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In Our Sacred Voice – An Exploration of Tribal and Community Leader Perceptions as Health Communicators of Disease Prevention among American Indians in the Plains

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ABSTRACT

American Indians (AI) are disproportionately and significantly impacted by disease morbidity, mortality and poor behavioral health outcomes. Health promotion and health communication programs exist to address these health disparities and health conditions; however, few programs fully integrate holistic approaches when targeting AI populations. The objective of this study was to explore how tribal and community leaders throughout the Central Plains (Kansas, Iowa, Missouri, and South Dakota) viewed themselves as health communicators and health promoters within their communities. Members of the Center for American Indian Community Health (CAICH) conducted 39 in-depth interviews with members of federally recognized tribes living in reservation communities as well as urban tribal communities across the region. Results from the sample show that these individuals do not necessarily see themselves as the “authority” health communicator or health promoter within their tribe or community. They did perceive themselves and others as gatekeepers of pertinent health information. Social and cultural authority within culturally centered messaging and collective delivery of this type of health information from trusted sources within tribes and communities is perceived to bolster health communication programs and positively impact health outcomes among AI populations.

Introduction

Health communication and health promotion programs exist to address health disparities and health conditions among American Indian peoples and communities; however, more is needed to fully integrate Native community members and leaders into the health promotion and health communication process. The integration of American Indian cultural, social, and spiritual values and norms, as well as oral traditions have shown impactful on American Indian health and wellness (Heaton et al., 2018; F. S. Hodge et al., 2002). Historically, and counter to the positive outcomes on these traditions, many cultural, social, and spiritual aspects of American Indian life have been impaired by Western cultures and the accompanying ethnocentrism, ethnocide, and genocide, resulting in many instances of historical trauma (Brave Heart, 1998; Duran & Duran, 1995; Evans-Campbell, 2008). These factors have perpetuated a cascade of negative health outcomes and other health issues among American Indians (Heckert & Eisenhauer, 2014, 2014; Morgan & Freeman, 2009; Szlemko et al., 2006, 2006).

Due to colonization, Westernization, and the paternal nature of the Euro-American biomedical model, health communication and health promotion about health disparities and disease prevention shared with American Indian peoples and communities may actually dissuade Native individuals from seeking better health

because of cross-cultural miscommunication (Kagawa Singer, 2012; Kagawa-Singer & Kassim-Lakha, 2003). Disease prevention information provided to Native peoples and communities through culturally responsive and inclusive health communication strategies is plausible to increase awareness and impact attitudes toward positive health behavior (Geana et al., 2012; Gearhart & Trumbly-Lamsam, 2017; Kalbfleisch, 2009; Rentner et al., 2012). Health communication and health promotion shared by medical personnel or researchers can also have a deleterious impact and contribute to health information inequalities and inequities (Kreps & Sparks, 2008). These forms of strategic communication with minimal inclusion of lived experiences of historical trauma, mistrust and other adverse events among Indigenous populations may hinder disease prevention. Further, exclusion of Indigenous health beliefs and behaviors in health communication and health promotion also minimizes message effectiveness (Hinnant et al., 2019). The present study aims were to explore perceptions that tribal leaders and elders in the Central Plains have about their role as promoters and communicators of disease prevention among Native peoples and communities. Our inquiry to explore credible and reliable sources within a communicative infrastructure (Dutta, 2018) among this sample was guided through an historical trauma and critical cultural communication lens. To our knowledge, this is one of the first community-based studies to explore perceptions that Native leaders have about being health communicators in their communities.

Health disparities among American Indians

According to the 2010 U.S. Census, 0.9% of the population, or about 2.9 million people, identify as solely American Indian or Alaska Native, while 1.7%, or about 5.2 million people claim to be either solely American Indian, Alaska Native or American Indian or Alaska Native in combination with one or more races (Norris et al., 2012). Currently, American Indian populations are disproportionately and significantly impacted by disease morbidity, mortality (Espey et al., 2014; Heron, 2013; Jacobs-Wingo et al., 2016; National Center for Health Statistics [NCHS], 2019) and poor behavioral health outcomes. These outcomes reflect a dire picture of overall health where American Indian populations have an almost 5-year shorter life span than all other racial/ethnic groups (Indian Health Service [IHS], 2015). Based on the U.S. Department of Health and Human Services data from 2017, American Indians have the highest infant mortality at 9.2 per 1,000 live births as compared to 4.7 for non-Hispanic Whites and 5.8 for all races (Office of Minority Health [OMH], 2020). A 2019 National Vital Statistics Report shows the five leading causes of death among American Indian populations are heart disease (18.1%), cancer (17.1%), accidents (11.6%), diabetes (5.8%), and chronic diseases of the liver (5.5%) (Centers for Disease Control [CDC], 2020). In the Midwest, health disparities among American Indian populations also reflect a deficit in oral health care and access to dental services (NCHS, 2019).

Health disparities among American Indian populations can, in part, be described by a variety of phenomena, barriers, and lived experiences. Within these populations historical trauma (Sotero, 2006) informs experiences with medical authority, medical conditions, distribution of power, and existing public narratives that impact health (Mohatt et al., 2014). These experiences then are probable to shape identified perceptions, attitudes, and beliefs toward health and wellness narratives and information (Larkey & Hecht, 2010). Reaching these populations with relevant communication and language that is culturally inclusive (Kreuter et al., 2003; Kreuter & McClure, 2004; Thomas et al., 2004), culture centered (Larkey & Hecht, 2010) and reflective of a diverse and vast American Indian population may assist in the mitigation of disease.

Historical trauma and medical mistrust

Historical trauma is multigenerational trauma experienced by a specific cultural, racial, or ethnic group. It is related to inhumane acts that have oppressed a particular group of people and have included slavery, the Holocaust, forced migration, and the violent colonization of Native Americans (Administration for Children and Families [ACF], 2020). Lakota clinician and researcher Maria Yellow Horse Brave Heart describes historical trauma as the “cumulative emotional and psychological wounding over the lifespan and across generations, emanating from massive group trauma experience,” (Brave Heart, 2003, p. 7). The traumas American Indian populations face include both the lived experiences of individuals, as well as the secondary responses by subsequent generations, allowing the traumas to persist past the generation of people on which it was initially inflicted (Brave Heart, 1998; Danieli,

1998; Figley, 1995; Motta et al., 1994). American Indian experiences tied to colonization, and the accompanying ethnocide and genocide, as well as the continued colonization and persecution of Native peoples are examples of these traumas (Brave Heart & DeBruyn, 1998; Denham, 2008; Evans-Campbell, 2008; Morgan & Freeman, 2009; Szlemko et al., 2006). Historical trauma has contributed to high rates of alcohol and drug abuse, family violence, suicide, homicide, and other violence and mental health issues American Indian peoples face today (Kunitz, 2006; Poupart, 2003). The negative effects of unresolved historical trauma among American Indian individuals and communities may also damage individual and/or community cultural identity (Sotero, 2006).

American Indian mistrust of the Euro-American biomedical establishment also presents barriers to positive health outcomes, as well as influences encounter with medical establishments and personnel. Mistrust of the scientific community is a significant reason for the lack of Native participation in medical activities (Baker, 1999; Beal, 2011; Cook & de Mange, 1995; Corbie-Smith, Flagg et al., 2002; Corbie-Smith, Thomas et al., 2002; Corbie-Smith et al., 2019; Pacheco et al., 2013; Wasserman et al., 2019). The mistrust of medical research and medical practice contribute, in part, to perceived overt racial/ethnic discrimination in healthcare settings (Colclough & Brown, 2014) and mistrust of researchers. Documented examples of unethical medical research (F. Hodge et al., 2000) and activity are grounded into incidences where, in one case, blood samples were taken from members of the Havasupai Nation by geneticists (Mello & Wolf, 2010; Santos, 2008). Racial/ethnic minorities have also participated in studies where researchers failed to obtain informed consent, modified protocols without consulting participants, withheld information, and failed to follow up, resulting in a lack of trust. Other studies have directly examined attitudes of racial/ethnic minorities, fear, and mistrust of medical research and identified them as deterrents to research participation (Moreno-John et al., 2004; Pacheco et al., 2013). Knowledge of these factors and, also historical, cultural, and medical abuses may provide a guide to overcoming gaps in health communication barriers. There also is an opportunity to explore how trusted communication of tribal leaders and elders serves as building blocks for effective disease prevention health promotion programming.

Tribal leaders and elders as health communicators and health promoters of culture-centered communication among American Indians

Health communication and health disease prevention promotion programs exist to address health disparities and health conditions. However, few programs fully integrate holistic approaches when targeting American Indian populations (Walters et al., 2020). Culturally tailored communication, focused on individual characteristics (Kreuter et al., 2003) (e.g., readiness to screen for colorectal cancer) and culturally targeted health communication (e.g., American Indians who are 45 and older who have never screened for colorectal cancer), that emphasize group characteristics have shown impactful among racial/ethnic minority populations. Tailoring has

been beneficial when employed to create awareness, increase knowledge, health literacy (Kreps & Neuhauser, 2015; Parker & Kreps, 2005), and intent to influence individual health behavior and foster positive health outcome (Kreuter & Wray, 2003; Rimer & Kreuter, 2006). Trusted individuals, the senders and source of information, and culture-specific communication tools resonate among racial/ethnic minorities, American Indians (LeMaster & Connell, 1994), Native Hawaiians, (Ka'opua et al., 2011), Latinos (Baezconde-Garbanati et al., 2014; Briant et al., 2018; Huerta & Macario, 1999), Asians (Nguyen & Bowman, 2007; Todd & Hoffman-Goetz, 2011; Wang et al., 2006), African Americans (Allicock et al., 2011; Campbell et al., 2007; Lumpkins et al., 2013; McNeill et al., 2018) and optimize effective health communication (Giri et al., 2020). Culturally tailored and targeted information promulgated and co-created from within the culture is inclusive of the population with health risk and maximizes the potential of relevance among recipients who receive culturally tailored or targeted information (Hicks et al., 2012; Lumpkins et al., 2016) through a culturally grounded process (Walters et al., 2020). Tailored and targeted communication at any part of the communication process (sender, message, receiver) may address and include information that is relevant at the individual level and to segments of the population. These strategies fall within the cultural-sensitivity approach according to Dutta (Dutta & Basu, 2008; Dutta-Bergman, 2005) and are used to bolster health communication strategies by including individual and group characteristics that will increase the cultural appropriateness of health communication. However, cultural sensitive health communication that includes tailored and targeted information that draws on the characteristics of a culture as the primary focus of the approach is a starting point. A culture-centered approach, according to Dutta, addresses hegemonic influences – incorporating culture within the process for not only how culture shapes health communication but also how the inclusion of structural and societal factors (e.g., economic, social, and political influences) may address communication inequities and subsequently health disparities that are an indirect result of these inequities. Greater, the communicative discursive spaces and meaning making of communication infrastructure between senders and receivers (actors) are centered to address power and dominant communicative structures that have contributed to the exclusion of marginalized voices (Dutta, 2018; Dutta & Basu, 2008). This approach builds on both tailored and targeted communication strategies and is inclusive of culture, society, shared power, dominance, and authority.

Social capital and cultural networks of health communication

Examples of viable communicative infrastructure components and thus representations of how healthy communication may be optimally exchanged and shared within any given community or culture are found in affinity or trusted organizations. Among African Americans, faith-based and community-based organizations (Butler-Ajibade et al., 2012) including faith leaders or pastors of these organizations perceive themselves to be strong channels of health communication and health promotion (Bopp et al., 2013; Lumpkins et al., 2013). There also is

evidence to support that faith-based organizations are efficacious in health promotion of cancer prevention, heart disease, and nutrition (Campbell et al., 2007; DeHaven et al., 2004; Peterson et al., 2002). These and other similar affinity and trusted organizations as communicative infrastructures have been theorized as meta-channels to optimize health and wellness (Stephens et al., 2004). Further, these trusted and affinity channels as culturally appropriate and relevant factors (e.g., source, message, communication channel, receiver) (McGuire, 1981) are woven into health communication programming to appeal to the target audience. Among American Indian populations, the necessary communication components include: a trusted source, message, communication channel, and receiver. These are viable modes of health communication and represent communicative infrastructures for relatable, credible, and reliable health information. Culture defined here moves beyond mere cultural group factors inclusive of racial/ethnic identification and social economic status but is the “processes of language acquisition and socialization; shared by all members of the cultural group; an adaptation to specific environmental and technical conditions; and therefore is a dynamic and ever-changing process” (Kagawa Singer, 2012, p. 357). The shared health communication of tribal leaders and elders within American Indian communities are networks of cultural exchanges, ideas, and information. Health information shared via a trusted cultural network (i.e., American Indian tribal leaders and elders) builds on social capital concepts of normative and trust factors and are conceptualized as facilitators of action and cooperation for mutual benefit processes and also a facilitator of interpersonal cooperation (Putnam et al., 1993, p. 35). Stephens and colleagues further theorized that social capital concepts of norms and obligations, trust and social (cultural) networks and voluntary associations are proposed to serve primarily two functions in health communication: instrumental (material support) and affinity (social support) (Stephens et al., 2004). Culturally relevant information disseminated through trusted channel(s) and cultural networks of communication (tribal leaders and elders), connected to the tribe, traditions, and the infrastructure/group dynamics fulfill these functions and thus the viability of impactful health communication. These entities of trust and culture become networks or meta channels of health communication.

Cultural authority

Cultural authority, one that “defines reality and judgements of meaning and value will prevail as valid and true,” and is a construction of reality. Cultural authority among American Indian tribal leaders and elders is embedded into the meaning making of communication about health and everyday lived experiences. Social authority, the type of authority that belongs to social actors and “involves the control of action through the giving of commands,” (Starr, 1982, p. 13) is integral to lived experiences and also dialogs about health but, rests within the action of actors who are often outside of the culture. These actors have adopted a dominant approach and thus non-culture centric approach or view. Cultural authority juxtaposed to social authority, captures more appropriately naturally occurring cultural exchanges of health information among Native elders and leaders within their communities. While these programs have

aided in mitigating some health disparities and reducing health information inequities among Indigenous populations, little is known about how American Indian tribal leader and elders perceive themselves as health communicators among their own people and how these narratives may inform culture-centric health communication and health promotion among American Indian populations.

Critical communication components in health programming (e.g., health literacy, health information seeking, social marketing) and identification of public health factors including environmental, social, epidemiological (downstream and upstream) are included however these programs are not fully integrated into holistic and culture-centric approaches targeting American Indian populations. Culturally appropriate health communication aimed to address diverse audiences strengthens the health communication process by infusing cultural beliefs and lived experiences to impact health behavior change and outcome. The primary goal is to create communication that is inclusive of and relevant to Native people. The primary purpose *then* of this study, was to explore how tribal leaders and elders perceived themselves as trusted entities of health communication and health promotion of disease prevention within their own communities. We also wanted to see how these perceptions informed a communicative infrastructure that addresses health communication inequities within these communities.

Given culturally tailored and targeted health communication approaches have shown as impactful among racial/ethnic minority populations (Kreuter & McClure, 2004; Rimer & Kreuter, 2006) and reflect a cultural-sensitive approach, it is a starting point (Dutta, 2018; Dutta & Basu, 2008). The centrality of opinions and perceptions among community American Indian tribal leader and elder perceptions as health communicators and promoters of disease prevention in culture-centered health communication was explored. We asked the following research question: *How do American Indian tribal community leaders/elders in urban and tribal communities from the Central Plains perceive themselves as health communicators and or health promoters of disease prevention?*

Materials and methods

Using a community-based participatory research (CBPR) approach, that involved community members from project conception to analysis, the research team set out to understand how tribal leaders perceive themselves as health communicators in their communities.

CBPR approaches continue to be more effective in American Indian communities than others, in part because the development of culturally appropriate programs is nearly impossible without the full participation of community members (Holkup et al., 2004; Whitewater et al., 2016). The team that conducted this research is composed of Native and non-Native members and represented what was at the time of this project, the Center for American Indian Community Health (CAICH) and the Center for American Indian Studies (CAIS).¹ CAICH and CAIS were the two founding centers of the not-for-profit American Indian Health Research and Education Alliance (AIHREA). AIHREA is a national organization dedicated to addressing health and educational disparities among Native peoples and in their communities. AIHREA's network of connections spans the United States and

includes reservation, rural, and urban Indian communities, American Indian focused organizations, and academic institutions.

Semi-structured interview guides – Symbolic interactionism and CCA

Tailored and targeted health communication and health promotion to underserved populations involves understanding *how* audience or community members perceive, understand, and act on information. From within the community, those who recognize and understand the culture, may increase effectiveness. Tribal leaders and elders are from within the community and can provide a non-threatening viewpoint. In-depth interviews included a grounded theoretical process whereby the individuals' experiences helped guide researchers in understanding how tribal and elder communication can impact health communication and health promotion of disease prevention. Health behavior theory, historical trauma, and the concepts of culture, critical cultural communication, and social capital were also applied. Grounded theory draws from symbolic interactionism, a perspective that uses lived experiences and perceptions of the population as a lens to query or investigate a phenomenon (Denzin, 1992). Constructs from the health belief model (Janz & Becker, 1984; Rosenstock, 1966) and components from the Culture-Centered Approach (CCA) framework (Dutta, 2018) were included to account for American Indian Culture, individual perceptions, and beliefs about their own barriers to health, health promotion, and health communication. As a meta-theory, the CCA served as a guide to investigate tribal and community members' insights and views via these in-depth interviews. Through the CCA, investigators were able to analyze knowledge of health communication and promotion of disease prevention among tribal and community leaders and how this knowledge contributes to the communication infrastructure within their communities. Social capital concepts allowed for an exploration of perceptions and beliefs about community investment in health promotion efforts and what the tribal leader or elder thought about the tribal community and environment for health promotion and health communication of disease prevention.

A semi-structured interview guide was developed by the research team through an iterative process that ultimately resulted in the coverage of a variety of topic areas including perceptions of the health of the participant's community; health promotion messaging in the community; role and participation in health promotion; beliefs about health promotion;

messaging; attitudes related to the importance of cultural communication in American Indian communities; and demographics. Following KUMC Institutional Review Board approval (#00141131), a series of semi-structured, ethnographic interviews (N = 39), lasting between 30 and 100 minutes, were conducted in English and recorded by team members. Study staff also approached tribal council for study approval however it was determined that individuals participating in the project were representing themselves and their own views as health communicators and not as an official voice for their respective tribes.

Participants were self-identified American Indian individuals and leaders in their communities representing four tribal nations and two urban communities from the Central Plains (see Table 1) and were recruited via word-of-mouth through the AIHREA Community Advisory Board, our broader network of community partners, personal connections, and recruitment at AIHREA powows and other community events. Our definition of tribal leaders was understood broadly to include any community member that might be viewed as an authority figure by members of their own community on health and their community generally. Thus, participants included formally elected officials in Tribal government, community health workers, educators, youth program organizers, cultural revitalization directors, spiritual leaders, and elders. This flexibility captured a more comprehensive representation of leadership in American Indian communities and allowed for representation in urban communities as well. Participants also provided informed consent prior to their interview and received a \$100 gift card for participation. Interviews were subsequently transcribed verbatim.

Transcriptions were analyzed using a grounded theory approach (Strauss & Corbin, 1990) an analysis method developed by researchers at CAICH (Daley et al., 2010) that included a team of four coders, representing both emic (within) and etic (outside) perspectives. The inclusion of emic and etic coders takes into consideration the differing experiences, backgrounds, and cultural contexts of our team members. Etic coders on our research team were researchers who have worked with American Indian populations and projects and emic researchers were from our American Indian staff and communities. Prior to formal analysis, these coders met, along with other members of the research team, to develop a codebook for analysis based upon preliminary review of the transcripts. This inductive codebook covered topic areas that included health, types of health communication programming, access to healthcare, modes of communication, and ideas about health promoters or communicators. Using this codebook, coders analyzed each stratum separately before comparing across strata, allowing thematic statements to emerge from the text. Each coder developed their own set of “pre-themes” and met, along with other members of the research team, to discuss their findings and develop the final set of themes. Disagreements among coders were resolved through consensus, taking into consideration both emic and etic perspectives of the data. The inclusion of the researcher perspective from

outside the culture and American Indian within the culture was integral to capturing formative data. This data analysis process was followed to increase reliability and replicability for future studies and to limit bias. Although emic coders were paid staff from CAICH, these were trained coders who had participated in coding for several other AI studies. Further, the process will lay a foundation for how these tribal and elder leader perceptions may inform measurement of indigenous capacity and its role in cultural communication within these populations (Oetzel et al., 2011).

Results

Most participants in the sample were women (51%) who were 45 years old or older (66%) (Table 1). Nearly 60% of participants were from reservation communities as opposed to non-reservation and urban communities (41%) in the Central Plains (Kansas, Missouri, Iowa, and South Dakota).

Overall, six themes emerged from the interviews and reached saturation across all demographic variables (see Table 2). No unique themes within demographic categories reached saturation.

Participants Infrequently Recognized Themselves as Health Communicators and Promoters. Despite being identified by the research team and their fellow community members as eligible participants, interviewees often did not think of themselves as health communicators and promoters within their communities. Participants had a variety of backgrounds including community health workers, educators, and tribal officials serving in administrative and political positions. Notably, spirituality was a sub-theme and thus component that some participants saw as central to health and wellness communication and as a characteristic that leaders in Native communities should possess.

“Culturally I think that . . . spiritually we need to connect to the environment. We need to connect to the, you know, things that we do with the trees and the plants and make sure that everything that we’re eating is safe, good soil health. I’m doing some training on that too.”

“You have to have folks who are known in the community to be a spiritual leader,” another participant explained, “it can’t be someone who is a spiritual leader once in a while.”

Other participants mentioned specific spiritual leaders within the tribe and the critical role that this individual had in disseminating health messages within the tribe.

“You know, a lot of us believe in traditional ways. And I think there should be some kind of support from the tribe for our medicine men. To go around and have ceremonies for

Table 1. In-depth interview demographics.

Central Plains Tribe (N = 39)	Gender	Age Group	Self-Identified Role*
Kansas, Iowa, Missouri and South Dakota	Female	25–34/	Tribal Government 20%
Tribes and	51%	3%	Youth Outreach 5%
Communities	Male	35–	Education 28%
	48%	44/	Healthcare/Social Services
		18%	28%
		45–	Cultural Promotion 10%
		54/	Religion/Spiritual/Traditional
		28%	Teaching Leader 15%
		55+/	Other 2%
		38%	

*Some Missing Data (Participants did not provide data and/or gave multiple answers in category).

Table 2. Focus group themes.

1. Participants infrequently recognized themselves as health promoters
2. Health promoters should be viewed as people who “practice what they preach”
3. Programs focusing on youth could affect entire households
4. Transportation to and from healthcare providers is the most significant barrier to receiving healthcare and health information
5. The majority of health programs focus on diabetes or obesity while mental health programming is still needed
6. Some degree of cultural tailoring is important for health communication programs in American Indian communities

the families that want it from the medicine man, you know. I think it would be great to do something like that for us. Especially us elderly who believe our way, you know? Our way brought us, thousands of years up to this point and I don't see nothing wrong with it."

Spiritual positions (e.g., medicine man) that tribal members recognized as possessing significant authority within respective communities were compartmentalized as those who had cultural authority in the areas of health and wellness. Participants self-identified (see Table 1) as community health worker, educator, tribal official but did not self-identify as a spiritual authority although these narratives were woven into their conversation about communicating disease prevention.

The other most frequently identified communicator and promoter of health in these communities were the Indian Health Service and contract health providers. Participants also identified representatives from nonprofit organizations, urban Indian centers, as well as community elders as potentially effective health communicators and promoters. Most importantly, it was agreed that any health promoter must have broad notoriety in their communities and that health efforts should begin with tribal leadership.

"These initiatives should start with the tribal chairman and the [tribal] council members who are aware of the avenues that we need to take to improve our health."

"My community expands in such a way that most of my interactions are coming with tribal leaders across our region so I talk about health disparities and health issues as a part of my job all the time . . . so it's an ongoing discussion, fundamentally, I think we've been missing the conversations with the right people."

The recognition of *other* leaders in the community as having the authority to speak about health and act as a health communicator or promoter points to participants' perceptions about their authority and others. The participants' collective identification of individuals with specific medical positions, roles, and affiliations were perceived to be those who would and could successfully fulfill and execute the role of a health communicator or health promoter. The defined and specific role of a health communicator and/or health promoter personally was perceived to be outside the scope of who they were, and the authority held within the community.

Health Communicators/Promoters Should be Viewed as People Who "Practice What They Preach." A central concern for many participants was the perceptions of health communicators and promoters in their communities. While they agreed that certain community members, by virtue of their position in the community, would make better health communicators and promoters than others, it was clear that these individuals must also participate in the practices that they themselves are promoting to be taken seriously. While reflecting on how they saw themselves as a community health communicator and/or promoter, participants expressed the importance of being a representation of what you teach and preach.

"I think you need to live that lifestyle if that's what you believe in [and] promote."

Another explained that health promoters needed to lead by example and that this should factor into who qualifies for this role.

"I think that I need to try and practice what I preach, live that lifestyle and live that way. You know people like to criticize you if you're saying you shouldn't drink, you shouldn't smoke and then you turn around and do it yourself. I think you need to live that lifestyle if that's what you believe in what you promote . . . so that's what I try to do."

A second participant echoed these sentiments.

"I think everybody's got a role in that (health promotion). Um, but again, it's kind of, you kind of have to lead by example. Everybody's got a role, but do they take that role? Do they know, are we – what are they doing for themselves? Ultimately, it's gotta be, you have to find those people that um, aren't doing it for themselves . . . because they want to, not because they're pushed, and try and get all of them involved and come with a plan."

A participant from another tribe reflected on the need and importance of being more involved in these health communication roles.

"I think like if our tribal leaders started being more active in the community and regaining the trust and the sense of community perhaps we could become you know, healthier as a unit and maybe if they took the lead or if they wanted to be invited maybe in some of our group chats, that you know like the cancer survivors have, then maybe they (community) would buy into it."

Participants' reflections here also echo the theme of *who* and *what* constitutes an authority figure as a health promoter and health communicator but also the importance of this individual's role. Here, the qualification and thus authenticity of living a life that represents the role of a health communicator or promoter is paramount. The leadership position role, and duties that these individuals have are often unspoken, non-verbal and are also important in the verbal process of health promotion and health communication.

Programs Focusing on Youth Could Affect Entire Households. Highlighting the importance of youth in many American Indian communities, interview participants suggested that mobilizing the power of youth in their communities to promote healthy living could be an effective strategy.

"Involve the youth and then the parents will come along, and then maybe even have some activities for the whole family."

Another participant spoke of the busyness of life and how this should be minimized to increase involvement among youth.

"We see some participation with the younger people, but the problem we have today is everybody is so busy with school activities and activities outside the Native community, that we don't have the participation with the younger people that we need and um that's one of the issues that we are trying to improve with."

A third participant spoke of the need for youth involvement and their impact however the challenges of getting youth involved.

"We are doing everything we can to get younger folks involved, get on the board of directors, you know anything we can do to get them involved. And it's difficult. It's really difficult to get younger people involved in leadership training."

Participants' identification of youth within their community signals a need to fill a gap in the health promotion and health communication process. Youth were identified as a missing link in communicating health to the parent and an ally in communicating health. Compared to the specific leaders within the community who were identified as having medical and cultural authority to serve as health promoters and communicators at the community level, youth were perceived as viable channels of communication at the local and familial levels. The inclusion of youth was also seen as a beneficial option to diversify health communicators and broaden the distribution of health information.

Transportation to and from Healthcare Providers is the Most Significant Barrier to Receiving Healthcare and Health Information. While an overall lack of healthcare providers continues to be a concern, access to reliable transportation to these services was a key barrier identified by participants. Interviewees living in both reservation and urban communities expressed concern about accessibility to healthcare and health education programming. Particularly for elderly community members, securing transportation, including funds to cover fuel costs, limits the reach of healthcare and health education programming in many American Indian communities.

"We have to drive about 47 miles to commute to get our medicine," one community member noted.

Another urban community member explained that the scarcity of Indian Health Service clinics required her to drive more than a hundred miles to receive care, illustrating that access to care is not solely an issue for reservation communities, but urban communities as well.

"Since we're urban we don't have any Indian Health clinics which would be nice. We do have AIHREA where we have check-ups at the powwow where you can get your blood checked, your weight, your breathing . . . Then we have (a) mental health counselor, but we only have one in XX area. And then of course our nearest Indian Health service is in XX which is like 130 away."

Another participant suggested that the need was so severe that it necessitated outside assistance for basic transportation needs. "Some kind of program to help us with fuel . . . and car repairs or anything like that to get us to where we have to go to see the doctor."

The prevalence of transportation barriers and limited number of health care providers among participants represents the overwhelming need for assistance but also speaks to missing communication components that contribute to a void in societal structures that reinforce inequity. Advocacy through health communication and health promotion points to identifying barriers and opportunities to positively change and impact health outcome on societal and systemic levels. The community's involvement and experiences help to inform the communication infrastructure and mitigate communication gaps and inequities between actors such as community members, community leaders, and policy makers.

The Majority of Health Programs Focus on Diabetes or Obesity While Mental Health Programming is Still Needed. Overall, participants explained that the health programming in their communities tend to focus on the prevalence of diabetes and obesity.

"We do have programs that bring about awareness and give you knowledge about what your diet should be and how you should eat, how you should exercise," one female participant explained when discussing the programs available in her community.

Another participant recalled a similar emphasis on this type of health programming. "Maybe in the last ten years there's been more of an initiative to do preventive type [programs] like with the diabetes program and weight programs."

However, participants noted that mental health programming and services were the areas most in need of attention in their communities. Recalling an earlier discussion about accessibility issues, one female community member explained the dire need for mental health services.

"We need the suicide prevention program; we need a facility here."

Another suggested programming specifically to deal with the impact of losing someone from mental health. "The trauma that a person goes through [when someone they know passes away]."

A female participant from one of the reservations spoke about the need also for programs that were culturally responsive. "I know a lot of clients or the patients you know just from personal knowledge, from them, just talking to them, they don't like some of the places that they get referred out to. Maybe that culturally relevant mental health aspect would be something that they would be more open to cause you know, there is a lot of stigma with mental health."

Similar to participants' identification of characteristics and the *type* of health communication leader; structural and societal factors are potential barriers to health promotion and communication among American Indians. The topic of mental health is seen as a top health priority among these participants. Cultural tailoring and targeting efforts from dominant communication efforts have brought diabetes and obesity to the forefront; participants' reflections point to the prevalence of mental health issues within the community and personally speak to their perceptions of the urgency when compared to other health topics deemed priority. This underscores the evolving landscape of communication and dosage of information that individuals, communities, and other entities deem culturally relevant, appropriate, or critical at different time points.

Some Degree of Cultural Tailoring is Important for Health Communication Programs in American Indian Communities. When asked about the content of programming designed to be used in American Indian communities, interview participants strongly encouraged future programs to be culturally tailored at least to some degree. They explained that it is particularly important for these programs to draw on and organize themselves around cultural values, languages, and spiritual traditions from the Native communities in which they will be implemented.

"When you're dealing with Native people, you have to respect . . . these values . . . and I think that you should probably know some of the language," one woman from a reservation explained.

One man expressed similar ideas. "Whoever does go and spread the [health] message, they definitely need to be culturally aware of the way that Native American people are."

To account for the rich diversity of tribal nations represented in many urban communities, urban community members suggested that health (communication/promotion) programming should not be as tribally specific in their communities.

“I think just a little, just enough to make it feel like it’s for them without getting bogged down in too much detail because the variation is just too wide in [this] community.”

This final theme that captures participants’ opinions about cultural tailoring and how they believe that it should work also points to appropriate dosage of health information detail but also points to the limitations of cultural tailoring. Participant experiences with cultural tailoring here show that they are *familiar* with the process and that it involves specific steps. Cultural inclusion by way of engaging community members in the communication process and including characteristics of the culture is expected and should be expanded. Participant expressions represent a continuum of health communication and health promotion that is reflective of what is needed beyond cultural tailoring to appropriately reach American Indian communities from one tribe or many through a culturally centered process.

Discussion

To our knowledge this is one of the first research projects that explores how American Indian tribal leaders and elders perceive themselves as health communicators and/or health promoters in their tribal communities. These exploratory interviews with tribal leaders and elders from Native communities in the Central Plains yield important lived experiences that highlight and suggest new strategies for employing American Indian populations in the health communication process of disease prevention. While participants infrequently identified themselves as “authorities” of health promotion and communication, they did see themselves as gatekeepers in at least some capacities and knowledgeable about *who* or *what* community agencies and entities were important and trusted to disseminate pertinent health information. This recalls differential notions of perceived authority of medical practitioners delineated by sociologist Starr (1982). He argues that medical authority can be broken down into different types, social and cultural, based on the context of their authorization. Specifically, Starr suggests that social authority is established through organizational certification or executive means. Individuals and entities in these positions (the Indian Health Service and elected tribal officials, for instance) were those who participants identified as potential communicators of health information and health promoters, generally. Starr further characterizes those possessing cultural authority as being granted through community consent because of shared cultural values and practices (Pescosolido & Martin, 2004; Pippin, 1996; Starr, 1982). Individuals and institutions with this kind of authority were often mentioned by participants when discussing who “practices what they preach.” The relationship between these two types of authoritative figures and institutions suggests that effective health promotion and communication programming in American Indian communities must mobilize both types of authority to be successful.

Emphasizing the importance of longstanding relationships with Native communities coupled with a working knowledge of perceptions of authority figures within the communities in question, stresses the importance of CBPR approaches in health communication, promotion, and culture-centered research with Native communities. These findings suggest that health communication and health promotions programming among American Indians would be most effective when it is sanctioned and disseminated by community partners possessing social authority, while also prioritizing individuals with cultural authority (e.g., medicine man, tribal council member) as examples of fellow community members who “practice what they preach.” Further, these findings reflect the need for culture centeredness in the health communication processes and inclusion of indigenous knowledge (Belone et al., 2016). The role of spirituality also was a sub-theme and part of participant expressions of what characteristics health communicators in Native communities possessed. Those within the Native community that held cultural authority to disseminate health information were characterized as not only spiritual but as individuals who practiced what they preached. Participants saw others in the community as spiritual leaders but self-identified themselves as community members who fulfilled traditional roles within their respective communities. Study staff identified participants as leaders; however, participants most likely did not see themselves as the “authority” on health communication because of perceptions about possessing authority (social or cultural). The perceptions might also point to Native culture that de-emphasizes centralized leadership, power, and authority (Bryant, 1998) and emphasizes collectivism.

Health communication messaging disseminated through shared processes and trusted-network sources is plausible and feasible to overcome mistrust of the medical establishment, address levels of historical trauma and other health-related issues among American Indian community members. Culturally appropriate channels of health communication are positioned as critical purveyors of health information that impact community health and health behavior (Gearhart & Trumbly-Lamsam, 2017). Modern medicine limits medical encounters (Pippin, 1996) while American Indian populations emphasize and describe medical problems “related to their own bodies and lives without the medical references or language to assist in facilitating the interaction,” (Kalbfleisch, 2009). Employing American Indian messengers in the capacity described above is important in establishing trust and increasing the veracity of the message. The identification of specific types of health topics to prioritize (mental health), engagement of under-utilized voices (youth) and barriers (transportation) also signaled critical components in the role of health communication of disease prevention. The inclusion or absence of these factors among American Indians may bolster or dilute important health communication.

The CCA in particular served as a central part of the framework to guide our understanding of how these tribal and elder leaders saw themselves as health communicators within their communities. As a meta-theoretical framework, in-depth interviews with participants allowed an exploration of the existing communication infrastructure within these communities and opportunities to address dominant communication structures that may compete, dilute, or even block authentic indigenous

knowledge and voices. These findings are central to cultural grounding within American Indian experience and important for cultural validation of (indigenous) community capacity for American Indian communication (Oetzel et al., 2011)

Linkage or adoption of other health communication strategies conducted among other racial/ethnic groups also provide a guide to centralize culture in interventions and programming. Community Health Workers (CHWs), also referred to as promotoras/os among Latinx and immigrant populations have shown essential in addressing disease prevention programs and health outcome. Within other cultural groups, trusted community members and leaders also are positioned to promote and communicate disease prevention and impact health outcome (Han et al., 2017; Santos et al., 2017). While racial/ethnic groups in the U.S. share similar cultural values, the process for defining culture in the experiences of the population and determination for health information shared within a community's trusted cultural network will differ. Strategic positioning of culturally responsive health communication and health promotion among American Indian populations is dependent on intended and intentional senders, messages, and recipients rather than predetermined components minimally informed by culture. Culturally grounded interventions that centralize community engagement and also indigenous knowledge may lead to culturally valid communication programs and (messages) products (Walters et al., 2020)

Some of the limitations of the study were that CAICH interviewers, the majority of who were from tribal communities and part of the research team, were familiar and knew some of the interviewees through previous research and community activities. This could have primed interviewees and or limited transparency however, following a CBPR process the goal is to work intimately with the community and incorporate community members into every phase of the research process (Israel et al., 2001). The sampling also was purposive and may not have included additional individuals who were considered leaders in the community such as representatives from the Indian Health Service and other agency interviewees named in data collection. Interviews also significantly varied in length where some were completed in 30 minutes while others were more than 90 minutes. The consensus of some of the data may have been overrepresented in certain parts of the Central Plains areas, however, data saturation was achieved.

Implications of this research can help shape and bolster health communication and health promotion program planning processes of development, execution, and evaluation on multiple levels, particularly when including tribal leader and elder perspectives. This is an opportunity for health communication and promotion professionals and researchers to more fully integrate American Indian tradition and trust of tribal elders and leaders into the health communication strategies that inform practice and program intervention research among this population at individual, organizational, community, and societal levels (Dickerson et al., 2020; Hicks et al., 2012; Walters et al., 2020). Health communication programs and evidence-based research that are inclusive of culture in addition to trusted sources of health communication and information is an avenue to

achieve culturally appropriate approaches and communication that resonate with American Indians about disease prevention.

There are 574 federally recognized American Indian and Alaska Native tribes (Saenz, 2020); this culture-centered approach is comprehensive and responsive to include tribe-specific targeting (American Indians nationally) or tailoring (tribe-specific) health communication where culture, values and language of elders and tribal leaders are infused into health communication messages and programming. Efforts with the Centers for Disease Prevention & Control (CDC) are examples of national initiatives to incorporate culture into health promotion among American Indians. The CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) was tasked to include Indigenous experience and knowledge into its process to build culturally responsive interventions (Lawrence & James, 2019). Those sessions included listening to tribal health leaders and visiting tribal organizations and other tribal areas. The Good Health and Wellness in Indian Country (GHWIC) program is centered on the knowledge of the community to help guide healthy living and chronic disease prevention (Williams et al., 2019). Inclusion of tribal leader and elder perspectives and lived experiences into health communication initiatives and programs has potential to increase cultural relevance in regional and local disease prevention strategies/programs targeting American Indian populations. Nationally, The National Congress for American Indians also (National Congress of American Indians, 2020) recognizes the importance of effective communication among tribes and created its own communication resource to facilitate effective health communication among tribes across the country. Tribal Communication officers representing tribes throughout the nation were interviewed about messaging, outreach, engaging with media to identify ways to effectively communicate and advocate for Native people. Communication goals and efforts are to further the success of tribal nations through these tactics and create opportunities for policy change through health and media advocacy.

The present study was a beginning to explore how regional tribal leaders and elders in the Central Plains perceived themselves as health promoters and health communicators in their communities. Additional research that explores perceptions among tribal and community members may provide additional insight and a comparison to how community members think of health communication via these trusted leaders. Formative research then can serve to test the effectiveness of cultural-centered tribal and elder health communication compared to other tailored and targeted or culture-sensitive health communication. Strategies inclusive of these elements are well positioned to capture and reflect American Indian cultures and help reduce disease burden among American Indian populations.

Note

1. The research teams and centers have combined and transitioned to a new university and is now known as the Institute for Indigenous Studies at Lehigh University in Bethlehem, PA.

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