Community Perspectives on Hearing Loss in Rural Alaska

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Objectives: The aim of this study is to present an explanatory model of hearing loss in the Bering Strait region of Alaska in order to contextualize the results of a cluster randomized trial and propose implications for regional hearing-related health care.

Design: To promote ecological validity, or the generalizability of trial findings to real world experiences, qualitative methods (focus groups and interviews) were used within a mixed methods cluster randomized trial evaluating school hearing screening and follow-up processes in 15 communities in the Bering Strait region of Alaska. Focus groups were held between April and August 2017, and semistructured interviews were conducted between December 2018 and August 2019. Convenience sampling was used for six of the 11 focus groups to capture broad community feedback. Purposive sampling was used for the remaining five focus groups and for all interviews to capture a variety of experiences with hearing loss. Audio recordings of focus groups and interviews were transcribed, and both notes and transcripts were deidentified. All notes and transcripts were included in the analysis. The constant comparative method was used to develop a codebook by iteratively moving between transcripts and preliminary themes. Researchers then used this codebook to code data from all focus groups and interviews using qualitative analysis software (NVIVO 12, QSR International) and conducted thematic analyses to distill the findings presented in this article.

Results: Participants in focus groups (n = 116) and interviews (n = 101) shared perspectives in three domains: etiology, impact, and treatment of hearing loss. Regarding etiology, participants emphasized noise-induced hearing loss but also discussed infection-related hearing loss and various causes of ear infections. Participants described the impact of hearing loss on subsistence activities, while also detailing social, academic, and economic consequences. Participants described burdensome treatment pathways that are repetitive and often travel and time intensive. Communication breakdowns within these pathways were also described. Some participants spoke positively of increased access via onsite hearing health care services in "field clinics" as well as via telemedicine services. Others described weaknesses in these processes (infrequent field clinics and communication delays in telemedicine care pathways). Participants also described home remedies and stigma surrounding the treatment for hearing loss.

Conclusions: Patient-centered health care requires an understanding of context. Explanatory models of illness are context-specific ways in which patients and their networks perceive and describe the experience of an illness or disability. In this study, we documented explanatory models of hearing loss to foster ecological validity and better understand the relevance of research findings to real-life hearing-related experiences. These findings suggest several areas that should be addressed in future implementation of hearing health care interventions elsewhere in rural Alaska, including management of repetitious treatments, awareness of infection-mediated hearing loss, mistrust, and communication breakdowns. For hearing-related health care in this region, these findings suggest localized recommendations for approaches for prevention and treatment. For community-based hearing research, this study offers an example of how qualitative methods can be used to generate ecologically valid (i.e., contextually grounded) findings.

Key words: Alaska Native health care, Community-based hearing research, Contextually relevant health care, Ecological validity, Explanatory models of illness, Hearing loss, Hearing Norton Sound, Qualitative methods, Rural Alaska.

Abbreviations: CHA/Ps = Community Health Aides/Practitioners; NIHL = noise-induced hearing loss; PE = pressure equalization; ENT = Ear, Nose, Throat physician.

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INTRODUCTION

Hearing well in childhood is important for social and emotional health, academic and vocational achievement, and economic trajectories for children using spoken language (Järvelin et al. 1997; Bess et al. 1998; Emmett & Francis 2015). In the Bering Strait region of Alaska, hearing is also important for subsistence activities (e.g., hunting) and oral traditions. Systems need to be in place that effectively prevent, identify, and treat childhood hearing loss to ensure children can reach their potential. This is especially important in rural Arctic and Alaska Native populations, where (1) historical data indicate a disproportionately high rate of childhood ear infections and hearing loss (Ayukawa et al. 2004; Langan et al. 2007; Singleton et al. 2009; Fitzpatrick et al. 2020), and (2) structural racism has contributed to such health disparities (Solomon et al. 2022).

To be patient-centered and effective, systems need to consider explanatory models of illness. As Kleinman wrote, illness is the subjective way that patients, their families, and their networks "perceive, live with, and respond to symptoms and disability"

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of a biomedical condition (e.g., hearing loss) (Kleinman 1988, p.3). Explanatory models represent ways in which patients and people in their networks describe the experience of an illness (Kleinman et al. 1978a; Conrad & Barker 2010; Dinos et al. 2018). Explanatory models of illness are fundamentally shaped by local sociocultural contexts, and health care providers can address patient and caregiver perceptions, expectations, and responses to diagnoses by better understanding these illness perspectives. Researchers have promoted the importance of this understanding within hearing health care research, specifically calling for the need for research and systems that prioritize ecological validity, defined as the degree to which research or clinical findings reflect real-life hearing-related function, activity, or participation (Keidser et al. 2020; Rapport & Hughes 2020). To achieve this understanding, Rapport and Hughes (2020) specifically called for the incorporation of qualitative methods into community-based hearing research.

To improve childhood hearing health in rural Northwest Alaska, we conducted a mixed methods cluster randomized trial called Hearing Norton Sound, which included both qualitative and quantitative methods. This trial sought to improve the school hearing screening and follow-up processes in 15 rural communities in the Bering Strait region of Alaska (see Figure 1; Emmett, Robler et al. 2019a; Emmett, Platt et al. 2022). To increase follow-up care after school screening, the trial compared a specialty telemedicine intervention to the standard of care (a referral letter home to parents/guardians). To foster ecological validity, community feedback informed the design of the trial (Robler et al. 2020), and focus groups and interviews collected community perspectives on hearing loss in rural Alaska (Emmett et al. 2019b). We sought to understand local experiences of hearing loss from the perspective of parents, children, elders, teachers/school staff, principals, and health care providers/clinic staff.

The results of the trial showed the telemedicine intervention increased follow-up more than two times compared to the standard letter home to parents (from 32.1% to 68.5% receiving follow-up within 9 months of referral; Emmett et al. 2022). This was the first randomized trial to demonstrate that telemedicine can reduce a key rural health disparity by improving access to specialty care. Yet without consideration of the contextual factors that influence uptake by families, schools, providers, and organizations, we recognize that even the most effective interventions are unlikely to lead to substantial change in public health outcomes. Here, we present a local explanatory model of hearing loss, which contextualizes the findings of our trial, presents implications for regional hearing health care delivery, and serves as a methodological example for pursuing ecological validity in community-based hearing research.

MATERIALS AND METHODS

Setting

Hearing Norton Sound was conducted in 15 rural communities in the Bering Strait region of Northwest Alaska, between April 2017 and August 2019 (Emmett, Robler et al. 2019a, 2019b; Emmett, Platt et al. 2022). The Bering Strait region spans ~23,000 square miles in Northwest Alaska (see Figure 1). The region has 15 rural communities and one regional hub town, with three culturally and linguistically distinct groups of Alaska Native people: Iñupiaq, Yup'ik, and St. Lawrence Island Yupik. In these groups, the ability to hear can be central to subsistence

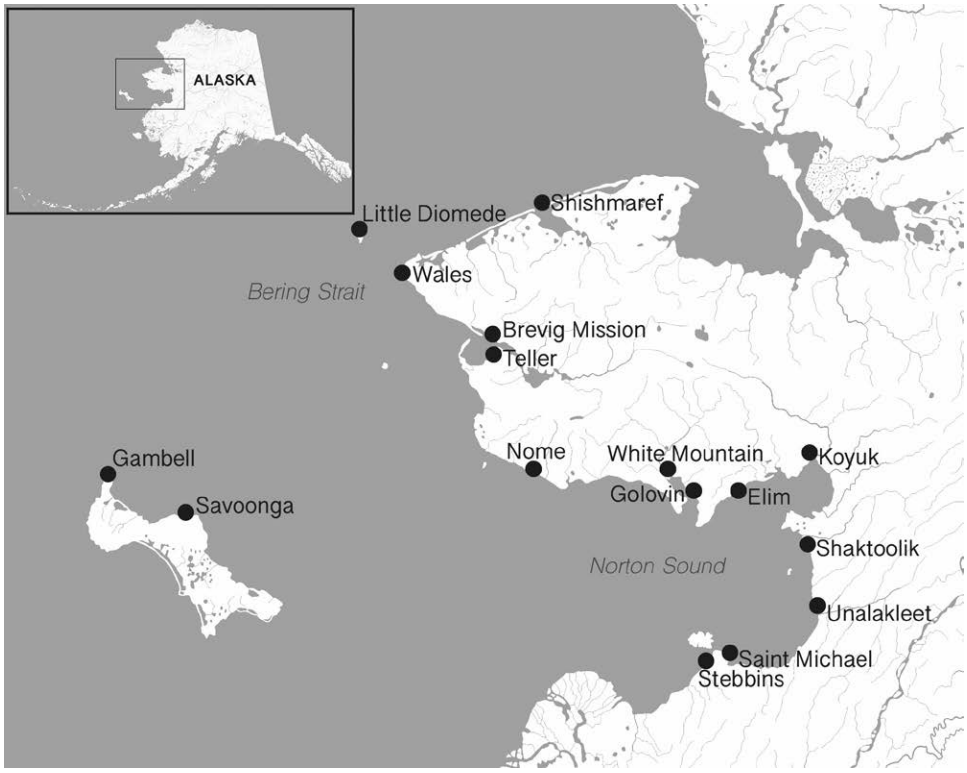

Fig. 1. Map of communities in Bering Strait region in Northwest Alaska.

activities, drumming and dancing, and the role of elders in the community (e.g., passing down oral traditional knowledge and history through storytelling). The primary health care organization in the region is Norton Sound Health Corporation, a tribally owned nonprofit health system based in the regional hub of Nome. Nome is ~500 air miles northwest of Anchorage and is accessible only by plane or helicopter. Each community has a Norton Sound Health Corporation clinic staffed primarily by Community Health Aides/Practitioners (CHA/Ps), local providers who are trained through a standardized state-wide curriculum to deliver emergency, acute, chronic, and preventive care in their communities (Overview of the Alaska Community Health Aide Program 2005). These local providers are ingrained in the communities they serve and are often from those communities. For hearing-related health care, CHA/Ps routinely use telemedicine technology to consult with audiologists and otolaryngologists based at the regional hospital in Nome and the state's tertiary hospital in Anchorage, where patients from the region are required to travel for ear surgery. The Bering Strait School District operates a school in each of the region's 15 communities. The Bering Strait School District Special Education Department coordinates annual hearing screenings at each school.

Participants

Community members and stakeholders with various experiences of ear and hearing-related issues were recruited for participation in focus groups or interviews. Stakeholder groups included parents, children, elders, teachers/school staff, principals, and health care providers/clinic staff. Focus groups were held prior to the start of the trial from April to August 2017, and semistructured interviews were held during the trial from December 2018 to August 2019.

Procedures

Participants were recruited via announcements (e.g., flyers, social media posts, and radio announcements) and via direct contact both in person and remotely (e.g., phone call and email). Using convenience sampling, six of the 11 focus groups were considered community events and were open to all community members to obtain feedback from the community at large. Using purposive sampling, the remaining five focus groups were stakeholder-specific and dedicated to teachers, parents, and CHA/Ps. Semistructured interview participants were recruited using purposive sampling to select individuals who had some experience with ear and hearing-related issues. Some individuals with such experience self-identified in response to the recruitment announcements and others were referred to the study team by school staff, health care staff, or community members.

Most focus groups and interviews occurred in person, although due to the prohibitive expense of additional air travel, some occurred remotely via phone or video call to ensure participation from across the region. Community event-style focus groups were held in community halls or multipurpose buildings, while stakeholder-specific focus groups were held in semiprivate spaces relevant to the stakeholder group, such as a meeting room in the clinic or the school. Interviews took place in private spaces such as empty classrooms, clinic rooms, homes, or rooms within a community building. Both focus groups and interviews used semistructured guides, which were designed collaboratively by the study's Scientific and Alaska Stakeholder teams (for a detailed description of team roles, see Robler et al. 2020).

Focus groups were audio-recorded and conducted in English. A technological error caused the loss of one focus group audio recording. The facilitators noticed this immediately after the discussion and wrote out detailed minutes using the video call chat history. These minutes were used in the analysis in lieu of a transcript. Semistructured interviews were conducted by trained members of the study team. During the interview consent process, participants opted for the interviewer to either audio record the interview or take handwritten notes. Interviews were conducted in English unless a participant preferred their native language of Iñupiaq, Yup'ik, or St. Lawrence Island Yupik. Interviews were conducted one-on-one with stakeholders or in pairs, if preferred (e.g., mother and child pair).

All participants reviewed and signed a written informed consent form. Any participant under the age of 18 years required a signed informed consent form from a parent/guardian and assent from the child. The study was approved by the Alaska Area Institutional Review Board, Duke University Institutional Review Board, and Research Ethics Review Board at Norton Sound Health Corporation.

Data Analysis

For analysis of focus groups, all audio recordings were transcribed and de-identified. Any written notes taken during focus groups were included at the bottom of each relevant transcript. The constant comparative method was used to develop a codebook by iteratively moving between transcripts and preliminary themes (Boeije 2002). A sample of transcripts were independently reviewed by two members of the study team to outline themes. Regular meetings were held over several weeks (eight meetings) to further develop themes and build the codebook. The codebook was then refined by the Alaska Native members of the Alaska Stakeholder team iteratively over two meetings. Senior study team members advised final refinements and approved the final codebook. Two members of the study team then independently double-coded the remainder of the focus group transcripts.

For analysis of semistructured interviews, all audio recordings and notes were transcribed and de-identified. The constant comparative method was used to develop a codebook by iteratively moving between transcripts and preliminary themes generated from the focus group analysis. Four study team members, including two senior members, independently read through a sample of transcripts from each stakeholder group (~10 total) and collaboratively developed a preliminary codebook, building from the codebook used for the focus group analysis. Using this preliminary codebook, three study team members, including one senior member, independently read through an additional sample of transcripts and independently created modified versions of the codebook to better fit transcript content. The independent versions of the codebooks were reviewed and synthesized into one version. Then two study team members used QSR International NVivo 12 to independently code the same 10% of the sample and run coding comparisons. They met to discuss each coding discrepancy, and refined coding definitions and criteria to create the final codebook. This iterative process

was supervised by senior study team members and members of the Alaska Stakeholder team, who approved the final codebook.

After agreement was achieved and code definitions were finalized, two study team members independently coded the remaining interview data using NVivo 12. Trustworthiness was increased through regular meetings held with the Scientific and Alaska Stakeholder teams, and the Lead Parent Stakeholder and the Lead Patient Partner were integrally involved in reviewing content and codes. Through iterative meetings and asynchronous review over email, the group reviewed the themes and quotes for authenticity, representativeness, and comprehensiveness (Morse 2015). The full study team conducted thematic analyses of the coded focus group and interview data to distill the findings presented in this article.

RESULTS

A total of 116 individuals participated across 11 focus groups (15 to 87 years of age). Within the semistructured interviews, a total of 101 individuals participated (12 to 86 years of age; Table 1). All interviews were conducted in English except for two conducted by a study team member in St. Lawrence Island Yupik with elders who preferred interviewing in their native language.

Participant feedback was categorized into three domains (etiology, impact, and treatment), with respective subdomains (see Table 2).

Etiology

Noise Exposure • Many participants attributed hearing loss to noise exposure. Participants explained that many men in their communities hunt big game for subsistence use, such as beluga whales, and are exposed to loud gunshots, resulting in hearing loss later in life (see Table 3, quote 1). One individual discussed the importance of children learning how to hunt at a young age, and acknowledged that consequentially, hearing damage from gunshot exposure may begin at a young age (see Table 3, quote 2). A mother shared that she believes three of her four boys have hearing loss from hunting, which involves boating and shooting as young as 12 or 13 years of age. Although less frequently, participants also described damaging exposure to community members' hearing via loud music played through earbuds, construction work, chainsaws, military service, motors (snowmobiles and boats), and rotary tools used to carve ivory (see Table 3, quote 3).

Ear Infections • Other participants attributed hearing loss to ear infections, such as otitis media, which were described as a recurrent issue in some children often resulting in hearing loss (see Table 3, quote 4). Participants also talked about the cause of ear infections. Some attributed ear infections to tobacco smoke exposure (both during pregnancy and childhood) and improper posture while bottle feeding babies. Mothers discussed the importance of propping up a baby while bottle feeding in order to avoid ear infections (see Table 3, quote 5). Other causes for ear infections described by participants included the seasonality of ear infections. One participant wondered if higher ear infection rates might be correlated with a lack of running water in certain communities' households. Very few participants spoke about hereditary hearing loss or hearing loss due to other causes, such as traumatic injuries or ototoxic medications.

TABLE 1. Summary of participant characteristics for focus groups and semistructured interviews

Participant Characteristics	Semistructured Interviews (n)	Focus Groups (n)
Age (yrs)		
5–18	11	2
19–40	35	42
41–55	30	30
56+	25	42
Gender		
Female	71	79
Male	30	37
Stakeholder group*		
Elders	14	
Parents	25	
Children	11	
Teachers/school staff	18	
Principals	6	
Health care providers/clinic staff	27	

Stakeholder affiliation was not collected for all focus groups; therefore, stakeholder group is only reported for interview participants.

TABLE 2. Domains and subdomains that structure the regional explanatory model of hearing loss, which emerged from analyses of semistructured interview and focus group data

Regional Explanatory Model of Hearing Loss	
Domain	Subdomain
Etiology	Noise exposure
	Ear infections
Impact	Communication
	Subsistence activities
	Social limitations
	Emotional well-being
	Childhood language development
	School performance
	Vocational opportunities
Treatment	Repetitive cycle
	Long time frame of observational treatment
	Communication gaps
	Access
	Home remedies
	Stigma

Impact

Participants described the impact of hearing loss across the lifespan. Recurring themes included communication, subsistence activities, social limitations, and emotional well-being. Impact related to children specifically included language development, school performance, emotional well-being, and vocational opportunities.

Communication • Strained communication was widely described as a direct consequence of hearing loss, resulting in tension in family relationships (see Table 3, quote 6). Miscommunications were also recounted (see Table 3, quote 7). In children, hearing loss was related to speech delays, which were in turn related to communication difficulties within families. One mother described her children's hearing loss

TABLE 3. Select participant responses during semistructured interviews and focus groups, grouped into the 3 domains of this regional explanatory model of hearing loss

Domain		Quotes
Etiology	1	"Most of the men that go out beluga hunting. I think most of them have problems hearing when they get a little older. Like I do. You go out there and you hear a lot of banging when you're hunting beluga… because a lot of them don't have ear plugs or anything like that. Most of them just go out with their boat and their rifle and go out hunting and they're banging at, shooting at beluga. And as they get older, like me, when I get gray hair, my wife said my hearing loss is kinda poor. That's what happens to all the hunters that always go hunt the beluga and big game."
	2	"…I started hunting about 6 years old. And this is where we hear a lot of noise, a lot of shooting. We don't have ear plugs, we don't have hearing protection. Maybe that's where part of my hearing has gone."
	3	"I'm a carver of 20 plus years. The blaring sound of the dremel, you know, it can have an effect over time. I noticed now that my hearing is not as sharp as it used to be. Sometimes I do wear a headset but I can't keep an eye on my kids at the same time."
	4	"You see a lot of kids—they get so many infections, they'll finally be referred to ENT in Anchorage, they usually go in and get ear tubes. The lucky ones that get ear tubes, they don't have much problems. The unlucky ones, you see time and time again to where they're using the same medicine and having a chronic ear infection, it's affecting their hearing…"
	5	"I noticed when maybe babies are bottle fed, and they're, you know, laying down flat instead of propped up with a pillow—seems like they have more hearing problems… I'm going to take my kids for example, they had hardly any ear infections when they were a baby, now they're teenagers. Because we took it upon ourselves to learn about proper bottle feeding so they don't have many ear infections."
Impact	6	"When I saw my parents towards the end of their days, they were constantly at each other, bickering at each other because my dad couldn't hear a dang thing."
	7	"My daughter, she struggles with hearing—and like I was stating earlier, that some people have miscommunication—I was giving my daughter a compliment one day and then she broke out crying because her ears made her hear different. And she thought I was scolding her."
	8	"As a hunter, hearing is very important. For example, you're chasing whale and you lose it. All you can hear is the blow. And you can't see the whale. All you can do is hear it. That's how we mostly get our whales when we go hunting."
	9	"You gotta listen. Those animals make distinctive sounds…when you learn those sounds you can tell what the animal is up to. Like when you're out looking for eggs, you know. Like if a little bird is trilling, if he's chirping real fast, you're near his nest. So hearing is very important in regards to doing things out here in our culture."
	10	"You need to be aware of your surroundings, like if you're crossing water. You need to listen for the wind, the water, the animals. And for safe awareness of environmental sounds like ice cracking and moving or branches breaking beneath an animal nearby."
	11	"Oftentimes when you're hunting you hear things before you see them. So being able to hear things is super important."
	12	"I talked to them every day, so I pretty much could make out what they were trying to say, but with people they weren't around, it was just garbled. Like baby talk. So they couldn't communicate real well what they wanted or what they needed with anyone but me."
	13	"I think hearing is important to me because we have to listen and to hear the world. And when people tell us what to do so we know what to do. And we understand."
	14	"I think it makes my nephew feel kind of left out…makes him feel…what's the word—disabled? In some sort. In some way."
	15	"He had tubes. And within two weeks it was a miracle. His speech. People around him could understand what he was actually saying because he could repeat and enunciate the words that he couldn't hear before."
	16	"I didn't really know she couldn't hear on one side, and she would get lower grades than my other kids and she wasn't slower mentally she just couldn't hear well. I finally caught on after a few years and then she finally got referred to the hospital at age 12, but she had poor hearing for 12 years."
	17	"It's important to detect hearing loss early in childhood. Because some kids might want to enlist in the military and if they have bad hearing, you won't be able to go to the military. Or pursue a career."
Treatment	18	"My granddaughter. She's had tubes ever since she was about 18 months…now she's 5. And she had tubes twice put in. One fell out and now she got hearing loss in one ear. And that took how many years of being on tubes. How come it don't correct it? The school say she got hearing loss in one ear because you know, they send her for tubes and then she'll come home. And then maybe not too far down the line, one of them pop out. And then they have to go Anchorage. And come home. And you know, that's a lot of traveling for tubes."
	19	"But see? Then they gotta go back to Anchorage and redo the tubes. See? That's the problem right there. See? I wonder how they could maybe improve that. Where parents don't have to get up, go travel. It's a lot of work when we got subsistence and some families work. And we don't have time and money to do this."
	20	"…now they say she got hearing loss. So how come, you know, how come they always put tubes? Seems like it don't help. And now she got a worse problem than before."
	21	"I know when we were kids, my generation, it was our tonsils. I remember getting lined up and getting our tonsils out, getting shipped to Nome. Seems like the latest trend, I mean this is my personal opinion, but the latest trend for Native students, Native kids, is to get tubes in their ears. So, I don't know if it's a new technology. Does the mainstream society get tubes in their kids' ears when they have issues with their ears? That's what I'd like to know."
	22	"I've seen a lot of people, most of these kids will have earaches for a long time because their parents won't even finish the antibiotic you gave them, or they won't finish the eardrop that's prescribed to them. They'll come in for an earache and you get this and this, they'll be back next week. Same problem. Did you do the medicine. Nope. Why didn't you. Ah, I forgot…"

(Continued)

TABLE 3. Continued.

Domain		Quotes
Treatment, cont.	**23**	"I stuck to [the antibiotics], like you know, with my second son, I said nope, we got it every single time, I gave it to him for the full treatment."
	24	"My daughter was scheduled for an ear appointment in [community name] and the guy never called us back. This was like going on two years now."
	25	"It would be nice if Audiology could do more up front and asking…how about making phone calls to the patients? Let them know we'll be in your village this day and that day, we would like to see you…"
	26	"…[with telemedicine] the provider can see the patient, the patient and the parent can see the provider, they can go through the treatment plan—it saves a lot of time, money, and effort. To get people moving and…getting their treatment plan done—I mean—it's been phenomenal just to see what type of technology that we're working with."
	27	"Sometimes like when the [telemedicine] case is sent to Audiology and then sent to ENT, especially on Fridays, you don't get a response back until Monday or Tuesday…I think patience is the biggest…like their waiting time….it's the biggest complication doing the telemed cases."
	28	"When I had earaches, my mother she would pour seal oil into my ears and that would soothe the ache and get the air out."
	29	"My nephew lives with me, and he had hearing aids but he stopped wearing them because he was teased."
	30	"I think my friend is ashamed of having a hearing problem and I think she was ashamed to use her hearing aids because she's young but I tried to tell her she could just use them because I don't think anyone would judge her."

ENT, ears, nose, throat physician.

and speech development delays when they were toddlers as so severe that certain family members could not understand their words.

Subsistence Activities • Subsistence activities—which in this region include activities such as hunting, fishing, berry picking, harvesting greens, or gathering bird eggs—were emphasized as activities that can be limited by hearing loss. Across all of these activities, keen hearing was described as key to success and safety (see Table 3, quotes 8 to 11).

Social Limitations • Limitations on social activities were described for various severities of hearing loss. An elder disclosed that he was not going out visiting or participating in any public activities because it was difficult to hear others. A participant recalled that another elder in their community could no longer sing with the community dance group because of his hearing loss. A mother explained her young child's inability to socialize well with others due to their hearing loss (see Table 3, quote 12). Another participant spoke of good hearing as important for social learning (see Table 3, quote 13).

Emotional Well-Being • In terms of emotional impact, hearing loss was characterized as troublesome, annoying, and frustrating for both the person experiencing hearing loss and their social circle. For children in particular, participants described the experience of isolation and disability (see Table 3, quote 14). When asked about impact on their school and home life, one child experiencing hearing loss expressed feeling awkward and shy about asking for people to repeat. Outside of communication dynamics, several participants emphasized hearing as a facilitator of general emotional well-being, through the enjoyment of sounds of music and nature.

Childhood Language Development • Delays in childhood speech development were described as a result of hearing issues. Parents characterized their children's speech as garbled, mispronounced, or mumbled. This impact of hearing loss was described as both lasting and temporary: one participant described a child whose speech was still affected after age 18, while another described a profound improvement in a child's speech after they received treatment with the insertion of pressure equalization (PE) tubes, a common surgical procedure to address recurrent ear infections (see Table 3, quote 15).

School Performance • Marginal school performance was noted as a danger of unaddressed hearing loss in children. Participants described children experiencing hearing loss and responding with frustration or disengagement at school. Several parents explained how they make sure to communicate to their child's teacher regarding the need to sit in the front of the classroom. One parent described late identification of her daughter's hearing loss and the impact on her school grades (see Table 3, quote 16).

Vocational Opportunities • Participants voiced concerns about limitations on future vocational opportunities for children with hearing loss. Specifically, the inability to join the military due to hearing loss was mentioned (see Table 3, quote 17). One mother termed it explicitly as an issue of opportunity: "I don't know what my girls will do when they get bigger, but I want them to have a chance."

Treatment

Participants described several themes related to the treatment of hearing loss: the repetitive cycle of medical treatments, long time frames of observational periods, communication gaps, access to care, home remedies, and stigma.

Repetitive Cycle • The cyclical repetition often inherent to childhood ear infections and treatment was heavily emphasized by participants. In particular, participants focused on the repetitious cycle of tube placement, extrusion, and replacement (see Table 3, quote 18). Another participant voiced frustration with clinical solutions that require constant and recurrent travel for treatment (see Table 3, quote 19). Two elders expressed generalized skepticism of PE tubes as a treatment for ear infections (see Table 3, quote 20). Another elder wondered if PE tubes were just the latest clinical trend in treating Alaska Native children (see Table 3, quote 21). Antibiotics were also discussed within treatment of ear infections. Some participants attributed recurrent ear infections to unfinished courses of antibiotics (see Table 3, quote 22). Meanwhile, other participants expressed the

importance of adherence to treatment regimens (see Table 3, quote 23).

Long Time Frame of Observational Treatment • The time frame of observational treatment was noted by many participants to be long. One recounted that audiologists and otolaryngologists in Anchorage and Nome will tell parents, families, and community health aides to "watch it, watch it, watch it" creating "a very slow process" of treatment.

Communication Gaps • Within these long treatment timelines, participants described communication gaps between the health system and parents/families (see Table 3, quote 24). One parent asked for more proactive communication from the specialists (see Table 3, quote 25).

Access • Regarding access to specialty care, such as frequency of field clinics and telemedicine consults, some participants spoke positively about audiology field clinics in the communities, while others wished that there could be more frequent or longer field clinics. Telemedicine was described positively as a tool that has increased access to care in the communities (see Table 3, quote 26). However, participants also described telemedicine process weaknesses, ranging from technical issues to communication delays (see Table 3, quote 27).

Home Remedies • Participants spoke of home remedies to treat draining ear (such as from otitis externa, suppurative otitis media, or myringitis). These included seal oil, warm water and vinegar, and lotion (see Table 3, quote 28).

Stigma • In describing interventions for hearing loss, multiple participants noted stigma around hearing aid usage. One participant recounted a child's experience of teasing (see Table 3, quote 29). Several other participants made statements about individuals not wearing hearing aids because of embarrassment. One child spoke about their friend being too ashamed to use her hearing aids (see Table 3, quote 30).

DISCUSSION

This is the first study to present an explanatory model of hearing loss in rural Arctic or Alaska Native populations, where data indicate a disproportionately high prevalence of ear infections and hearing loss in children (Ayukawa et al. 2004; Langan et al. 2007; Singleton et al. 2009; Fitzpatrick et al. 2020). Our study engaged a wide range of stakeholders, recognizing the multilevel socioecological influences that impact health behavior, both generally and within hearing loss in particular (Manchaiah et al. 2015). By using qualitative methods to document and present this regional explanatory model of hearing loss as a part of a cluster randomized trial, we are answering the call for increased ecological validity in hearing research (Dinos et al. 2018; Keidser et al. 2020; Rapport & Hughes 2020). This work builds upon qualitative research conducted in other contexts, which has documented knowledge, attitudes, and beliefs around ear and hearing-related health care to inform health care delivery (Curry et al. 2002; Crandell et al. 2004; Manchaiah et al. 2015; Zhao et al. 2015). We believe our findings contextualize the results of our cluster randomized trial, present implications for regional hearing health care delivery, and offer an example of how qualitative methods can produce ecologically valid findings within a mixed methods community randomized trial.

When describing causes of hearing loss within their communities, participants focused heavily on noise-induced hearing loss (NIHL) and less on hearing loss related to ear infections. This may be because NIHL is permanent, while infection-related hearing loss can be transient. It may also be because NIHL affects individuals across the lifespan, from childhood through adulthood. While NIHL occurs in many contexts beyond this region (Daniel 2007; Henderson et al. 2011; Su & Chan 2017), the focus on NIHL versus infection-related hearing loss here is notable given the high prevalence of ear infections in the region and the impact of childhood hearing loss on hearing-related quality of life (Hicks et al. 2022; Emmett et al. 2023, p.2). This finding indicates the need for increased health education efforts regarding infection-related childhood hearing loss. Meanwhile, participant feedback on the etiology of ear infections suggests a need for increased awareness around the following: (1) the potential protective effect of breastfeeding against ear infections; (2) the negative effects of secondhand smoke on childhood ear and hearing health; and (3) lack of clarity on whether bottle feeding posture is a significant risk factor for ear and hearing issues.

The impact of hearing loss on subsistence activities is unique to this population and has not been reported elsewhere. While the regional health system has made efforts to make hearing protection (e.g., ear plugs) readily available for rural community members, feedback presented here indicates that community members are still being exposed to high levels of noise without having or using hearing protection. While the relationship between recreational noise exposure and hearing loss is not unique to this region (Ivory et al. 2014; Neitzel & Fligor 2019), region-specific information may inform hearing health promotion efforts moving forward. Participants discussed how hearing is both important for successful hunting and can be damaged by hunting. This duality highlights the importance of using hearing protection while hunting and presents a potentially effective messaging approach for future health promotion campaigns. The other effects of hearing loss that participants described (e.g., difficulties in intrafamily communication, withdrawal from social activities in the community, and children's difficulty with school) are consistent with negative effects that have been described elsewhere (Bess et al. 1998; Daud et al. 2010; Umansky et al. 2011; Emmett & Francis 2015; Tomblin et al. 2015; Nordvik et al. 2018). During clinical encounters, providers could ensure they are listening for these impacts on daily life. Clinicians could motivate treatment by focusing on the treatment's alleviation of these negative impacts of hearing loss rather than the immediate effect of the treatment itself (e.g., hearing aids can ease family communication and social interactions versus hearing aids can facilitate increased audibility).

Within treatment pathways, participants specifically requested more proactive and early communication about treatment needs and appointments. In a context where external factors like weather heavily impact rural travel by plane, this underscores the need for communication systems that are both time-efficient for provider offices and nimble enough to notify patients of last-minute changes. These requests align with findings in other contexts, which have emphasized the importance of clear communication pathways from health care providers and involvement of the child's parents/caregivers in care decisions (Stephens et al. 2020; Campbell et al. 2022). Regarding treatment choices, several elders expressed skepticism about the effectiveness of PE tubes, while one elder even questioned whether PE tubes are just the latest trend in treating Alaska

Native children. Given that health care systems have historically been perpetuators of structural racism against Alaska Native people, this kind of mistrust is nuanced and context-specific, and must be considered in all health care delivery in this region, including hearing health care (Solomon et al. 2022).

Within treatment pathways, participants' commentaries on watchful waiting, repetitive treatment cycles, and use of home remedies resemble previous reports from other contexts (Chando et al. 2016; Poole et al. 2016; Stephens et al. 2020). Participants particularly expressed frustration with the repetitiveness of treatments such as antibiotics or tube placement for ear infections, as well as the inconvenience these repetitive treatments pose to their daily lives, especially when travel over great distances is required. Some of their frustration may stem from the gap Kleinman has written about, where in biomedicine, there is often an unaddressed need for attending to illness problems ("experiential, interpersonal, family, economic, occupational problems created by the disease") in addition to disease problems ("diagnosis and evaluation of clinical status, complications, etc.") (Kleinman 1978b, p.430).

Clinical providers could highlight and offer telemedicine options, where feasible, as pathways that pose less disruption to patient lives. Such use of telemedicine for ear and hearing health care has been shown to reduce patient wait times while resulting in medical decision-making comparable to an in-person examination (Patricoski et al. 2003; Kokesh et al. 2008, 2009; Hofstetter et al. 2010) and can be an effective tool for furthering hearing health equity (Robler et al. 2022). Increased and improved use of telemedicine, particularly when used by CHA/Ps who live in and are often from these rural communities, may mitigate interruptions to patients' daily lives (e.g., plane travel for in-person audiology or ENT care) while still addressing clinical needs. As Kleinman wrote, "merely structuring the clinical process as a negotiation has beneficial effects on compliance, satisfaction, and management problems" (Kleinman 1978b, p.430). However, as participants described, the current telemedicine system is subject to technical issues and communication delays. Further work is needed to understand how telemedicine processes may be adapted to harness their full potential in this and other rural settings.

These findings provide context for our trial results and present considerations for future implementation of similar interventions in other regions of rural Alaska. While the trial showed substantially improved access to care for children who received a specialty telemedicine encounter following school hearing screening, future iterations of this intervention must anticipate and address the concerns documented in this model, especially weaknesses in the telemedicine system, low awareness of infection-mediated hearing loss, mistrust, and communication breakdowns.

This work aligns with increasing calls for the use of qualitative methods in hearing research to foster ecological validity in trial findings (Keidser et al. 2020; Rapport & Hughes 2020). We present qualitative findings produced from a mixed methods design, which provide an example of how qualitative data can contextualize the experience of hearing loss for a particular group. Although parts of this model resemble phenomena documented elsewhere in other contexts, the intention of this article is to present the experience of hearing loss in this region of rural Alaska. Such contextually specific information is important to inform regionally appropriate health care and activities for health promotion. Future community-based hearing research should continue to use qualitative methods to contextualize quantitative findings and enhance ecological validity.

There are several limitations to this study. Some study team members held positions as staff and/or providers at the regional tribal health organization through which many of the participants receive health care. While the trust these study members had established was beneficial, it is possible that some participants' feedback may have been influenced by these positions. To mitigate potential influence, research staff emphasized that participation or feedback would have no impact on clinical care. Another limitation was the use of purposive sampling for individuals with hearing health care experience. While this sampling strategy was important to capture a wide range of relevant experiences, it may have artificially inflated the significance of hearing in the sample. To mitigate this, the study team conducted some convenience sampling to involve community members at large and not just those with experience of ear and hearing-related issues. A third limitation is the "inevitable gap between the experience…and any communication about it" (Riessman 2002, p.224). With a social constructivist lens, we can understand that these communications are fundamentally shaped by the researcher and participant interaction and then interpreted dialectically and actively by the researcher (Charmaz 1990). The study team avoided treating each individual's feedback as objective truth and instead considered feedback in aggregate across the full dataset (Miczo 2003). Layers were built into thematic review and involved a large diverse team, including regional stakeholders and scientific members.

We have presented an explanatory model of hearing loss in a rural region of Northwest Alaska. In doing so, we have contextualized the results of our cluster randomized trial, provided information that may be used to improve hearing-related health care delivery in the region, and offered an example of how qualitative methods can enable the production of ecological valid (i.e., contextually grounded) findings in hearing-related research.

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