverty Level, including large numbers of previously uninsured American Indians. In states that accepted the expansion, IHS facilities were thus able to anticipate an infusion of new funding from IHS users who were newly eligible to enroll in Medicaid. Given the chronic underfunding of the IHS, many IHS facilities and tribes undertook significant efforts to perform outreach, enroll tribal members in health insurance plans, and encourage members to use this coverage to pay for care. In fact, in the years after the passage of the law, uninsured rates among American Indian people fell from 23% to 15% in states that accepted the Medicaid expansion (Artiga et al., 2017).

In the wake of these changes, a group of American Indian healthcare advocates approached our research team with the concern that elders in their local communities remained woefully underserved. The analysis in this article is part of a resulting mixed-methods study on healthcare access and utilization among American Indian elders in two states in the U.S. Southwest (Willging et al., 2018). The study engaged elders, healthcare providers, outreach workers, tribal leaders, and administrators of government agencies and public-sector healthcare systems responsible for providing care to elders in quantitative surveys and qualitative interviews focused on how elders understand, use, and experience health care and health insurance. Here, we specifically examine discourses of fear, doubt, and uncertainty that emerged as particularly salient in elders’ descriptions of their experiences of the healthcare system and deliberations about the care they needed, now and in the future.

2. Methods

In keeping with community-engaged approaches to conducting research with indigenous peoples (Brave Heart, 2016), this study was conceptualized and designed in collaboration

with a group of American Indian elders and allies called a Community Action Board (CAB). The members of the CAB have overseen each step of the research, including creating and reviewing data collection instruments and procedures, assisting with recruitment, and interpreting findings. Secondly, we paired researchers with 12 American Indian elder “consultants” who were fluent in languages likely to be spoken by potential research participants and had histories of community involvement. These consultants assisted with data collection to increase local participation and enhance the cultural and linguistic relevance of the study. A full description of our community engagement approach can be found elsewhere (Willging et al., 2018).

Between June 2016 and March 2017, as part of the larger parent study (Willging et al., 2018), we conducted semi-structured in-depth interviews with 96 American Indian elders, aged 55 and older. Although age 65 is used to delineate older people as a group for Medicare and Social Security eligibility, age 55 is considered a more appropriate threshold for elderhood among American Indians by the Indian Health Service (Hendrix, 2010) and major elder-serving advocacy organizations, including the National Indian Council on Aging and the National Council of American Indians. This earlier threshold reflects in part the cumulative effects of historical trauma and stressful life experiences on aging (Palacios and Portillo, 2009). Participants were recruited during regular visits to American Indian senior centers, community health fairs, and meetings of other elder-serving organizations. The interviews were administered in English, although participants were given access to elder consultants fluent in their indigenous languages if they so desired. In accordance with the official written informed consent document, pertinent identifying features (e.g., names, locations) are withheld from the data reported here. The sampling method, research design, and consent procedures were approved by the Southwest Tribal Institutional Review Board.

The interviews included a quantitative survey to obtain information about demographics, education, health and socioeconomic status, health insurance, and healthcare access, utilization, barriers, and satisfaction. We then used a semi-structured interview guide to ask elders a series of open-ended questions about their perspectives on wellness and interactions with health care and health insurance, including their knowledge of and any experiences with the ACA. We also asked elders about their confidence in their ability to access care if they needed it, as well as in the ability of the IHS and their health insurance to cover the costs of their care (e.g., “How confident are you that PRC would cover the costs of your care if you need it?”).

The interviews were conducted in person and lasted between 60 and 90 minutes. They were audio-recorded and professionally transcribed. We then analyzed the transcripts iteratively, using a combination of open and focused coding techniques. First, we assigned codes to segments of text ranging from a phrase to several paragraphs based a priori on the topics and questions in the interview guide as well as key sensitizing concepts from the literature on American Indian health care (e.g., “trust,” “help-seeking,” “system navigation”). These concepts provided “a general sense of reference” and supplied descriptive data based on the words of elders, enabling us to examine their salience and meaning (Patton, 2015, 545). Second, we used open coding to locate new themes and issues related to elders’ experiences seeking out and using health care and insurance (e.g., “provider turnover,” “obstacles to

care”) and focused coding to determine which themes emerged frequently or represented particular concerns (Corbin and Strauss, 2014). We grouped codes with similar content into broad themes linked to segments of text (Corbin and Strauss, 2014; Glaser and Strauss, 2017). The themes presented here emerged both as especially common among elders and as appearing to have particular weight in their experiences and decisions about health care.

For our interpretive process, we shared our preliminary analyses of the interviews with the members of our CAB, who then assisted in interpreting the significance of the findings. The CAB members also reviewed and provided feedback on the specific findings presented here, thus “grounding” our analysis in data through an iterative process of drawing out themes and sharing them with the CAB for guidance (Glaser and Strauss, 2017).

3. Results

The elders we spoke to for this study came from a number of different tribal backgrounds and resided in both reservation and non-reservation settings. The majority (88.5%) used the IHS or another tribally-operated program for their medical care at least some of the time. Our interview participants were predominantly women (70.8%) and they ranged in age from 55 to 89 years with an average age of 67 years. All participants identified as American Indian; 17.7% also identified as being of Spanish, Hispanic, or Latina/o origin. The vast majority of elders (97.9%) reported that they had health insurance at the time of the interview, largely via public insurance programs (i.e., Medicaid and Medicare). Most also reported that they had a place they usually went when they were sick or needed advice about their health (91.7%) and had seen or talked to a doctor about their health within the previous six months (89.6%). Of those who had a usual place to go for care, 66.7% indicated that this place was run by the IHS or a tribe. When asked directly in qualitative interviews, few indicated that there were healthcare services that they needed that they had not been able to get or that they had experienced any problems paying for health care in the previous year.

Yet, as they reflected on their experiences with healthcare systems and thought about the future for themselves and their families, the elders we interviewed often communicated doubt, fear, skepticism, confusion, and uncertainty about the availability, affordability, and reliability of health care—emotions that reportedly contributed to decisions not to pursue care that they wanted or needed. As we describe in the following sections, this dearth of confidence revolved around three thematic areas: interactions with healthcare providers and facilities, especially the IHS; calculations regarding health insurance and the potential costs of healthcare services; and dynamics at the national level around health policy, particularly for American Indians. In each of these areas, elders described a sense of insecurity in their ability to rely on vital resources and support systems. While the majority of these comments came from elders enrolled in Medicaid and Medicare, mirroring the enrollment status of our entire sample, expressions of insecurity emerged from individuals across a range of health and insurance statuses.

3.1. “Nobody knows anything”

In the quantitative survey portion of our interviews with elders, the majority of elders reported that they were either very satisfied (43.8%) or somewhat satisfied (31.3%) with the

health care they had received in the previous year. Nonetheless, when we asked elders to discuss their experiences with health care in more depth, many voiced doubts or confusion about whether they could fully trust their healthcare providers. For example, one woman wondered about conflicting information that she had received about medications, musing, “Sometimes when you read something or you go to a health session, they’ll tell you a certain medication is good, and then you go to [the IHS] and ask and they say, ‘I don’t recommend that you take that.’ Sometimes I wonder, ‘Should I take it or just believe him and not take it?’” Elders often worried that their healthcare providers over-prescribed medications or were not paying attention to the medications that they were taking. One individual confessed that he had quit taking one of his prescriptions without telling anyone, commenting, “When I had my heart surgery, the doctor... told me, ‘I just gave you 25 more years.’ So I think about wanting to have a long life, so then why do I need all these medicines that I’m taking?”

Many of the elders we interviewed expressed suspicions about the trustworthiness of healthcare facilities and providers based on the experiences of friends and family members. They recounted stories of incorrect diagnoses or denials of care that seemed to loom large in decisions about their own care. For example, when asked about her level of confidence in the place she went for health care, one woman commented, “I know a lot of people complain.” Another elder related that, “The doctor wanted me to [test my blood sugar] but I said no because I know that nationwide, a lot of Natives have become diabetic all at once. I just said, ‘I can’t get on insulin. I don’t want to get on insulin.’” Other elders were simply overwhelmed by the prospect of verifying that they were receiving the appropriate care, such as one woman who resignedly explained, “[Healthcare providers] always ask, ‘Do you have any questions?’ Then I said, ‘I don’t know this enough to ask any questions.’”

Even among elders who liked and trusted their healthcare providers, most appeared to share a sense that they could not always count on care being available when they needed it. Two nearly ubiquitous concerns were turnover among healthcare providers and unexpected changes in available services and facilities. In an exemplary comment, one elder reflected back on the different doctors she had had and appreciated, recalling, “I like Dr. [name].... He was a very nice doctor. Then I had another one, I can’t remember her name, she was really good too. I got to know her and every time I saw her she was my primary doctor and she left. Now I don’t even know who my primary doctor is.” This elder concluded, “If I go over there [IHS], I already know it’s going to be changed, it’s going to be different.” A second individual recalled being “leery” of the physician’s assistant who replaced a doctor she had known and liked, commenting, “You get used to a doctor.” Many elders reiterated these frustrations with frequent, sudden, or unexplained changes. For instance, another woman complained about changing hours for dental care at her local IHS facility, explaining, “All of a sudden, they’ll just change it... and so you can’t get an appointment.” Echoing many others, this individual concluded with a sigh, “I don’t know what’s going to happen.” Elders often shared their sense of insecurity around changes in providers with one another. The same woman who mentioned the changing dental care hours explained, “We [elders] talk, ‘Did you hear that [that doctor’s] no longer there, did you hear that, and why?’ ‘I don’t know.’ Nobody knows anything.”

Notably, for some elders, these experiences contributed to decisions not to pursue medical treatments or other forms of assistance that should have been available to them. When asked whether he had tried to get a referral for specialty care from the PRC office, one man responded, “I don’t know anything about that. It’s probably something new. The doctor told me one time to go up and talk to them about my finances, but I didn’t go. I figured that my doctor was leaving, so what was the point?” In this case, although the turnover of this individual’s provider should not have affected his ability to get referrals or financial assistance, the experience of losing his doctor left him with a sense of futility about seeking help. A second elder chose to avoid dealing with what she perceived to be the unreliability of doctors in general, explaining that she preferred getting her health monitored at health fairs at her local Sam’s Club (a chain of membership-based retail warehouses). She explained, “Well, you have to wait for three months and a lot of times you can’t afford them [doctors]. A lot of times you don’t agree with them. And because they [Sam’s Club] give me information that I can read... [T]hey give me all that at the health fairs for free and I get the answers instantly.”

While many of the IHS facilities that elders visited were known for high rates of provider turnover, we also spoke to health system administrators who expressed doubt that the elders we interviewed had really experienced the frequency of turnover that they reported, pointing to changes that had been made to reduce such experiences in some facilities. Similarly, when we asked elders specifically about the last time they had changed providers, many reported no recent experiences but went on to talk about such changes as frequent and common for themselves and their families and friends. It was thus clear that despite efforts to reduce provider turnover in some facilities, elders largely shared a sense that they could not trust that their access to providers and facilities was stable, that reliable information was scarce, and that among elders, “nobody knows anything.”

3.2. “They get you all confused”

These sentiments of doubt and dissatisfaction were mirrored in many elders’ comments about health insurance. Although most elders were covered by health insurance and relatively few reported that they had experienced major problems with unexpected medical bills or medical debt, they commonly expressed fear or skepticism about whether the costs of their health care would be adequately and reliably covered, either by health insurance or by the PRC program. Many were deeply concerned about the prospect of going into medical debt, often based on stories they had heard about other elders. In an exemplary comment, one woman marveled at how an insurance representative at a community health fair had “just pressed a button” on the computer and gotten her signed up for health insurance, but then in the same breath, worried that she would lose the insurance or perhaps already had, concluding, “I haven’t gotten... an exit letter, so I hope I don’t.” When asked about her experiences with health insurance, another elder replied, “Often it’s waiting for the bill to come to see how much I owe.”

In many communities, growing Medicaid enrollment numbers were accompanied by efforts among healthcare providers to bill elders’ health insurance seamlessly so that elders did not have to deal with insurance statements. Yet, these efforts sometimes appeared to backfire as

elders were left confused about whether their insurance was working at all. One woman worried about supplies for her sleep apnea machine, explaining, “I got it when I was on the ACA.... I’m not positive what happened, I never saw the bill. What insurance covered the machine? Now if it breaks down, I don’t know.” Several others stated that they had not knowingly used their health insurance, although it is likely that the care they received at IHS was being billed to their health insurance. One elder explained, “It’s probably hard because I don’t understand it; having used IHS all my life, I’ve never had to deal with health insurance. I kind of don’t want to use it because I might end up with a bill because I don’t know what it’s all about.” Another asked, “I haven’t used [my Medicaid]... but I think about it in case I do need it, will it work? I mean I haven’t had to use it, but I hear stories about it.”

Another common source of doubt and suspicion about health insurance was the flood of health insurance company representatives who visited senior centers and health fairs to enroll tribal members in new health plans. Agents selling Medicare Advantage and Medicaid Managed Care plans (i.e., health plans offered by private companies that contract with Medicare and Medicaid) were reportedly especially frequent visitors. Echoing the sentiments of other elders, one man worried that insurance agents’ explanations about coverage were unclear or unreliable, explaining:

The people that are providing the insurance for us that our people are enrolled in, maybe they can be more instrumental in explaining what is covered because we find ourselves in a dilemma like... for example the emergency truck comes over and they do the surveys and you say, ‘Well, I have [health plan],’... they say, ‘Don’t worry about it.’ Later down the road in about 30 days you’re getting a bill and you thought it was taken care of and then it falls on you.

This individual compared his health insurance unfavorably with his perception of the way medical costs had been covered by the IHS before tribal members were encouraged to enroll in health insurance, commenting, “See like we knew what was covered at the Indian Hospital if we had an urgent matter... they would pay for it, but now it’s up in the air.” Other elders pointed to the volume of mail they received from different health insurance companies, causing many to wonder whether there were better plans available. As one elder summarized, “They get you all confused.” Another complained:

I don’t know how much they [a healthcare plan] can give you or how much without paying anything out of your pocket because nowadays it’s changing every year and then the older you get something else comes up different.... I worry about where I’m going to be at when I’m... like 70 or 80 years old. Am I going to have it still or is it still going to be there for us when we reach that age?

A conversation with a third elder poignantly illustrated how insecurity around health insurance compounded with provider turnover. This elder began by explaining, “There’s so many plans being thrown out at you. You don’t know what’s what. You need somebody that can take the time and explain. We do have that here.” However, this individual then had second thoughts and, turning to her friend nearby, asked, “I think we do have it, don’t we, at [IHS]? I know it used to be [name]. He’s no longer here. So who’s here?” When her friend was unable to answer, she sighed and concluded, “Ok, this is what I mean.”

Although health insurance was a particular source of insecurity, elders articulated parallel concerns about the reliability of the PRC program, commenting for example, “I’m not confident [in PRC] because it’s scary.... Each time I do that, every time we go there, I worry about that if it’s going to be covered or not, because I don’t know how they handle the cost.” Another woman worried about whether she would be able to get care at her local IHS facility, wondering, “Do they have the money?” Similarly, when asked whether he was confident that the IHS would meet his needs in the future, a third elder summed up his sense of helplessness, laughing, “You never know. People do run out of money, so I don’t know. It’s just an up-in-the-air thing.”

Such concerns appeared to deter some elders from getting help that they needed. After recounting her unsuccessful efforts to enroll in Medicaid, get her medical care covered by both Medicare and the Veterans Administration, and even visiting the office of her Congressional representative, one woman summed up the sense of frustration that thwarted elders seeking help, “I’m damned if I do, and I’m damned if I don’t. And to me the way I feel right now is it seems like every time I try something new, I always have that blocking stone right there so I can’t go any further than what I’ve gone, so then I go a different avenue and the same thing happens.”

3.3 “I’m really worried about the future”

Finally, it was clear from our interviews that insecurity around healthcare access and health insurance was aggravated by the years of contentious national discussion that surrounded the passage and implementation of the ACA. When we asked elders what they knew about the law and how they had heard about it, the vast majority referenced the ubiquity of news media reports, most often those focused on “the trouble [former President Barack Obama] was facing,” “that bickering that was happening,” and “when they were fussing.” Although many elders had a sense that the ACA was intended to help people get health insurance, they felt confused about whether it had affected them in good or bad ways. At worst, the law introduced new sources of confusion and insecurity, such as the tax penalty for not having health insurance. Although American Indians were exempted from the penalty, some elders worried about advertisements and emails from the health insurance exchange warning of the penalty. One woman complained,

“I was confused.... The government sent me a letter now in November and [they’re] still sending me emails telling me that I’m going to be penalized, that you’re running out of time and that. Then people here were telling us, ‘You’re Native American, you get an extension. Don’t pay attention to those alerts,’ or whatever. That made it confused.”

As our interviews took place in the months before and after the 2016 presidential election, elders’ doubts about the ACA mingled with questions about whether it would last. In one representative comment, an elder asked, “I don’t know whether, will it provide services for me at some point? Will it last a long time? Congress seems like they will override it. And then there’s this presidential race.” A second summarized, “I guess the only thing I would say is that I’m really worried about the future of the ACA.” Many elders also expressed concerns about younger relatives who relied on the Medicaid expansion or private health

insurance obtained through the law to pay for their care. For example, one woman commented, “My son needs a lot of medical attention. Now, I wonder how long is it going to be paid or if they’re actually going to put a stop to it or you know it worries me.”

After the election of 2016, these worries became even more common among interviewees. Echoing the comments of many others, one man asked of newly-elected President Donald J. Trump, “With this new guy, how does that affect us?” Another woman stated, “I don’t know what’s up his sleeve. He’s talking about doing away with [the ACA].” As efforts by the Republican-controlled Congress to repeal the ACA ramped up in the spring of 2017, elders worried about the future of Social Security, Medicaid, Medicare, and “health care” in general. An elder reflected, “I wonder what will happen with Social Security. That’s a fear of mine.”

For many elders, these concerns were aggravated by a perception that the new presidential administration was uniquely unfriendly to American Indian people. In one community, multiple individuals repeated a rumor that President Trump had promised to “take all Native American people and send them ‘back’ to India.” For example, one woman worried, “For our future, we need to know how we’re going to be cared for. Especially now with Trump. I heard he wants to send Indians back to India.” For several of the elders we interviewed, the president’s approval of an easement under the Missouri River for the Dakota Access oil pipeline in the face of protests from the Standing Rock Sioux and other indigenous people from around the world significantly colored their perception of the new administration and their concerns about the future. In one exemplary comment, explaining her belief that the president would disregard the needs of elders, one woman commented, “It’s already happened with the pipeline. He’s not listening.” However, among some elders, the administration’s perceived callousness toward American Indians was simply a continuation of an ongoing pattern. Speaking of national politicians in general, one individual concluded, “I don’t care whether or not they’re Republican or Democrat... these people are just out of touch. They’re out of touch with you and I.”

4 Discussion

Since the passage of the ACA, the law’s provisions for American Indian people have enabled well-documented improvements in closing health insurance coverage gaps and infusing the IHS, tribally-operated health programs, and other health facilities that serve American Indians with new funding, especially in states that accepted the Medicaid expansion (Frerichs et al., 2019; Warne and Frizzell, 2014). These gains should not be underestimated in their beneficial effects on the health of American Indian elders like those we interviewed for this study. Yet, in keeping with the history of health system reform in the U.S., the ACA’s effects have been imperfect and uneven (Mulligan and Castañeda, 2018). The financial pressure for tribes and healthcare providers to enroll tribal members in individual insurance led to some advances in the availability of healthcare and health insurance options for the elders in our study; however, these individual plans introduced new complexities that elders often compared negatively to the way they used to exercise their collective right to health care through the IHS. At the same time, elders continued to worry about provider shortages and scarcity of care at IHS and tribal facilities. Their experiences of

the health system were thus shaped by the illogic of shifting and complex medical bureaucracies, the circulation of horror stories about health system failures, and the distant rumblings of an unstable political environment. Together, these experiences resulted in a persistent sense of insecurity that colored elders' ability to trust that care would be available to them when they needed it and, in some cases, even deterred them from seeking care at all.

This research resonates with a substantial body of scholarship on the material and affective effects of biomedical bureaucracies (Gupta, 2012; Mulligan, 2014; Petryna, 2013). Researchers have documented how the complexities and frustrations of everyday engagement with healthcare facilities and systems produce profound experiences of disempowerment, especially for populations that are already marginalized within historically-based social structures of inequality, like American Indians (Auyero, 2012; Chary et al., 2016; Graeber, 2015; Herd and Moynihan, 2018; López, 2005). Our study echoes these findings, as elders repeatedly reported that although they generally liked their healthcare providers, they perceived healthcare and insurance systems as confusing, unreliable, and unresponsive to their needs. These perceptions, in turn, contributed to expressions of disempowerment that ranged from the sense that "nobody knows anything" to the conviction that pursuing assistance was basically futile. However, elders' comments also suggest that, in the context of national-level upheaval, some elders experienced these disempowering effects as reproducing colonial structures of inequality that marginalize American Indian people specifically (Chary et al., 2016). These participants saw their experiences of frustration and doubt with health and insurance systems as part of a pattern of disregard for American Indians on the part of national leaders, exemplified by the struggle over the Dakota Access pipeline. In this light, elders' lack of confidence in health care and insurance reflects their keen awareness of the wider structural failures that have characterized the U. S. government's relationship with American Indians.

Notably, our interviews revealed that elders' shared perception of the unreliability of healthcare and health insurance systems often persisted regardless of positive individual experiences. Many elders who reported being satisfied with the health care they received and not having had a problem with medical costs in the previous year still conveyed a lack of trust in their continued ability to get the care they needed in the future, often citing stories they had heard and conversations with other elders. This discrepancy is likely due in part to the limitations of the closed-ended survey questions on healthcare satisfaction and access, which were not able to capture the doubts stemming from histories of healthcare scarcity and discrimination, along with the experiences of others, that emerged in response to the qualitative interview questions. Moreover, the apparent incongruence between elders' and system administrators' perceptions of the frequency of provider turnover in some facilities highlights how past negative experiences among elders and their friends and family members may outweigh any recent improvements in their calculations about whether they can rely on health systems to meet their needs. In this sense, elders' perceptions of the unreliability of the health system are similar to descriptions of the experience of resource insecurity, such as scarcity of food and water. For example, a review of scholarship on food and water insecurity shows that unreliability of access to such vital resources produces emotional and mental distress rooted in experiences of uncertainty and unpredictability, stigma and shame, and anger at being the victim of social injustice (Wutich and Brewis,

2014). Similarly, elders' accounts of their healthcare experiences underscored the uncertainty of their access to trustworthy providers and services, as well as the financial unpredictability of costs associated with both medical treatments and the IHS programs and health insurance plans that were supposed to protect them from medical costs. Additionally, elders' comments surrounding the 2016 presidential election and their perceptions of the Trump administration's mistreatment of American Indian people attest to the ways that perceptions of social injustice are connected to their experiences of healthcare insecurity.

These findings are in keeping with existing anthropological and sociological research on the ways that health reform processes—especially those that expand the privatization of healthcare services, like the ACA—may reproduce political exclusions for marginalized groups (Joseph, 2018; López, 2005; Mulligan and Castañeda, 2018). This substantial body of scholarship documents how reforms that ostensibly expand access to new programs and resources rely on devilishly complex bureaucratic procedures that effectively drive away those in need of support, a process Leslie López (2005) calls “de facto disenfranchisement.” Echoing our findings, this process is often aggravated by the affective pressures of a broader political environment that is perceived as hostile to marginalized people (Castañeda, 2018; Joseph, 2018). Jessica Mulligan and Heide Castañeda (2018, 12) suggest that such political exclusions can have consequences that “range from ambiguous and incomplete to cruel and life-threatening.” Indeed, our findings show that a sense of insecurity contributed to numerous instances where elders decided not to ask for help or take advantage of assistance that was available to them in ways that likely negatively impacted their health. This phenomenon recalls Elizabeth Povinelli's (2011, 144) notion of “quasi-events,” which she defines as mundane hardships that “resist cause-effect characterization,” but that create over time an overall sense of helplessness, exhaustion, and resignation. Repeated experiences and fears of provider turnover, bureaucratic complexity, and uncertainty around costs reportedly produced a keen sense of exhaustion for the elders we interviewed, such as the man who refused to seek financial assistance because, he noted, “What's the point?” The very real possibility of preventable suffering and ill-health that may result from these experiences is precisely what Povinelli calls (2011, 243) “the violence of enervation, the weakening of the will rather than the killing of life.” Similarly, David Graeber (2015) links what he calls the “stupidity” of bureaucracies to the violence of contemporary fusions of public and private power like those that populate the U.S. healthcare system. The inadequacies and failures of health and insurance systems on which American Indians are supposed to be able to rely thus expose them to a persistent, everyday experience of physical and financial precarity (Allison, 2014; Butler, 2004; Tsing, 2015) centered on the instability of health and health care.

To date, the majority of interventions to improve health disparities for marginalized populations, such as American Indian elders, focus on enhancing individual and interpersonal factors (Brown and Ma, 2019), such as health literacy, insurance enrollment, and engagement with care. However, our findings suggest that the current health system in fact may *produce* the lack of knowledge that we call “health illiterate” (e.g., not knowing how to use health insurance) as well as the health behaviors that we seek to change (e.g., lack of help seeking). Administrative and bureaucratic burdens like those that affected the elders in our study are constructed, not coincidental. Their consequences in disenrollment

from health insurance plans and lower rates of healthcare utilization are likely to be connected to profit-generating mechanisms for powerful stakeholders, as well as ideological efforts to erode support for public programs, such as the Medicaid expansion under the ACA or the U.S. government's federal trust responsibility to provide health care for American Indians (Herd and Moynihan, 2018; Skinner, 2016). For these reasons, although individual-level interventions are valuable, the experiences of the elders in our study highlight their inadequacy in improving the pervasive, socially- and historically-rooted sense of instability that perpetuates inequities in access to and utilization of care. In fact, a single focus on individual-level approaches to improving health disparities risks reinscribing narratives of personal responsibility that are characteristic of neoliberal approaches to health and absolving states and health systems of blame for health disparities that affect marginalized populations (Brown and Baker, 2012).

Addressing the health disparities that American Indian elders face will require imagining long-term provider- and system-level changes that can encourage trust and confidence over time, rather than reproducing doubt and fear. For example, administrators of healthcare organizations should recognize the destabilizing effect of provider turnover on elders and consider making changes to hiring practices and the ways that appointments are scheduled and managed to cultivate interpersonal connection and continuity for patients. Interventions to improve elder health disparities should also emphasize navigation assistance not only to streamline elders' interactions with the health system but also to demystify the workings of health insurance programs by making information about resources and services transparent and widely accessible. Similar efforts have been found to be acceptable and effective among American Indians (Burhansstipanov et al., 2014). However, the insecurity that elders experience within the current healthcare system must also be tackled at the policy level. This will include advocating for policies that shift administrative burdens associated with public programs like Medicaid away from individual patients (Herd and Moynihan, 2018).

Yet, policymakers must also recognize that, regardless of the effects of individual health policies, the instability and unpredictability of the U.S. healthcare system takes a significant physical, mental, and emotional toll on the wellbeing of citizens, especially among historically marginalized populations like the American Indian elders in our study. Scholars of precarity suggest that the everyday instability that elders disproportionately experience can only be survived and possibly transformed by relying on social ties and shared experience (Allison, 2014; Butler, 2004). Indeed, the elders we interviewed commonly answered questions about their own health care and insurance with expressions of collective perception (e.g., "For our future, we need to know how we're going to be cared for"), in part reflecting the fact that health care is a collective right of American Indian people. Consequently, a system based on the expansion of individual insurance plans is likely to be inadequate to resolve the insecurity that elders feel. Creating healthcare security for elders will need to be a collective project, requiring that policymakers first take seriously their treaty-established responsibility to guarantee health care to all American Indian people.

4.1 Limitations

Although we made an effort to include the perspectives of American Indian elders with a variety of life experiences and circumstances (e.g., rural and urban, men and women, older and younger elders, users of IHS and other healthcare systems) and to obtain feedback from the CAB to enhance the accuracy of our analysis, there may be biases in our sample of participants so that our findings may not represent the perspectives of all American Indian elders. For example, we likely oversampled elders who were especially willing to share their opinions about health care and other topics; these were primarily women. However, participants were often asked to reflect on the needs and experiences of elders in general, which may have mitigated some limitations in representativeness.

Due to the linguistic diversity of American Indian communities, potential participants were offered the opportunity to take part in the interview in their Native language; however, elders who were not completely comfortable with the presence of an interpreter from their own community may have declined to participate.

5 Conclusion

The experiences of doubt, fear, and uncertainty described by the American Indian elders in our study are undoubtedly shared by individuals of all ages, as much of the national conversation about health insurance and health system reform over the last decade attests. As Mulligan and Castañeda (2018, 18) describe, insecurity around health care is uniquely destabilizing as solutions that purport to mitigate risks (e.g., new health insurance options) also generate new hazards “where health is precarious and always in danger of unraveling.” Our study shows that this experience extends to a population that is supposedly protected by guaranteed access to health care, aggravated by memories and stories of past health system failures and haunted by fears of those to come. Although efforts to expand access to individual health insurance plans and improve American Indian elders’ abilities to navigate the health system are valuable, this research illustrates that simply introducing new options and resources like those that became available through the ACA is not enough to address the insecurity that characterizes elders’ experiences of health care and insurance. Rather, the reproduction of insecurity through funding and provider shortages, bureaucratic complexity, and political instability highlights the urgent need to conceptualize long-term system- and provider-level changes designed to build trust and confidence for American Indian elders over time and to securely establish their collective right to health care.

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