

3-11-2020

## Urban American Indian Community Health Beliefs Associated with Addressing Cancer in the Northern Plains Region

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### Recommended Citation

Idoate, R., Gilbert, M., King, K.M., Spellman, L., McWilliams, B., Strong, B., Bronner, L., Siahpush, M., Ramos, A.K., Clarke, M., Michaud, T., Godfrey, M., & Solheim, J. (2020, March 11). Urban American Indian Community Health Beliefs Associated with Addressing Cancer in the Northern Plains Region. *Journal of Cancer Education*, 36, 996-1004. <https://doi.org/10.1007/s13187-020-01727-z>

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# Urban American Indian Community Health Beliefs Associated with Addressing Cancer in the Northern Plains Region

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## Abstract

American Indians residing in the Northern Plains region of the Indian Health Service experience some of the most severe cancer-related health disparities. We investigated ways in which the community climate among an American Indian population in an urban community in the Northern Plains region influences community readiness to address cancer. A Community Readiness Assessment, following the Community Readiness Model, conducted semi-structured interviews with eight educators, eight students, and eight community leaders from the American Indian community in Omaha's urban American Indian population and established the Northern Plains region community at a low level of readiness to address cancer. This study reports on a subsequent qualitative study that analyzed all 24 interview transcriptions for emergent themes to help understand the prevailing attitude of the community toward cancer. A synthesis of six emergent themes revealed that the community's perceptions of high levels of severity and barriers, paired with perceptions of low levels of susceptibility and benefits, lead to low levels of self-efficacy, all of which are reflected in minimal cues to action and little effort to address cancer. These findings, interpreted through the lens of the Health Belief Model, can inform the development of more community-based, comprehensive, and culturally appropriate approaches to address the multilevel determinants of health behaviors in relation to cancer among American Indians in the Northern Plains region.

## Keywords

American Indian, Cancer, Urban, Perceptions, Attitudes, Health beliefs, Community climate

## Introduction

For decades, some of the highest cancer mortality rates have been found among American Indians (AIs) in the Northern Plains region of the Indian Health Service (NPR) [1–3]. Many factors that increase the risks of cancer development in AI communities,

including heavy drinking, smoking, and obesity, are significantly higher among AIs in the NPR than in other regions [3]. Guadagnolo and colleagues also found that AIs in the NPR exhibit higher mistrust of the medical system and lower satisfaction with health compared to whites [4]. Increasing our understanding of the NPR AI community's perspectives, beliefs, and attitudes toward cancer is necessary to successfully build trust [4, 5] and ensure that appropriate cultural perspectives are respected to build real partnerships and effective ways of addressing cancer through prevention and intervention efforts within the AI NPR [6–8]. This study employed the Community Readiness Model (CRM) to examine the urban AI NPR community's prevailing attitude (i.e., community climate) toward cancer in a Midwest metropolitan area in Nebraska [9].

Michael Bird and colleagues at the National Urban Indian Health Coalition explained that the lack of urban AI data perpetuates their invisibility to the nation [10]. Approximately seven out of 10 AIs live in urban areas [10]. According to the US Census, the NPR's Midwest metropolitan area, including Douglas and Sarpy counties, is an area with a high AI population count [11]. Multiple tribes are represented in a Midwest metropolitan area, with the majority being tribal members of the Omaha, Lakota, Winnebago, and Ponca tribes [12]. This urban AI population is served by the Nebraska Urban Indian Health Coalition and the Ponca Tribe of Nebraska's Fred LeRoy Health and Wellness Center, among many other healthcare facilities such as the Buffett Cancer Center at Nebraska Medicine.

In 2018, a Community Readiness Assessment (CRA) was conducted to measure overall community readiness to address cancer in a Midwest metropolitan area's urban AI NPR community. This study, following CRM protocol, assessed five distinct dimensions of community readiness: (1) community climate and attitude toward cancer (*Community Climate*), (2) community knowledge of efforts to address cancer, (3) leadership support for preventing, treating, and researching cancer, (4) community knowledge about cancer, and (5) availability of resources to address cancer [9]. The CRM identifies nine stages of readiness, ranging from one, no awareness of cancer as an issue, to nine, a high level of community ownership of cancer as an issue (See Table 1). To conduct the CRA, researchers interviewed 24 key respondents (KRs) who self-identified as part of the AI community in the Midwest metropolitan area. All interviews were transcribed, analyzed, and scored, demonstrating that the community's overall level of readiness to address cancer was at a stage three, which corresponds with a level of *Vague Awareness* (manuscript under review). As explained by the CRM, at an overall level of *Vague Awareness* "some community members believe that this issue may be a concern in the community, but it is not seen as a priority. They show no motivation to act" [9]. In the dimension of *Community Climate*, scores range from the lowest level of one, where "community members believe that the issue is not a concern," to the highest level of nine, where "the majority of the community are highly supportive of efforts to address the issue", and "community members demand accountability" (See Table 1) [9]. Further qualitative examination of a Midwest metropolitan area's urban AI NPR *Community Climate* toward cancer could help inform

efforts to develop strategies to improve community readiness to address cancer and increase community members' participation in cancer prevention, screening, research, and healing. To our knowledge, no previous study has ever conducted an in-depth examination of *Community Climate* with regard to cancer in an urban NPR AI community.

## Methods

CRA data collected through the semi-structured interviews conducted with 24 key respondents (KRs) from three distinct community subgroups (students, educators and leaders) of a Midwest metropolitan area's urban AI community were analyzed qualitatively [9]. The interviews assessed the dimension of *Community Climate*, following CRA interview protocol, by asking KRs multiple questions about community perceptions of cancer, including: How does the community support the efforts to address cancer?; Are there ever any circumstances in which members of your community might think that cancer should be tolerated?; What are the primary obstacles to efforts addressing cancer in your community?; What do you think is the overall feeling among community members regarding cancer? Respondents were asked to answer keeping in mind their perspective of what community members believe and not what they personally believe. For the purposes of this study, all 24 transcriptions of key respondent (KR) interviews in the CRA were qualitatively analyzed with specific focus on questions and responses related to the dimension of *Community Climate*.

A five-member analysis team was formed, including two lead evaluators and one key KR from each of the three community subgroups interviewed in the original CRA study. One student, one educator, and one community leader from the urban AI community independently analyzed qualitative data in all eight interviews specific to their respective subgroup's *Community Climate* data. Lead evaluators, more experienced in qualitative research, independently analyzed *Community Climate* data across all 24 interviews and facilitated collaboration among the multi-sectoral team. Using framework analysis, we conducted an in-depth examination of CRA interview transcripts and inter-tribal, inter-generational perceptions, beliefs, and attitudes toward cancer. We followed the framework analysis five-step process to conduct thematic analysis of the CRA semi-structured interviews for *Community Climate* [13,14]. This resulted in emergent themes that describe the Midwest metropolitan area's urban AI NPR community climate toward cancer.

The study was reviewed and deemed exempt by the Institutional Review Board of the University of Nebraska Medical Center (UNMC).

## Results

KRs reported the community's shared stories or experiences about cancer, yet community ideas about why cancer occurs, who has cancer, and how people deal with cancer tended to be limited and/or vague. Framework analysis of the CRA interview

transcripts led us to the following six emergent themes that summarize the community perceptions, attitudes, and health beliefs about cancer:

**Table 1** The nine stages of community readiness specific to community climate

Stage 1. No awareness	Issue is not generally recognized by the community or leaders as a problem (or it may not be an issue)
Stage 2. Denial/resistance	Community members believe that the issue is not a concern At least some community members recognize that the issue is a concern, but there is little recognition that it might be occurring locally
Stage 3. Vague awareness	Community members believe that this issue may be a concern in this community, but do not think it can or should be addressed Most feel that there is a local concern, but there is no immediate motivation to do anything about it
Stage 4. Preplanning	Some community members believe that this issue may be a concern in the community, but it is not seen as a priority. They show no motivation to act There is clear recognition that something must be done, and there may even be a group addressing the issue. However, efforts are not focused or detailed
Stage 5. Preparation	Some community members believe that this issue is a concern in the community and that some type of effort is needed to address it. Although some may be at least passively supportive of efforts, only a few may be participating in developing, improving, or implementing efforts Active leaders begin planning in earnest. Community offers modest support of efforts
Stage 6. Initiation	At least some community members are participating in developing, improving, or implementing efforts, possibly attending group meetings that are working toward these efforts Enough information is available to justify efforts. Activities are under way
Stage 7. Stabilization	At least some community members play a key role in developing, improving, and/or implementing efforts, possibly being members of groups or speaking out publicly in favor of efforts, and/or as other types of driving forces Activities are supported by administrators or community decision-makers. Staff are trained and experienced
Stage 8. Confirmation/expansion	At least some community members play a key role in ensuring or improving the long-term viability of efforts (e.g., example: supporting a tax increase). The attitude in the community is "We have taken responsibility" Efforts are in place. Community members feel comfortable using services, and they support expansions. Local data are regularly obtained
Stage 9. High level of community ownership	The majority of the community strongly supports efforts or the need for efforts. Participation level is high. "We need to continue our efforts and make sure what we are doing is effective" Detailed and sophisticated knowledge exists about prevalence, causes, and consequences. Effective evaluation guides new directions. Model is applied to other issues The majority of the community are highly supportive of efforts to address the issue. Community members demand accountability

(Plested, Edwards, & Jumper-Thurman, 2006)

### **Cancer Is Fatal. *Death, death, it means death***

Participants overwhelmingly associated cancer with death. When asked about their personal understanding of cancer, many community members equated a cancer diagnosis with a death sentence, stating: "You're gonna die. You're gonna die. You get cancer, you're gonna die or you have cancer, you're going to die." Another KR

answered, “cancer means my grandmother’s going to die by Christmas.” The general understanding was that cancer “is a killer; it kills people.” As one community member said, “cancer affects everyone in some way.” Many KRs shared stories about relatives with cancer and relayed intimate details about loved ones who have died from cancer. The overwhelming majority commented on the loss of loved ones to cancer, such as “it devastated my family, my own father died of liver cancer, I’ve lost a couple of friends with breast cancer, my grandma did die from cancer, I’ve seen people die in my family from it, my father and my brother both had colon cancer.” Conversely, one KR said, “I know some people living today, right now, that have cancer. Several of our grandmothers have cancer.” Some KRs shared stories about people who are “living with cancer,” yet, few personal accounts attested to the potential to prevent or treat cancer. When asked about the regional AI community’s perspective on cancer, KRs reiterated the idea that cancer means death, explaining that the community views cancer as “lethal,” “fatal,” and “terminal,” describing cancer as “the bad stuff,” as “terrible” and “ugly” and “catastrophic.” One KR answered that, “cancer means death to the majority of people... especially in the Native community.” Some described the community’s perception of cancer as “a dreadful thing,” “a death sentence,” “a show stopper.”

### **Cancer is feared. *Cancer’s a scary thing.***

When asked “How do you see members of the Native community in your region dealing with cancer?,” one KR said, “I don’t see people dealing with cancer. We don’t deal with it... and if you don’t deal with it you fear it.” When asked, “What does cancer mean to you?,” one KR answered, “I think cancer in our community is, is fear... it’s so scary a subject.” Another KR explained, “It’s something that I’ve always grown up fearing” and described how her “mother instilled a fear” in her because her grandfather died from cancer. In a similar sentiment, one KR explained that cancer is “a scary word” to her because [her] “grandmother died of stomach cancer, [her] father passed away from liver cancer, [her] aunt had a fight with leukemia.” Another KR expressed fear when he said, “I don’t want to get it (cancer).” Some said, “it’s scary” and described community members as “feeling scared of what they will find.” In fact, another KR admitted, “I put off having a mammogram, longer than I should have, because I was really scared and it wouldn’t surprise me if that was a Native thing.” Cancer is, as reported by one KR, “just something that’s kind of feared and kind of to be afraid of.” In general, most people hear that, “there’s no cure, and the treatments that’s available is pretty, pretty intense” and that is a daunting story.

### **Cancer Is Taboo. *It’s not something that people talk about***

Simply put by one KR, “cancer does not come up” in conversation. When asked about community perceptions of cancer, another KR said that cancer is “one of those tabooish subjects that we don’t deal with” and later elaborated, “oddly we don’t talk about it...we don’t talk about it, we talk around it...we don’t talk about how your chemo’s going. We don’t talk about ‘how do you feel?’ We don’t talk about how you look.” When asked what cancer means to the Native community, many KRs felt unable

to answer or replied, “I’m not aware,” “I don’t know,” or “I have no idea.” Numerous KRs gave the same reason for not knowing, stating, “I don’t really know because I don’t hear it talked about much,” or “I don’t know... it’s not a conversation I’ve had” or “I don’t know... I’ve never talked with anyone about it (cancer).” Other responses included, “I don’t feel that it (cancer) is something that a lot of the community talks about.” This was corroborated by other KRs who said, “I haven’t really talked that much about cancer to the Native community” or “we don’t talk about it. People are reportedly somewhat secretive about it (cancer).” Furthermore, one KR said:

*I think of my aunt and uncle who died from lung cancer and who were both heavy smokers...specifically with my aunt, she was from a generation we didn’t talk about it... I don’t think she wanted to know the diagnosis... but it was just never, the word (cancer) wasn’t said in her presence.*

One KR explained, “I see them (community members) seeking care at a very late stage and being somewhat secretive about it. And, and I guess being very particular with whom they confide in about their diagnosis.” Another explained:

*When I talk to my friends up on the rez...when there’s somebody that passes, they always say it to me like this, (in a low voice) well I think they had cancer. Like it’s a shame or they don’t want to say it out loud.*

Another KR described a similar sentiment, explaining that he “didn’t know his auntie was suffering from it (cancer)” until he saw her in the summer with a scarf and no hair. As one KR said, “when you hear about these things, they’re in the late stage of cancer.” Many KRs explained the late-stage diagnosis or treatment as a result of avoidance. For example, one KR said:

*I was talking to [a friend] about her sister and she said, we’ve been telling her, you’re bleeding, you’ve been bleeding, go to the doctor, go to the doctor. And, she didn’t want to go because she didn’t want to know. And, I think that’s where our community is. If we shut our eyes about a lot of issues, not just cancer, but I think if we shut our eyes then it’s not real. It’s not happening. If we talk about it then we have to deal with it. Then we have to really look at cancer numbers in our own people. Then we have to really think, you know, what are we doing? I smoke. I’m killing myself and I know it, but if a doctor doesn’t tell me not to then I won’t die...If we don’t talk about it, it’s not real. If we talk about it, we have to accept it and find things to do for it. So, that’s kind of the thought process in the community.*

One KR reasoned, “If we don’t know, it can’t happen...which is a horrible way to live, but I think that’s where we are.” When asked to describe community responsiveness to cancer, many KRs were unable to because they simply did not know how the community deals with cancer. However, one KR explained, “I don’t see people dealing with cancer.” Cancer is something that people in the community reportedly “tend to ignore” and so many purportedly “don’t seek help and care.” KRs revealed some of the



thinking behind the silence and inaction, maintaining that, “there’s some that might be in denial” and said that there are others that reason “If I don’t think about it, if I don’t get tested, there’s nothing to find.” In fact, one KR said, “I don’t see a lot of preempted steps to avoid it (cancer).” In general, KRs observed, “community members addressing it (cancer) as it occurs.”

This notion of cancer being taboo can negatively influence people’s belief that they can take action to reach out for help, get screened, or seek care. As one KR put it, “It’s kinda at the end of the stage when it’s (cancer) finally talked about.” In fact, one KR recognized this within her own family, explaining, “I would say every family member that has died, of some form of cancer whether it’s liver, leukemia, lung, breast, anything, they presented and within 3 to 4 months were dead.” Another described finding out that a community member was diagnosed and described how cancer “took her real fast.” This is a common story, one that perpetuates the sense of hopelessness and seeing cancer as fatal. Numerous community members evidenced this in first-hand accounts such as, “I haven’t been to the doctor in 25 years or I don’t ever go to the doctor or if I go to the doctor he’s going to say you have cancer you’re going to die.” Others shared second-hand accounts, such as, “I had a good friend die of pancreatic cancer and that was pretty bad. Caught it late, stage four, which is almost too late by then with pancreatic cancer. I’ve lost a couple of friends with breast cancer because they didn’t take, you know, they didn’t follow up like they should have on that.” One KR explained, “I think it’s just so scary people just don’t wanna know about it. It’s part of that trauma... if you don’t know about it, it will go away or it won’t get you if you just don’t know about it.” That said, one KR did attest to having taken preventive measures, saying, “I’ve taken tests and I’ve had a colonoscopy....I get my mammograms done every year” and another expressed a real desire to get screened for cancer but questioned whether or not it was worth it, saying, “you wanna know but is it worth all that to go through all of that?.... I’d have to go through all these screenings.” Talking about negative topics including death (or cancer which can be equated to death) is suppressed. Thus, addressing cancer can also, resultantly, be suppressed.

***Cancer Is Confusing. I do not think everyone knows...they think, oh yeah, you get cancer and either you survive it or you do not.... Its life or death to a lot of people ....But they do not know what happens in-between those two places... They do not understand the layers of it***

KRs expressed an overwhelmingly higher level of knowledge about cancer when it came to personal experiences specific to family and friends. Many identified breast cancer, colon cancer, skin cancer, pancreatic cancer, lymphoma, or leukemia as relevant to their family and friends and noted a spectrum of varying levels of knowledge about the causes, signs and symptoms, treatments, and more. Although most people identified a relative or loved one that has been touched by cancer and some acknowledged that cancer is “very, very common”, one KR explained that in certain ways, some of the community thinks that “It (cancer) probably don’t bother us.” Another

explained, “I don’t think it’s an ignorance so much as a naivety about what really is, causes cancer, you know, like, the environmental things like smoking and drinking bad water and nutrition and those kinds of things. I think that they don’t think, I think we don’t think about that.”

One KR described cancer as an issue that creates “a lot of confusion” for the community. In fact, some KRs alluded to this when they explained that they “don’t know why that’s (cancer’s) happening” or they do not fully understand the causes of cancer, “you don’t really know where it comes from or I really don’t know how it starts.” Others concurred, stating “there’s a lot of misunderstandings surrounding cancer and how people, you know, how it develops and how it’s cared for, if you die from certain types or not and how quick.” One person, when describing community members’ attitudes said, “I don’t think they really dwell on the whys and why nots and things like that.”

Numerous KRs expressed the desire to have access to more knowledge about cancer. Although one person reasoned, “I don’t think we learn, because we don’t want to,” others expressed a genuine desire to learn more about cancer. The majority of community knowledge about cancer comes from family experience. The community recognized a need and want for more information about the causes and treatment of cancer.

**Cancer Is Not a Native Thing. Cancer Is *someone else’s problem*. Native Americans do not get cancer**

Although cancer is a real concern to the AI NPR population as a whole, on an individual level, many KRs from the urban AI NPR feel dissociated from the issue. As one KR explained, “I think until it happens to someone in the family we don’t know because we don’t want to know. And, I think when it happens to friends we also again don’t know, cause we don’t want to know.” That said, others explained that, “when it’s in your family you can’t avoid knowing.”

Many interview responses placed cancer out of the scope of the Native American community. For example, one KR explained, “I think in our Native communities people just think, well that’s not us. We think of it as a white man’s disease and it probably don’t bother us.” Many recognized cancer as “a plague on society” generated by environmental factors that are beyond control, such as contaminated water and soil, additives in food and other environmental toxins. One KR testified how this understanding was part of her story, “my mom had, non-Hodgkin’s lymphoma. I didn’t even know it existed until she got it and then you can trace it to certain chemicals that get into the Ogallala Aquifer.” Cancer was described by one KR as “evidence that the environment can be deadly.” With this understanding, one KR explained that, “a lot of people would just say it’s outside reasons that we have cancer.” Another explained, “it’s seen as something that happens to us.” This prevailing sentiment that “there’s nothing you can do” can promote an external locus of control. The same can be said for the understanding that cancer is genetic, as one KR explained, within the Native community

in our region there is “the belief that they can’t do anything about it, it’s inherited and they’re gonna get it or they’re not.” This perspective demonstrates a low locus of control.

One KR explained, “as it relates to the Native community, I think that it’s a new disease for us... I think it’s an environmental disease and it’s a white man’s issue. Because, prior to the beginning of contact or conquest, I don’t think there was cancer. And, prior to mining and tearing up of the trees and damming the water and digging in the breast of the Earth, I don’t think there was cancer among tribal people.” Often, KRs expressed a shared mentality that “it won’t happen to me.” This understanding can feed misconceptions such as, “Native Americans don’t get cancer” and can give the impression that cancer is not a Native thing; it’s “someone else’s problem.”

***Cancer Is a Community Concern of Low Priority. It’s just one of many issues...you are looking at a multi-faceted cluster of problems***

When we asked KRs “how much of a concern is cancer to the Native community in our region?”, most felt unable to answer this as they did not know. One person explained, “it’s a concern because we don’t deal with it.” Another said, “it’s a concern by inference.” Many said that they could not give a valid answer because they have not discussed cancer with the community. When we asked, “how much of a priority is addressing the issue of cancer to the Native community in our region?”, we found that priority is high for individuals affected but generally low for the community in general. When someone in the community has cancer, it becomes a concern for those in the community who know that person. This is evidenced in KRs’ descriptions of how they see people dealing with cancer, “people will ask for help if folks are fighting, there’s prayers asked for spirituality” or they will raise money through a “taco feed and raffle.” However, overall, “there are more pressing issues” in the Native community in our region because “people are simply struggling to get through every day and when cancer enters the picture it is overwhelming.” Most people’s concerns are focused on “keeping a roof over [their] head, taking care of [their] grandkids, visit[ing] relatives, etc.” As one KR said, “most people are in survival mode and there are other things to talk about,” other things to be concerned with.

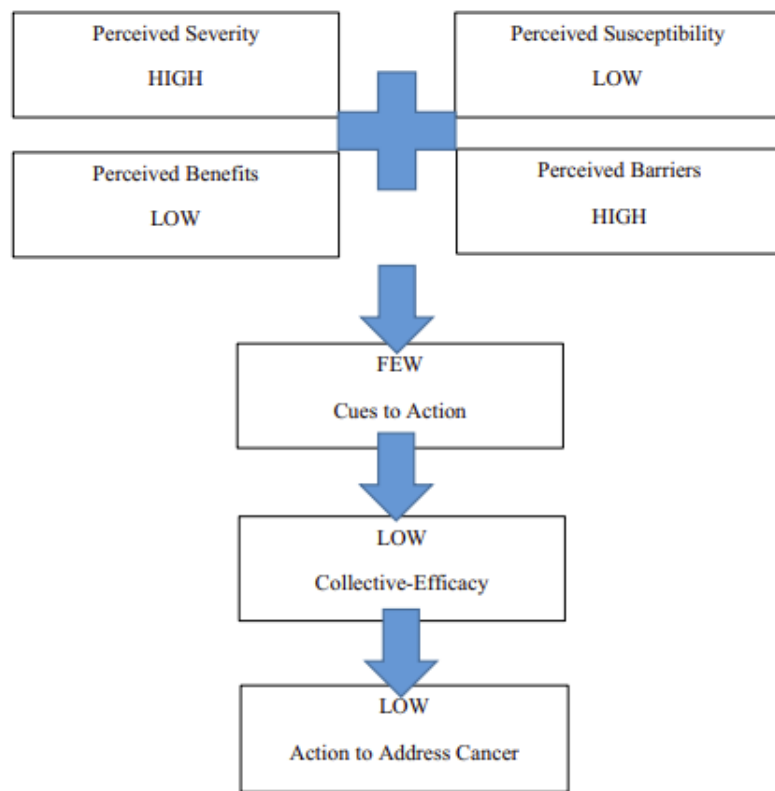
Cancer was described by KRs as being on “the back burner” when compared to other public health concerns, such as diabetes, alcohol abuse, and illegal drug use prevention. That said, one KR asserted, “it’s so important that they become more aware of it (cancer), that they find it early. If they know they have signs of cancer and they know where to get help.” Overall, KRs think that it’s (cancer’s) a concern within our community,” but the level of priority assigned to addressing cancer varies depending on personal experience as well as other competing public health concerns, resources, and as one KR described it, “there are other things that are more important: ... food for the family, having a job, paying for your bills.” As another KR clarified, “when I talk to people the things that come up are diabetes, diabetes, diabetes, alcohol, substance abuse,

mental health and violence.” Although the majority of KRs agreed that cancer is a concern, cancer is “not the largest concern for the AI community.”

Based on these six emergent themes (Fig. 1), we developed a conceptual model for this urban AI Community Climate’s impact on health beliefs with regard to cancer. Synthesizing our data reveals that this urban AI community’s high level of perceived severity paired with a high level of perceived barriers and low levels of perceived susceptibility and perceived benefits can lead to low levels of self-efficacy, cues to action, and ultimately low levels of action to address cancer (e.g., preventative screenings, education, physical activity, etc.).

**Fig. 1** Urban AI NPR community climate’s impact on health beliefs with regard to cancer

*Urban AI NPR Community Climate’s Impact on Health Beliefs With Regard To Cancer*



## Discussion

The purpose of this study was to examine the perceptions, attitudes, and health beliefs about cancer within an urban AI community residing in the NPR. We aimed to illuminate the underpinnings of how Community Climate can influence community readiness to address cancer. Our findings, when interpreted through the Health Belief Model (HBM), informed a conceptual framework for the urban AI NPR community, explaining how a high level of perceived severity and barriers along with low levels of perceived susceptibility and benefits can lead to low levels of collective efficacy, few cues to action, and an ultimately low level of community-based action to address cancer (See Fig. 1). The HBM is extensively used in assessing health-seeking behaviors

related to cancer [15]. According to the HBM, for a community to change their behavior to address cancer, people must feel threatened by their current situation (experience high levels of perceived severity and susceptibility) and feel competent in their actions to overcome perceived barriers to address cancer [16], believing that efforts to address cancer will result in a positive outcome at an acceptable cost (high perceived benefit).

The prevailing attitude of the urban AI NPR community toward cancer acknowledges a high level of severity of cancer, noting cancer as fatal. The idea that cancer is foreign to tribal history and only a more recent phenomenon brought about by European contact supports beliefs that “Native Americans don’t get cancer,” demonstrating a low level of perceived susceptibility. Communal experiences of cancer, including community ideas about why cancer occurs, who has cancer, and how people deal with cancer tended to be limited and/or vague. If people do not know what causes cancer, it is challenging to understand what can be done to prevent or cure cancer; this is highlighted in the urban AI NPR community’s belief that they cannot do anything about cancer. A perceived low level of benefit to addressing cancer was noted within the urban AI NPR community; this could be the result of the overwhelmingly low level of self-efficacy evidenced in the general perception that there is “nothing you can do.” As Jones and colleagues explained, self-efficacy may be required to recognize the benefit of engagement in behaviors to address cancer [17].

Als contend with historical and present-day oppression on a day-to-day basis, resulting in multidimensional factors including social, cultural, psychological, spiritual, behavioral, environmental, and biological influences that present challenges to cancer prevention, treatment, and control. High barriers to addressing cancer were also noted in interview comments about other pressing health concerns (e.g., higher levels of diabetes, obesity, substance abuse, suicide, violence, etc.) and other potential differences in life experience (e.g., poverty, adverse childhood experiences, limited education, poor access to healthcare, limited internet access). This is consistent with the findings of Burhansstipanov and colleagues [18] who reported that less than one third of the AI community has private health insurance and two thirds live below the federal poverty level.

A stage three level of community readiness with regard to the dimension of Community Climate indicates that the community is neutral, uninterested, or does not believe that cancer affects them as a whole [9]. Our qualitative findings from a framework analysis of Community Climate are consistent with the urban AI NPR community’s overall low level of readiness to address cancer (manuscript under review). The HBM can help guide strategies to develop ways to increase the AI NPR community’s awareness and knowledge of cancer and to facilitate prevention efforts that increase screening, early detection, treatment, and research. The HBM informed conceptual framework for the urban AI NPR community can help guide the development and implementation of cancer prevention and intervention in diverse cultural contexts [13, 19]. The findings of this study can be used to create more effective, culturally

relevant community-based strategies to promote cancer prevention and control in this urban AI NPR community. Future efforts can work to pair the community's high level of perceived severity with a lower level of perceived barriers, to increase awareness of the urban AI NPR population's susceptibility to cancer, to increase the community's understanding of the benefits of screening and treatment, and to build more collective-efficacy and establish community-based cues to action that lead to more AI participation in cancer education, prevention, treatment, and research. We anticipate that this framework can potentially inform and guide the development of policies and practices in support of culturally relevant and effective cancer prevention and care in urban AI NPR communities and beyond.

## **Acknowledgments**

The authors thank the Omaha Metro Area Urban Indian Community who shared stories, beliefs, and perspectives that are included in this article.

## **Funding Information**

We appreciate the National Institute of Health National Cancer Institute for funding this project through the Youth Enjoy Science, YES, grant (NCI R25 CA221777) and the Fred & Pamela Buffett Cancer Center Core Grant (P30 CA036727).

## **References**

1. Espey DK, Wu X-C, Swan J, Wiggins C, Jim MA, Ward E, Wingo PA, Howe HL, Ries LAG, Miller BA (2007) Annual report to the nation on the status of cancer, 1975–2004, featuring cancer in American Indians and Alaska natives. *Cancer* 110:2119–2152
2. Espey DK, Paisano RE, Cobb N (2003) Cancer mortality among American Indians and Alaska natives: regional differences, 1994–1998. Indian Health Service, Rockville  
<https://digitalrepository.unm.edu/cgi/viewcontent.cgi?article=1035&context=nhd>. Accessed 30 Oct 2019
3. Watanabe-Galloway S, Flom N, Xu L, Duran T, Frerichs L, Kennedy F, Smith CB, Jaiyeola AO (2011) Cancer-related disparities and opportunities for intervention in Northern Plains American Indian communities. *Public Health Rep* 126:318–329
4. Guadagnolo BA, Cina K, Helbig P, Molloy K, Reiner M, Cook EF, Petereit DG (2009) Medical mistrust and less satisfaction with health care among native Americans presenting for cancer treatment. *J Health Care Poor Underserved* 20:210–226.  
<https://doi.org/10.1353/hpu.0.0108>

5. Juarez G, Mayorga L, Hurria A, Ferrell B (2013) Survivorship education for Latina breast cancer survivors: empowering survivors through education. *Psicooncologia* 10:57–68. [https://doi.org/10.5209/rev\\_PSIC.2013.v10.41947](https://doi.org/10.5209/rev_PSIC.2013.v10.41947)
6. Petereit DG, Burhansstipanov L (2008) Establishing trusting partnerships for successful recruitment of American Indians to clinical trials. *Cancer Control* 15:260–268. <https://doi.org/10.1177/107327480801500310>
7. Harjo LD, Burhansstipanov L, Lindstrom D (2014) Rationale for “cultural” native patient navigators in Indian country. *J Cancer Educ* 29:414–419
8. Watanabe-Galloway S, Zhang W, Kate W, Islam KM, Nayar P, Boilesen E, Lander L, Wang H, Qiu F (2014) Quality of end-of-life care among rural Medicare beneficiaries with colorectal cancer. *J Rural Health* 30:397–405
9. Plested BA, Jumper-Thurman P, Edwards RW (2009) Community readiness: advancing HIV/AIDS prevention in native communities (community readiness model manual, revised). Ethnic Studies Department, Colorado State University, Fort Collins [http://www.oneskycenter.org/wp-content/uploads/2014/03/CommunityReadinessManual\\_FINAL.pdf](http://www.oneskycenter.org/wp-content/uploads/2014/03/CommunityReadinessManual_FINAL.pdf). Accessed 30 Oct 2019
10. Urban Indian Health Commission (2007) Invisible tribes: urban Indians and their health in a changing world. Urban Indian Health Commission, Seattle <https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=2ahUKEwjN3PrswsnIAhUMWqwKHQlcAG8QFjAAegQIBRAC&url=https%3A%2F%2Fwww2.census.gov%2Fcac%2Fnac%2Fmeetings%2F2015-10-13%2Finvisible-tribes.pdf&usq=AOvVaw1tk1whVslaED8GgJSLt0EJ>. Accessed 30 Oct 2019
11. Norris T, Vines PL, Hoeffel EM (2012) The American Indian and Alaska Native Population: 2010: US Census Bureau. <https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=4&cad=rja&uact=8&ved=2ahUKEwin0ZKoxcnIAhUBL6wKHWbcDTAQFjADegQIAxAC&url=https%3A%2F%2Fwww.census.gov%2Fhistory%2Fpdf%2Fc2010br-10.pdf&usq=AOvVaw05KEU7bS-RmJtzvJ822csD>. Accessed 30 Oct 2019
12. Nebraska Urban Indian Health Coalition Inc (2019) FAQs Nebraska Urban Indian Medical Center. Nebraska Urban Indian Health Coalition. <http://www.nuihc.com/faq/> Accessed 30 Oct 2019
13. Scarinci I, Bandura L, Hidalgo B, Cherrington A (2012) Development of a theory based, culturally relevant intervention on cervical cancer prevention among Latina immigrants using intervention mapping. *Health Promot Pract* 13:29–40

14. Gale NK, Heath G, Cameron E, Rashid S, Redwood S (2013) Using the framework method for the analysis of qualitative data in multidisciplinary health research. *BMC Med Res Methodol* 13:117
15. Glanz K, Bishop DB (2010) The role of behavioral science theory in development and implementation of public health interventions. *Annu Rev Public Health* 31:399–418
16. Champion VL, Skinner CS (2008) The health belief model. In: Glanz K, Rimer BK, Viswanath K (eds) *Health behavior and health education: theory, research, and practice*. Jossey-Bass, San Francisco, pp 45–62
17. Jones CL, Jensen JD, Scherr CL, Brown NR, Christy K, Weaver J (2015) The health belief model as an explanatory framework in communication research: exploring parallel, serial, and moderated mediation. *Health Commun* 30:566–576
18. Burhansstipanov L, Krebs LU, Harjo L, Ragan K, Kaur JS, Marsh V, Painter D (2018) Findings from American Indian needs assessments. *J Cancer Educ* 33:576–582
19. Griffin MJ (2011) Health belief model, social support, and intent to screen for colorectal cancer in older African American men. University of North Carolina at Greensboro, Greensboro  
[https://libres.uncg.edu/ir/uncg/f/Griffin\\_uncg\\_0154D\\_10607.pdf](https://libres.uncg.edu/ir/uncg/f/Griffin_uncg_0154D_10607.pdf). Accessed 30 Oct 2019

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