

USING CONCEPT MAPPING TO UNDERSTAND GENDER- AND AGE-SPECIFIC FACTORS INFLUENCING HEALTH CARE ACCESS AMONG AMERICAN INDIAN ELDERS

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Abstract: Inequities in access to health care create barriers to physical and mental health treatment for the rapidly aging American Indian population in the United States. This study uses concept mapping—a participatory, mixed-methods approach to understanding complex phenomena—to examine the perceived impacts of multilevel factors influencing Elders’ ability to access and use health care and how these perceptions vary according to gender and age, with the aim of identifying tailored strategies to address inequities. Using data from a purposive sample of American Indian Elders (n = 65) in two states, we compared ratings of thematic clusters and individual factors perceived to impact Elder health care across four participant subgroups: women aged 55-64, women aged 65+, men aged 55-64, and men aged 65+. Provider Issues and Relationships and Tribal/National Policy were themes perceived to have a particularly high impact on Elder health. Key variations between subgroups regarding individual health care access factors reflected unique interpersonal and accessibility challenges among older women, problems stemming from lack of familiarity with health care among younger Elders and men, and challenges navigating complex bureaucracies and tribal decision-making processes among older Elders. Findings underscore the need to address multilevel gender- and age-specific factors contributing to health disparities for Elders.

INTRODUCTION

Although members of the 567 federally recognized American Indian (AI) tribes in the United States have a treaty-guaranteed right to health care, inequities in access to and utilization of health

care compared to other groups create persistent barriers to physical and mental health treatment for the nation's 5.2 million indigenous citizens (Adakai et al., 2018; Gone & Trimble, 2012). Among AIs, aged 55 and over, these disparities persist even among those with access to Medicare. In fact, by the time they reach old age, most AIs have experienced significant racial and social inequities over the course of their lives (Grandbois & Sanders, 2009; Smedley et al., 2003), contributing to a greater likelihood of poor health and barriers to care compared to all other aging populations in the United States (Boccuti et al., 2014; Jacobs et al., 2019). Elders encounter barriers at multiple contextual levels (i.e., personal and interpersonal; community and health care system; and tribal, state, and national policy) and may experience them differently based on their individual circumstances and life experiences, including those shaped by gender and age. The rapid growth of this population creates further urgency to understand and improve mechanisms that promote health care access and utilization to enhance both physical and mental health outcomes. This study utilizes concept mapping, a participatory mixed-methods research approach, to examine the perceived impacts of multilevel factors influencing whether AI Elders are able to access and utilize health care and how these perceptions vary among elderly women and men as they age.

The ongoing demographic shift towards an older population throughout the United States has been widely documented; however, this transformation is occurring among AIs at over twice the rate of the general U.S. population. Between 2000 and 2030, the percentage of AIs and Alaska Natives aged 65 and older is projected to increase from 5.6% to 13.4%, 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; 2012). This dramatic change means that systems that have not historically served many AI Elders must now prepare to address their complex health care needs while relying on the “patchwork” of funding sources and state and federal programs that provide health and social services to Elders (Bylander, 2018).

Tribal members can receive primary care services from the Indian Health Service (IHS) at no cost and without health insurance and can be referred elsewhere for treatments that they cannot access at an IHS facility, such as diagnostic tests and specialty care, through its Purchased/Referred Care program (PRC), formerly known as Contract Health Services. Although physical and mental health services provided through the IHS are more likely to be tailored to the needs of AIs than those obtained elsewhere, these programs are not available to Elders who do not meet tribal affiliation criteria or who live outside their tribe's IHS service area, including the majority of the approximately 70% of AIs who live in urban areas (Artiga et al., 2017; Gone & Trimble, 2012). Moreover, the IHS

has never been adequately funded to meet the needs of AIs. In 2017, the per capita health care expenditure for IHS users was \$4,078, compared to \$9,726 for the general U.S. population (IHS, 2020a). Only a fraction of the IHS budget for clinical services are allocated to mental health and substance use treatment (IHS, 2020b). Many AI Elders have experienced the consequences of this underfunding throughout their lives, including health care facilities that are outdated and short-staffed, as well as limitations on the services covered by PRC, sometimes forcing them to go without recommended treatments or face major medical bills (Fox, 2011).

The 2010 Patient Protection and Affordable Care Act (ACA) updated the 1976 Indian Health Care Improvement Act to authorize the provision of long-term care, such as assisted living and community-based care; however, Congress has not dedicated funding to these vital supports for older AIs (Bylander, 2018). Although many older AIs have benefited from the ACA's expansion of Medicaid eligibility to most low-income adults (Artiga et al., 2017), Medicaid coverage of long-term care is still not available to many Elders in states that did not accept the Medicaid expansion. Others cannot get coverage for home- or community-based services because of the extremely complex and burdensome procedures required to establish their medical and financial needs.

In addition to these barriers, numerous other intersecting factors influence the ability of AI Elders to access and utilize health care. These may include low health literacy (i.e., the ability to locate, understand, and use information about health and health care) stemming from inequities in educational opportunity (Brega et al., 2012; Centers for Disease Control and Prevention, 2009), discomfort with the technology required to find and use health information (Kim & Xie, 2016), and difficulties with information processing due to cognitive, vision, or hearing impairments (Verney et al., 2008). AIs are also more likely than other populations to avoid care because they lack trust in health care providers and organizations, often because of prior experiences of discrimination and poor treatment (Simonds et al., 2014). Elders, especially women, may also prioritize the care of children or grandchildren over their own health (Haozous & Goins, 2012; Jaramillo et al., 2019). Together, these factors contribute to disproportionately higher rates among AIs compared to non-Hispanic Whites of physical health problems, including stroke, heart disease, diabetes, and obesity, and mental health concerns, such as alcohol dependence, posttraumatic stress disorder, and depression (Beals et al., 2005; Espey et al., 2014; Garrett et al., 2015; IHS, 2015; Shieb et al., 2014; Veazie et al., 2014).

Published reports repeatedly underscore these disparities, yet scholars have also noted that existing research on racial/ethnic disparities may not account for internal variation or “hidden

heterogeneity” within groups (Institute of Medicine, 2002). For example, few studies to date examine how differences in gender and age among AI Elders shape their ability to access and utilize health care. In one national study of AIs and Alaska Natives aged 55 and older, women were significantly more likely than men to have at least one chronic health condition, even after controlling for other sociodemographic characteristics (Adamsen et al., 2018). Prevalence of chronic health conditions was also found to increase with age. In order to develop effective approaches to reducing the severe health disparities affecting AI Elders, it is critical to understand variations like these in Elders’ health and health care needs, as well as the resources that are available to them.

In this study, we use concept mapping to compare the perspectives of younger (i.e., aged 55-64) and older (i.e., aged 65 and older) female and male Elders. Concept mapping is a community-driven, participatory approach to organizing complex, multilevel information and prioritizing areas for further study and intervention (Kelly et al., 2007; Windsor, 2013). It involves methods (i.e., listing and pile sorting) that are useful for eliciting emic perspectives on a particular phenomenon in a variety of sociocultural contexts (Bernard, 2017; Trotter & Potter, 1993). In this study, concept mapping illuminates areas of consensus and difference among sub-populations of AI Elders regarding the relative health impacts of factors affecting their health care access. A deeper understanding of these differences allows for the identification of tailored, locally relevant intervention strategies to address the problems impacting AI Elders with diverse life experiences and at different life stages.

METHODS

We conducted concept mapping between June and December 2017 as part of a larger study on access to and utilization of health care and health insurance among AI Elders in two states in the U.S. Southwest (Willging et al., 2018). One state had expanded Medicaid eligibility under the ACA, while the other had not. In keeping with community-engaged approaches to research with indigenous peoples (Brave Heart et al., 2016), we conceptualized and designed the overall study and the concept mapping activities in consultation with a group of AI Elders and allies called the Seasons of Care Community Action Board (CAB). The CAB members were distinguished for their knowledge and expertise related to AI health and Elder issues. They both initiated the planning for the larger study and supervised each aspect of this research, from reviewing data collection instruments and assisting with recruitment to strategizing efforts to promote Elder health. The Southwest Tribal Institutional Review Board approved the study design.

Participants

We utilized a purposive sampling strategy to recruit a diverse set of AI Elders to take part in concept mapping activities. To ensure that the Elders participating in this study represented a range of knowledge, beliefs, and experiences related to health care and health insurance, recruitment efforts occurred in multiple tribal communities with targeted outreach to Elders living in urban settings. Elders were recruited through in-person outreach during regular visits to AI senior centers, health clinics, and meetings of health-focused AI groups and organizations in reservation and urban communities. Members of the research team (including the first, third, and fourth authors) presented the research study to Elders in these settings and remained available on site for several hours afterward to share information, answer questions, and conduct concept mapping activities with individuals who volunteered to participate. Research staff also provided printed copies of presentation materials featuring a toll-free number that Elders who were interested could call to be screened for eligibility at a later date. Inclusion criteria included self-identification as an AI Elder, aged 55 or over, and comfort in engaging with written English to complete the concept mapping activities. No one who volunteered to participate was deemed ineligible. Researchers were prepared to administer the MINI-COG[®] (2017) to test for cognitive impairment if they felt that a candidate was not able to understand or complete study procedures; however, no potential participants were identified or excluded for this reason. Informed consent was obtained from all participants, all of whom received an honorarium of \$25.

Of the 65 AI Elders participating in concept mapping, 69.2% ($n = 45$) were women. The average participant age was 68.7 years with a range of 55 to 85 years old. All participants identified as AI, and approximately 10% ($n = 6$) reported that they also had Hispanic, Latino, or Spanish heritage. All were members of federally recognized tribes. For our analysis of the role of gender and age on perceptions of Elder health care access and utilization, we divided participants into four subgroups: women aged 55-64 ($n = 14$), women aged 65+ ($n = 31$), men aged 55-64 ($n = 9$), and men aged 65+ ($n = 11$). Age 65 was selected to split the sample for reasons that were both pragmatic (i.e., allowed for a reasonable number of participants across the four subgroups) and conceptual (i.e., full Medicare eligibility for these cohorts occurs by age 65, which might affect attitudes about and experiences with accessing health care).

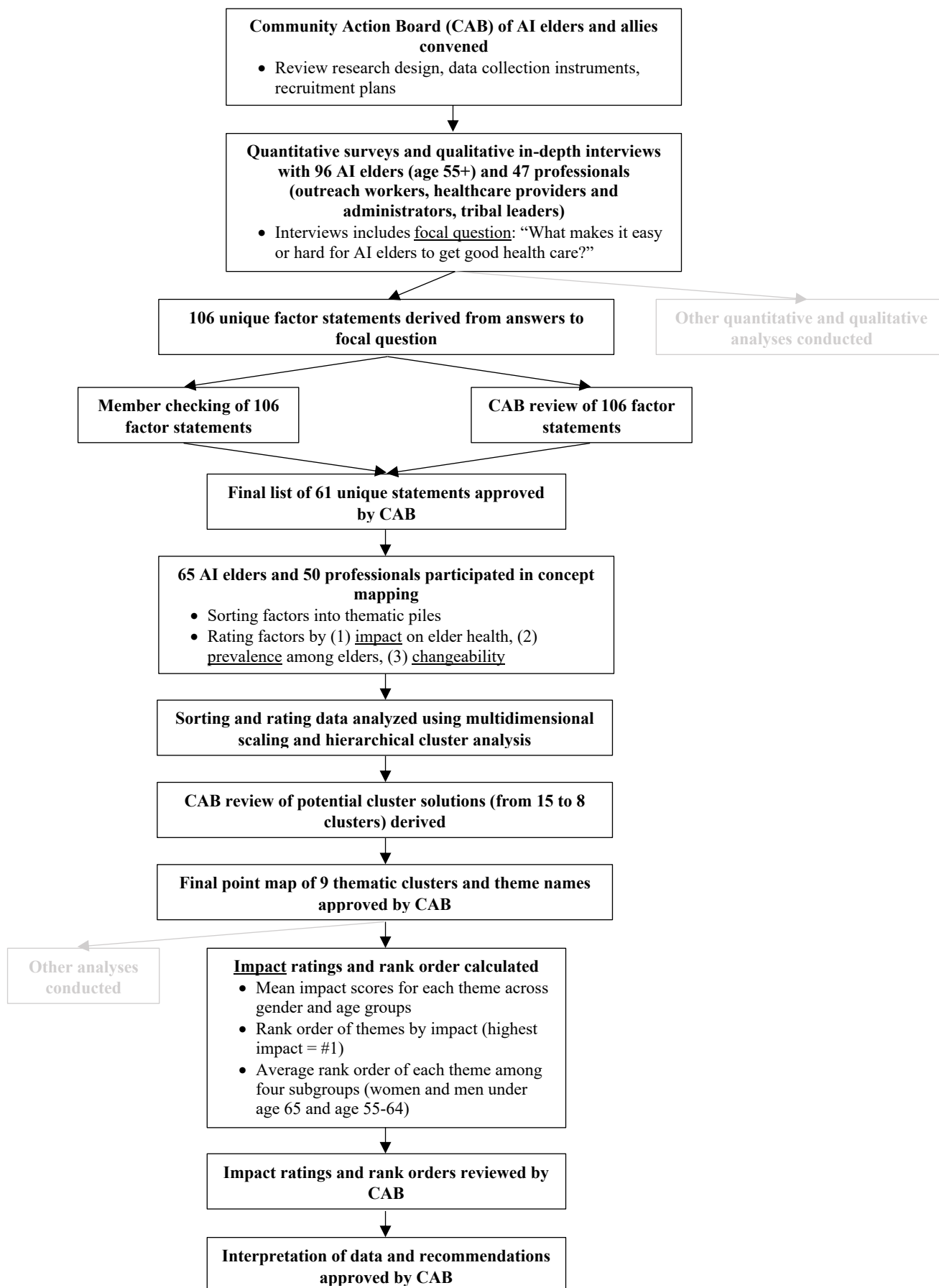
Concept Mapping Approach and Procedure

Concept mapping is a structured and iterative methodology involving both qualitative and quantitative data collection and analysis steps (Figure 1). Concept mapping is particularly useful when trying to obtain input from multiple stakeholders to better understand and identify areas for improvement in complex, multi-factorial domains such as health care access for AI Elders. First, we developed a focus question (“What factors make it easy or hard for AI Elders to get good health care?”), which we included in a separate series of semi-structured interviews that were conducted as part of the parent study.¹ Second, we created a list of 106 discrete factor statements derived from the interviews. Using member checking and advice from the CAB, we consolidated the list into a final set of 61 unique statements (e.g., “Not being comfortable/confident enough to ask questions”) to reduce conceptual overlap/redundancy and result in a manageable number of statements for concept mapping participants to review. Third, we asked participants, along with 50 professional stakeholders (not the focus of this analysis),² to individually sort the statements into thematic groups or “clusters” that were meaningful to them. With each statement listed on a separate card, participants physically organized statements into groups. Participants were then asked to indicate a name to describe the general content of the statements included in each group (e.g., “Health care costs”, “Accessibility of clinics”). Using worksheets, each participant was then asked to individually rate each statement (using a Likert scale) on three dimensions: impact (i.e., “How much do you think this factor affects the health of Native American Elders?;” 1 = *no effect* and 10 = *very large effect*), prevalence (i.e., “How common do you think this factor is among Native American Elders?;” 1 = *not common at all* and 10 = *very common*); and changeability (i.e., “How easy do you think it is to change this factor?;” 1 = *very difficult* to change and 10 = *very easy to change*). Sorting and rating activities were conducted in person in a setting that was deemed private and convenient by the participant (e.g., private room at a senior center).

¹ Ninety-six Elders and 47 professional stakeholders took part in these individual interviews, which were conducted prior to the remaining concept mapping activities. Recruitment and interview procedures and content of the interview guides are described in Willging et al. (2018). Other interview findings are published elsewhere (Jaramillo et al., 2019; Jaramillo & Willging, 2021; Willging et al., 2021).

² Professional stakeholders included outreach workers, health care providers, tribal leaders, and administrators of health systems. Because this analysis focuses on Elders’ assessments of the factors that impact their access to and use of health care, professional stakeholders’ rankings are not reported here; they are published in Sommerfeld et al. (2021).

Figure 1. Concept mapping steps



Fourth, sorting data were manually entered into Concept Systems software (Concept Systems Inc., 2018) to be analyzed using multidimensional scaling and hierarchical cluster analysis (Davison, 1983). The multidimensional scaling techniques produce a two-dimensional “point map” that provides a visual representation of how similar or dissimilar each individual factor statement is from all other factor statements based (mathematically) on how commonly the statements are grouped together by the participants. The results of the quantitative hierarchical cluster analyses identify which statements will cluster together when a fixed number of clusters is applied to the underlying point map data. Fifth, to arrive at the final cluster solution, we presented potential solutions ranging from 15 to eight clusters to the CAB members, who collaboratively settled on the nine-cluster solution as the best representation of the data without losing important distinct thematic content areas. The CAB also reviewed each cluster in this final model and ensured that the label assigned to it accurately reflected the nature of the statements that it contained. In this manner, the identification of the thematic clusters represented a truly mixed-method approach in that quantitative and qualitative steps were integrated through a specific concept mapping sequence to generate the final result.

The present analysis examines perceptions of each factor’s impact (i.e., how much each factor affects Elders’ health) among the AI Elder participants in our sample and how these perceptions varied according to gender (i.e., males vs. females) and age (i.e., “younger” vs. “older” Elders). To identify the thematic clusters that were consistently rated as having high impact on Elder health across gender and age groups, we calculated the mean “impact on health” scores for each thematic cluster by averaging the impact rating of each statement contained in the cluster. We then created an impact rank cluster order (i.e., with the cluster rated highest on the impact dimension ranked as #1, second highest as #2, etc.). Finally, we calculated the average cluster rank order across the four gender and age subgroups (i.e., women and men under age 65 and aged 65 and older) for each thematic cluster.

In addition to the analyses at the level of the thematic clusters, we examined the individual factor statements to determine which factors were identified as particularly impactful on Elder health among the gender and age subgroups. To conduct these analyses, we created *z*-scores for each individual factor by indicating how many standard deviations each subgroup’s impact rating of the factor was above or below the subgroup’s mean impact rating for all factors. We then identified the individual factor statements that were rated as having a mean impact on Elder health

at least one standard deviation higher relative to the respective subgroup's overall mean impact rating for at least two of the four subgroups.

RESULTS

As reported in Sommerfeld et al. (2021), the final concept-map model comprised nine thematic clusters, each representing a key domain related to factors affecting whether Elders can obtain health care. These clusters were (in no particular order): Difficulties Obtaining and Using Insurance; Insecurity from Lack of Knowledge; Limited Availability of Services; Scheduling Challenges; Provider Issues and Relationships; Family and Emotional Challenges; Health-Related Self-Efficacy and Knowledge; Accessibility and Transportation Barriers; and Tribal/National Policy. Table 1 lists each of the nine clusters and the individual factor statements assigned to them.

Table 1
Cluster themes and factors affecting access to and utilization of health care among American Indian Elders

Cluster name	Statements included in cluster
1. Difficulties obtaining and using insurance	Uncertainty about what healthcare services/medications are covered by insurance Insurance or Indian Health Service won't cover enough healthcare costs Difficulty communicating with insurance company (including rude or unhelpful insurance representatives, understanding insurance lingo) Having to deal with billing departments and debt collectors Not knowing how to report or appeal health care/insurance decisions Needing to change insurance companies Difficulties using insurance at Indian Health Service Too many forms to fill out to get insurance Difficulties using multiple types of insurance Difficulties paying for the cost of insurance Lack of education about insurance plan choices Doctors/healthcare professionals not accepting insurance plan Insurance or Indian Health Service refusing to cover certain healthcare services or prescriptions Not having insurance/prescription card to show for services Too many forms to fill out when getting healthcare services Not being aware of Purchased Referred Care or how to use it
2. Insecurity from lack of knowledge	Not knowing where to find healthcare information Limited knowledge of computers or the Internet to obtain information about insurance Not having access to Native language interpreters/translators to help with insurance enrollment Difficulties paying for healthcare costs Getting inaccurate healthcare/insurance advice from IHS and/or Tribal services

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Table 1 Continued

Cluster themes and factors affecting access to and utilization of health care among American Indian Elders

Cluster name	Statements included in cluster
3. Limited availability of services	<p>Not having a health facility open on weekends or after hours in or near my community</p> <p>Not knowing where to obtain good health care</p> <p>Health services/providers being shut down</p> <p>Not having access to Native language interpreters/translators when communicating with healthcare professionals</p>
4. Scheduling challenges	<p>Needing to change to a new doctor and/or healthcare facility</p> <p>Difficulty communicating with healthcare professionals (including rude or unhelpful providers, not understanding medical “lingo” or terminology)</p> <p>No same-day appointments available or walk-in access</p> <p>Long waits at healthcare facilities</p> <p>Doctors/healthcare professionals cancelling/rescheduling appointments</p> <p>Difficulty scheduling appointments (i.e., being told to call back at a later date when trying to schedule an appointment or having to schedule appointments more than a month in the future)</p> <p>Difficulties getting medication prescriptions filled/refilled</p>
5. Provider issues and relationships	<p>Not having a qualified/skilled doctor who can be trusted</p> <p>Rushed appointments with the doctor (e.g., five-minute visit)</p> <p>Not being able to see the desired doctor or health care professional</p> <p>Not having all your doctors, nurses, pharmacists, and facilities know the right information about you</p> <p>Not having a “regular” doctor that knows your personal health history</p> <p>Concerns about doctors or health care professionals not maintaining privacy/confidentiality</p> <p>Not knowing how to choose the right doctor</p> <p>Being over-prescribed too many drugs</p>
6. Family and emotional challenges	<p>Family being unwilling or unavailable to advocate on behalf of the Elder</p> <p>Difficulties dealing with emotions related to health care (e.g., feeling like a burden on family)</p> <p>Living alone</p> <p>Not wanting to tell others about personal health issues</p> <p>Not being able to be honest with family about health care-related wants and needs</p> <p>Denying the need for care (“tough guy” mentality)</p>
7. Health-related self-efficacy	<p>Not being comfortable/confident enough to ask questions</p> <p>Not knowing how to advocate for own personal health care</p> <p>Reluctance to use services provided by Indian Health Service or Tribe</p> <p>Not being able to read or understand instructions for taking medicines correctly</p> <p>Not knowing when to go to the doctor (i.e., knowing the “warning signs”)</p>
8. Accessibility and transportation barriers	<p>Limited availability of Elder-specific services (including home health caregivers)</p> <p>High cost of transportation to obtain health care</p> <p>Needing to travel long distances to obtain care (e.g., doctors or emergency care)</p> <p>Not having reliable transportation to get to health care appointments</p> <p>Not having access to community health programs (e.g., senior center or clinics) that provide transportation</p>
9. Tribal/national policy	<p>Health care is a low priority for Tribal leadership</p> <p>Information not shared with the community or general meetings</p> <p>Tribal affiliations or blood quantum restrictions make it hard to get good health care</p> <p>Not knowing how to influence Tribal leadership</p> <p>Health care is a low priority for national politicians</p>

Table 2 shows the average “impact on health” ratings for the nine thematic clusters and their relative rank order. The average ratings for the clusters indicate that each age and gender group perceived all domains as exerting large impacts on Elder health (i.e., all rating values were above a value of 6.5 on the 10-point scale where 1 = *no effect* and 10 = *very large effect*). Across the entire sample, impact on health ratings ranged from 6.63 (women 65+: Family and Emotional Challenges) to 8.40 (men 65+: Tribal/National Policy).

Table 2
Impact on American Indian Elder health ratings and rankings of thematic clusters by gender and age subgroups

Thematic Clusters of Health Care Access Factors	Women 55-64 years (n = 14)		Women 65+ years (n = 31)		Men 55-64 years (n = 9)		Men 65+ years (n = 11)		Average Subgroup Cluster Rank
	Cluster “Impact” Mean	Cluster “Impact” Mean	Cluster “Impact” Mean	Cluster “Impact” Mean	Cluster “Impact” Mean	Cluster “Impact” Mean	Cluster “Impact” Mean	Cluster “Impact” Mean	
Provider Issues & Relationships	7.88	3	7.39	2	8.33	1	7.69	2	2.0
Tribal/National Policy	8.14	1	7.33	3	7.53	9	8.40	1	3.5
Scheduling Challenges	7.90	2	6.87	6	8.00	4	7.30	6	4.5
Insecurity from Lack of Knowledge	7.82	5	7.32	4	7.93	6	7.49	4	4.8
Limited Availability of Services	7.81	6	7.13	5	7.77	8	7.63	3	5.5
Accessibility & Transportation Barriers	7.60	8	7.40	1	7.82	7	7.22	7	5.8
Difficulties Obtaining & Using Insurance	7.53	9	6.82	7	8.06	3	7.42	5	6.0
Family & Emotional Challenges	7.83	4	6.63	9	8.00	5	6.83	8	6.5
Health-related Self-efficacy	7.66	7	6.75	8	8.27	2	6.66	9	6.5

Note: 10-point rating scale (1 = *no effect* on Elder health and 10 = *very large effect* on Elder health)

The cluster rankings facilitated a standardized comparison of the relative perspectives among the gender and age subgroups. For example, while the average impact ratings for Limited Availability of Services were very similar for men in the 55-64 and 65+ age groups (7.77 and 7.63, respectively), this theme ranked #8 on health impact (i.e., almost the lowest rank order) for men 55-64, but #3 for men aged 65+.

An examination of the average rank score (i.e., the average of the rank order across the four subgroups) indicated that Provider Issues and Relationships was the overall highest-ranked thematic cluster for impact on health (average rank score of 2) and was ranked in the top three across all four subgroups. The second highest ranked theme was Tribal/National Policy (average rank score of 3.5). This thematic category was rated in the top three for three out of the four subgroups. However, while Tribal/National Policy was generally perceived as impactful on health, men 55-64 differed substantially by ranking this category lowest of the nine thematic categories. Additionally, the highest ranked domain among women 65+ was Accessibility and Transportation Barriers, while this category was ranked no higher than #7 among any of the other subgroups. Similarly, among men 55-64, Health-Related Self-Efficacy was ranked #2, but no higher than #7 among any of the other subgroups.

Table 3
Impact on American Indian Elder health ratings of individual health care access factor statements by gender and age subgroups^a

Item #	Individual Health Care Access Factor Statement	Women 55-64 years (n = 14)		Women 65+ years (n = 31)		Men 55-64 years (n = 9)		Men 65+ years (n = 11)		Groups with Z-score >=1
		Mean "Impact" rating	Z-score diff. from group mean	Mean "Impact" rating	Z-score diff. from group mean	Mean "Impact" rating	Z-score diff. from group mean	Mean "Impact" rating	Z-score diff. from group mean	
	<i>Average impact rating for all 61 items</i>	7.76	SD=0.73	7.10	SD=0.63	8.02	SD=0.64	7.40	SD=0.86	
1	Long waits at healthcare facilities	9.46	2.3	7.71	1.0	7.89	-	8.73	1.5	3
2	Limited knowledge of computers or the Internet to obtain online information about insurance	8.69	1.3	7.97	1.4	7.56	-	8.30	1.0	3
3	Not knowing how to report or appeal healthcare/insurance decisions	8.77	1.4	8.11	1.6	9.11	1.7	7.18	-	3

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Table 3 Continued
Impact on American Indian Elder health ratings of individual health care access factor statements by gender and age subgroups^a

Item #	Individual Health Care Access Factor Statement	Women 55-64 years (n = 14)		Women 65+ years (n = 31)		Men 55-64 years (n = 9)		Men 65+ years (n = 11)		Groups with Z-score >=1
		Mean "Impact" rating	Z-score diff. from group mean	Mean "Impact" rating	Z-score diff. from group mean	Mean "Impact" rating	Z-score diff. from group mean	Mean "Impact" rating	Z-score diff. from group mean	
	<i>Average impact rating for all 61 items</i>	7.76	SD=0.73	7.10	SD=0.63	8.02	SD=0.64	7.40	SD=0.86	
4	Health care is a low priority for national politicians	8.77	1.4	8.41	2.1	7.33	-1.1	9.27	2.2	3
5	Not having a "regular" doctor that knows personal health history	7.85	-	7.43	-	9.38	2.1	8.30	1.0	2
6	Difficulties dealing with emotions related to health care (e.g., feeling like a burden on family)	8.77	1.4	7.82	1.1	7.44	-0.9	6.09	-1.5	2
7	Difficulty scheduling appointments	8.77	1.4	7.45	-	8.89	1.4	7.40	-	2
8	Not knowing how to influence tribal leadership	7.83	-	7.72	1.0	7.22	-1.3	8.82	1.7	2
9	Health care is a low priority for tribal leadership	8.08	-	7.73	1.0	6.89	-1.8	9.00	1.9	2
10	Not being aware of Purchased/Referred Care or how to use it	8.08	-	7.83	1.2	8.33	-	8.45	1.2	2
11	Lack of education about insurance plan choices	8.92	1.6	7.57	-	7.89	-	8.45	1.2	2
12	Information not shared with the community or general meetings	9.08	1.8	6.90	-	8.44	-	8.73	1.5	2

^a Z-scores are listed only if they exceed +/- 0.75. Note: 10-point rating scale (1 = *no effect* on Elder health and 10 = *very large effect* on Elder health)

Table 3 lists the 12 (out of 61) individual factor statements that participants perceived to be particularly impactful on Elder health (i.e., having a z-score difference from the group mean of at least 1.0 in at least two subgroups). Four individual factors were rated as particularly impactful on health across three subgroups: "Long waits at healthcare facilities," "Limited knowledge of computers/Internet to obtain online information about insurance," "Not knowing how to report or

appeal healthcare/insurance decisions” and “Health care is a low priority for national politicians.” Eight additional factors were rated as especially impactful by two subgroups (see Table 3).

Two factor statements reflected a gendered response pattern. “Not having a ‘regular’ doctor,” was highly rated only among men, while “Difficulties dealing with emotions related to health care,” was highly rated only among women (with men highly underrating this item per the large negative z -scores). Similarly, there were four factors with an age-related pattern. Both women and men 55-64 identified “Difficulty scheduling appointments” as particularly impactful on health and only persons 65+ highly rated “Not knowing how to influence tribal leadership,” “Health care is a low priority for tribal leadership,” and “Not being aware of Purchased/Referred Care or how to use it.”

Of note, as shown in Table 3, the mean ratings for the impact for all 61 factors differed across the four subgroups in a systematic manner. For example, within both women and men, the aged 55-64 overall mean impact rating was approximately 0.6 higher than the aged 65+ group mean of the respective gender. Additionally, for both age groups, the group mean for men was approximately 0.3 higher than the corresponding age group mean among women.

DISCUSSION

Concept mapping is a community-based methodology that incorporates qualitative and quantitative data on complex, multilevel phenomena—in this case, factors influencing the ability of AI Elders to effectively access health care. Use of this approach helps to identify and prioritize key areas for intervention to improve the physical and mental health of Elders in general and to extricate the unique perspectives and needs of subgroups of Elders, specifically women and men, as well as younger and older Elders. Overall, our findings emphasized several areas of agreement among Elders, particularly the perception that Provider Issues and Relationships and Tribal/National Policy have a significant impact on Elder health. Likewise, rankings of individual factor statements underscored that difficulties associated with interactions with health care organizations (i.e., “Long waits at healthcare facilities,” “Not knowing how to report or appeal healthcare/insurance decisions”), unfamiliar technology (i.e., “Limited knowledge of computers or the Internet to obtain online information about insurance”), and a policy environment perceived to be indifferent to Elders’ needs (i.e., “Health care is a low priority for national politicians”) were broadly shared and thought to be impactful among Elders.

The above results resonate with the findings of our larger study on health care access and utilization, which revealed shared experiences of frustration, confusion, and inadequate care resulting from program and funding shortages at IHS and tribal facilities, the bureaucratic complexities associated with health insurance, and a pervasive atmosphere of uncertainty surrounding the stability of public health insurance programs (Jaramillo & Willging, 2021). They also fit within a historical context of discrimination, abuse, and neglect against AIs within the U.S. health care system that has not been redressed. Individual and cultural memories of atrocities, such as the forced sterilization of AI women well into the latter half of the 20th century (Lawrence, 2000), as well as everyday experiences of stigma and mistreatment at the hands of medical providers, shape Elders' trust in, and engagement with, the health care system (Armenta et al., 2021; Guadagnolo et al., 2009; Simonds et al., 2014). As we argue elsewhere (Sommerfeld et al., 2021; Willging et al., 2021), our findings illuminate an urgent need to prioritize system and organizational changes to facilitate Elders' use of health care, including advocating for state and federal governments to meet their treaty obligations by securing stable and adequate funding for tribal health care facilities to provide a full range of care and devoting more resources to helping Elders navigate the health care system. Given the particular emphasis on Provider Issues and Relationships indicated across all four subgroups, this domain should be prioritized for improvement, both at the individual level (i.e., via health literacy efforts on how to navigate, understand, and build productive relationships with health care providers), and at the system level (i.e., ensuring that providers have the time and education to serve populations that have been historically marginalized and disenfranchised, such as AI Elders). In addition, the ubiquity of web-based information and communication in health and insurance systems highlights the need for increased investments in efforts to bridge the "digital divide" for the many AI communities that lack equitable access to broadband internet (Goldstein, 2018), as well as for AI Elders with limited financial and educational resources to obtain and use digital technology.

Although our data suggest that there are many commonalities among Elders in their perspectives on barriers to health care, each of the subgroups had particular areas of concern. Analysis of these differences, facilitated by discussions with our CAB members, allows us to elucidate important ways that Elders' experiences may vary according to gender and as they age. For example, women of both age groups accorded special importance to "Difficulties dealing with emotions related to health care." CAB members noted that this finding points not only to conventional expectations about women exhibiting more emotionality than men, but also to

women's roles as caregivers (Byers, 2010; Gallant et al., 2010). They explained that women's relative difficulty dealing with their own emotions related to health care may stem from the perceived obligation to subordinate the expression of such emotions to those of others and "put on a brave face" for their children and families. Another difficult emotion that was common among elderly women was the fear of "becoming a burden" and no longer being able to care for others if they require care themselves. For example, one CAB member recounted how her cancer diagnosis made her fear that her family would treat her like "a sick person" and not like the grandmother they were used to (Jaramillo et al., 2019). Additionally, we found that the theme of Accessibility and Transportation Barriers was ranked as having the most impact on health among women over age 65, even though no other groups ranked this theme any higher than seventh. Among AIs, women have a higher life expectancy and thus make up a majority of the over-65 population (U.S. Department of Health and Human Services, 2018). Consequently, older women may not only be more likely to experience age-related accessibility barriers, such as not being able to drive or having a hard time making appointments due to hearing impairments or language differences, but also may live alone or have lost former sources of social and material support, such as a spouse who drives them. Moreover, AI women may experience emotional and financial hardships as they utilize their own limited resources to care for others (Gallant et al., 2010; Haozous & Goins, 2012; Letiecq et al., 2008). These findings underscore the influence of social relationships on the mental and physical well-being of Elder women in particular (Roh et al., 2015; Sherman et al., 2011) and the need to acknowledge Elder women's roles as caregivers. Interventions for Elder women should thus include increased opportunities to cultivate social relationships that offer both emotional and pragmatic support, especially as they get older.

In contrast, our findings suggest that Elder men have specific needs around access to and routine use of health care. The higher ranking of "Not having a 'regular' doctor that knows personal health history" among men compared to women is likely due to lower rates of health care utilization among men in general, which would allow them to establish a relationship with a regular care provider (Pinkhasov et al., 2010; Vaidya et al., 2012). A relative lack of familiarity with health care may also explain the higher ranking of Health-Related Self-Efficacy among men aged 55-64 compared to the remaining subgroups. CAB members suggested that younger Elders who were less familiar with health care might emphasize individual-level factors like the ability to self-advocate and "ask the right questions," while older Elders with more complex health care needs would highlight the difficulties of dealing with convoluted health systems, as we describe

below. A similar dynamic may occur among younger Elders in general, contributing to their higher ranking of “Difficulty scheduling appointments” compared to older Elders. Moreover, younger Elders’ challenges with scheduling appointments are likely to be related to variability in health insurance enrollment (Artiga et al., 2017). While Elders aged 65 and older are commonly enrolled in Medicare and are thus more likely to receive regular check-ups and follow-up visits (Boccuti et al., 2014), younger Elders may avoid making appointments because they lack health insurance or struggle with finding providers who are covered by the insurance they have. These findings suggest that efforts to improve health for younger Elders and men should focus on integrating individuals into usual sources of care. This includes ensuring that younger Elders have adequate health insurance coverage and increasing Elders’ comfort with seeking care and interacting with health care providers.

Other age-related variations in our findings relate to challenges for older Elders in navigating complex bureaucracies (“Not being aware of Purchased/Referred Care and how to use it”) and tribal decision-making processes (“Not knowing how to influence tribal leadership,” “Health care is a low priority for tribal leadership”). Older Elders are likely to need more frequent, more complex, and potentially more expensive health care as they age (Okoro et al., 2007), necessitating those who use the IHS to increasingly rely on the PRC system to arrange and pay for specialty services. However, Elders may avoid using PRC due to experiences of rationed care and unexpected medical bills (Artiga et al., 2013). Similarly, while younger men are likely to be involved in tribal government, older Elders—particularly women—may feel unable to access tribal leaders and advocate for their own needs. This tendency is underscored by our finding that men aged 55-64 rated Tribal/National Policy as the least important theme, while all other subgroups rated it among the top three themes in importance. Consequently, efforts to support Elders should focus on helping them navigate health systems by facilitating access to understandable and effective information about resources and services to which they are entitled. For example, interventions to provide culturally congruent health navigators, who can help Elders with decision making, scheduling, transportation, and communication with health care providers, have been well-received among AIs and have been shown to increase knowledge about health and health care, improve access to care, and avoid delays in diagnosis of serious health problems (Burhansstipanov et al., 2014; Grimes et al., 2017). Additionally, tribes can work to increase accountability and responsiveness of tribal leaders—who are often young, rarely have a background in health care or insurance, and frequently are preoccupied with

other matters of relevance to their community—by educating them about the needs of Elders (Jaramillo et al. 2019).

Overall, this study underscores the need to craft interventions that address the multilevel gender- and age-specific factors contributing to physical and mental health disparities for AI Elders. Our findings confirm that health interventions focused on health literacy and behavior (e.g., Centers for Disease Control and Prevention, 2009), particularly those that include technological and online literacy, are needed by Elders. Yet, this research also suggests that such interventions are primarily beneficial to younger Elders and men, whose health struggles are more closely linked to issues with health care utilization. Improving the health and well-being of older Elders and women will require multilevel approaches that target interpersonal and community relationships, the functioning of health care organizations, and broader social and historical factors that contribute to emotional and financial hardships. For example, health care providers should consider the “structural vulnerabilities” of their elderly women patients, meaning the upstream social structures and forces that may influence their health and ability to attend appointments or adhere to medical advice (Bourgois et al., 2017). Addressing these vulnerabilities may include modifying health care environments or procedures (e.g., the ways that appointments are scheduled) and making “prescriptions” of social and economic resources (e.g., food assistance, help with transportation; Metzl & Hansen, 2014). Finally, Elder advocates and tribal, state, and federal policymakers must step up their efforts on meeting treaty-established obligations to guarantee health care for AI people.

Limitations

To promote accurate interpretation of these data, we obtained input from the CAB and contextualized the data within the findings of our broader study, which included the perspectives of many different stakeholders. However, the sample sizes—especially of men—are relatively small and there may be biases in the sample such that these findings are not generalizable to all AI Elders, given the cultural and sociopolitical heterogeneity that characterizes Native North America. The small sample sizes also precluded the identification of issues unique to other subgroups of Elders, such as the “oldest old” (i.e., over age 75) or rural vs. urban residents, which should be prioritized in future research. In addition, individuals targeted for this study were usually fluent in English. However, Elders who were not completely comfortable with written English

may have declined to participate. Although we did not identify any participants as potentially having cognitive impairment, it is possible that individuals with cognitive or other limitations (e.g., of hearing or vision) may have declined to participate.

Because concept mapping is an attention- and time-intensive process, we did not ask our elderly participants to consider separate factor statements related to physical and mental health. However, primary care is the de facto mental health system for patients of all ages (Starfield et al., 2005); consequently, we expect that themes considered here contribute to both physical and mental health disparities.

CONCLUSION

As the population of AI Elders in the United States grows, researchers and policymakers must prioritize efforts to understand and address the persistent inequities that affect their health and quality of life. Findings from this study underscore the inadequacy of broad, primarily individually focused health interventions that do not account for variations in the experiences and needs of AI women and men of different ages, nor for the multilevel challenges that they encounter (Manson, 2020). Rather, this research highlights the need to tailor physical and mental health interventions to Elders' specific life histories and circumstances. Moreover, tribal, state, and federal policymakers must engage in efforts to address the funding shortages, bureaucratic complexity, and inattention to Elders' needs that contribute to their alienation from systems of care. Finally, given the long history of abuse and neglect of AIs in the U.S. health care system, this study points to the need for future research to delve more deeply into variations in the cultural memories and experiences of Elders over the course of their lives and how those experiences influence their access to health care.

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ACKNOWLEDGEMENTS

The authors wish to thank Dr. Emily Haozous, Bear Bennalley, and the Seasons of Care Community Action Board for their valuable contributions to the conduct of this research and to this manuscript.

FUNDING INFORMATION

This study was funded by the National Institute of Minority Health and Health Disparities (R01 MD010292). The funding source had no role in the design of this study, its execution, analyses, interpretation of the data, or decision to submit results.

CONFLICT OF INTEREST DISCLOSURE

The authors declare they have no conflicts of interest.

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