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## Healthcare barriers and supports for American Indian women with cancer

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### Abstract

Although American Indian (AI) women continue to experience cancer at higher rates and have not seen the same decline in cancer prevalence as the general U.S. population, little research examines how interactions with health care providers may influence and exacerbate these health disparities. The purpose of the study was to understand the experiences of AI women who receive cancer treatment, which is integral for eradication of AI cancer disparities among women. A qualitative descriptive methodology was used with a sample of 43 AI women with breast, cervical, colon, and other types of cancer from the Northern Plains region of South Dakota. Interviews were conducted from June 2014 to February 2015. Qualitative content analysis revealed that women experienced: (a) health concerns being ignored or overlooked; (b) lack of consistent and qualified providers; (c) inadequate healthcare infrastructure; (d) sub-optimal patient–healthcare provider relationships; (e) positive experiences with healthcare providers; and (f) pressure and misinformation about treatment. Results indicate the types of support AI women may need when accessing health-care. Culturally informed trainings for healthcare professionals may be needed to provide high-quality and sensitive care for AI women who have cancer, and to support those providers already providing proper care.

### Keywords

American Indian or Native American; cancer; health disparities; patient-provider interaction; qualitative research

### Background

American Indian/Alaskan Native (AI/ANs) individuals experience extreme health disparities compared to their White counterparts. For instance, AI/AN women experience cancer at 1.6 times the frequency of White women, and it is the main cause of mortality for AI/AN

women (Espey et al., 2014). Because cancer prevalence and treatment outcomes differ between men and women, it is important to examine the experiences of AI women with cancer specifically. For instance, though lung cancer rates have been decreasing for AI males, for AI women, lung cancer rates have continued to increase (Plescia, Henley, Pate, Underwood, & Rhodes, 2014). AI/AN women have also not experienced the same decline White women have in death rates for breast cancer (White et al., 2014). For colorectal and kidney cancers, there is a higher overall incidence, and higher death rate, for AI/AN women than for both White women and AI/AN males (Perdue, Haverkamp, Perkins, Daley, & Provost, 2014). These cancer disparities are alarming, especially in light of the Treaty Agreements between the U.S. government and the 567 federal sovereign tribes to provide for the healthcare and well-being of AI/AN individuals (Bureau of Indian Affairs, 2017; Espey et al., 2014; U.S. Commission on Civil Rights, 2004).

The root causes of these health disparities can be linked to broader inequalities and social injustices and continuing poor access to care (Culhane & Elo, 2005; Misra & Grason, 2006). Throughout colonization and Western expansionism, AI women have frequently experienced human rights atrocities and have had their medical autonomy undermined (Gurr, 2014). Even after controlling for socio-economic differences, racism has been linked to earlier health deterioration and consequently impacts the health needs of minority women (Geronimus, Hicken, Keene, & Bound, 2006).

An extensive body of feminist scholarship has identified and explored how the treatment of female patients is contingent on their respective social locations (Ehrenreich & English, 1988; Marsh & Ronner, 1996). For example, women with higher socio-economic status tend to receive more optimum treatment by providers than those with lower socioeconomic status. Historically, women with less privilege have had their autonomy undermined by health care providers performing medical procedures or treatments without the explicit, or full consent, of their patients (Kluchin, 2011; Marsh & Ronner, 1996). Less privileged women are less likely to have their different treatment options explored, explained, and discussed with them, and frequently do not have their treatment wishes followed or respected (Gomez, Fuentes, & Allina, 2014).

Research has documented that Medicaid patients receive care that is less respectful when receiving healthcare services than patients with private insurance, perhaps because physicians may have less incentive to spend additional time explaining treatment and procedures to patients, or to provide additional services to patients, if they perceive that their reimbursement for those services will be capped (Morris, 1997). Studies also show that physicians (who are frequently White, and/or middle/upper-middle class) perceive their minority and lower class patients negatively compared to White or higher class patients (Street, Gordon, & Haidet, 2007; Van Ryn & Burke, 2000). This also likely impacts the quality of care of those patients (Street et al., 2007; Van Ryn & Burke, 2000). This is important since provider-patient interactions for less privileged women are typically characterized by seeing a provider from a higher socioeconomic and different ethnic background, such that minority women are likely to see a provider who is White, and to see a provider of a higher and different social class than them. This is frequently not the case for higher class and White women. Despite a large body of research demonstrating the

inequality in these interactions, little research has explored this topic for AI individuals (Saha, Arbelaez, & Cooper, 2003).

Additionally, the long history of oppression experienced by AIs, causes some AI individuals to have ambivalent and contradictory feelings about seeking support or help from formal healthcare services (Broome & Broome, 2007; Burnette & Figley, 2017; Canales, 2004a; Canales, 2004b; M. K. Canales et al., 2011; Garrett, Baldrige, Benson, Crowder, & Aldrich, 2015). This ambivalence may also entail patients not wanting or feeling like they can discuss their health problems with their healthcare providers because of this history of abuse and exploitation (Broome & Broome, 2007). Patients may also be wary about the extent to which their healthcare provider will be willing to include traditional healing practices in their treatment plans, or if their provider will be dismissive of these traditions (Broome & Broome, 2007). The health disparities of AI women are compounded by the intersection of colonization and the continuing experience of discrimination and widespread poverty (Walters & Simoni, 2002).

AI women have historically had their well-being undermined through interactions with medical providers who pathologize the more holistic view of health and well-being that is often important for AI women, and by providers who often act in a paternalistic and patronizing way to their female patients (Walters & Simoni, 2002). Furthermore, researchers, and public health and social workers, have frequently contributed to the exploitation of AI women through conducting exploitative research projects or restricting access to healthcare resources and the right of AI women to bear and raise their children (Brown et al., 2015; Cochran et al., 2008; Gurr, 2014; Minkler, Blackwell, Thompson, & Tamir, 2003; Smith, 2012). These concerns make an analysis of these relationships necessary.

Though there is extensive documentation of the continuing health inequalities between American Indian women and the general U.S. population, little research examines how interactions with health care providers may influence and exacerbate these health disparities. Indeed, many women desire relationships with their healthcare providers where they feel their personal worth is recognized and supported, where caring communication takes place, and where they are encouraged to participate in decision-making (Records & Wilson, 2011). The purpose of the study was to understand the experiences of AI women who receive cancer treatment, which is integral to the eventual eradication of AI cancer disparities among women.

## Methods

### Research design

This study used a community advisory board (CAB) of AI health care professionals and different AI community leaders. The CAB ensured that the research questions were culturally appropriate and relevant for AI women with cancer, that the study design and protocol was ethical and appropriate for the AI community, assisted in recruiting participants, conducting member-checks, and disseminating results to the community. A qualitative descriptive methodology was used to explore the reported cancer experiences of

AI women as they related to their interactions with medical practitioners and health systems. The main research question was: “What are AI women’s experiences in the healthcare treatment service system(s) for cancer?” Qualitative description, since it prioritizes the experiences of the research participants instead of the more abstract extrapolation of researchers, was selected (Sullivan-Bolyai, Bova, & Harper, 2005). This design has also been found to frequently be more culturally-relevant in research with vulnerable groups because of its emphasis on understanding cultural nuances (Sullivan-Bolyai et al., 2005). Because the abstracted conclusions of researchers are often limited, hearing the suggestions and interpretations of events from participants directly results in knowledge that is more translatable to real-world applications, in this case, what obstacles and strengths do AI women perceive in medical institutions (Sullivan-Bolyai et al., 2005).

### Setting and sample

This research project was developed through cooperative partnerships with two eastern and western community-based hospitals in the Northern Plains region, in the state of South Dakota: (a) the Avera Medical Group Gynecologic Oncology in Sioux Falls and (b) the John T. Vucurevich Cancer Care Institute, Rapid City Regional Hospital in Rapid City. These research sites were selected since they were the main medical institutions accessible for AI women in these respective areas of South Dakota.

The sample included 43 AI women with cancer ( $n = 15$  colon cancer and other forms of cancer,  $n = 14$  cervical cancer, and  $n = 14$  breast cancer). We included a variety of forms of cancer in the study to explore any possible differences in the experiences of AI women with cancer across different cancer types. Purposeful sampling was used for participant recruitment. Inclusion criteria was comprised of: (a) having had any form of cancer in the past 10 years; (b) having finished their cancer treatment and having no indication of cancer recurrence; (c) identifying as a woman; (d) being above the age of 18 years; (e) living in South Dakota; and (f) identifying as AI.

Participant age ranged from 32 to 77 years, ( $M = 56.33$  years,  $SD = 12.07$ ). In relation to educational attainment, 97.7% of participants had either a GED or a high school degree. Slightly less than half (49%) reported a monthly household income that was below \$1,499. Approximately 67.5% reported their health as being either good or excellent, although 32.5% of participants reported their health as being either *poor or fair*. The forms of cancer included: cervical ( $n = 14$ , 32.6%); breast ( $n = 14$ , 32.6%); colon ( $n = 5$ , 11.6%); lung ( $n = 2$ , 4.7%); Non-Hodgkin Lymphoma ( $n = 2$ , 4.7%); and others ( $n = 6$ , 13.9%). Most participants ( $n = 39$ , 90.7%) reported having a religious affiliation, and 93% ( $n = 40$ ) had some form of medical insurance. However, only 30.2% ( $n = 13$ ) had private insurance. Medicare or Medicaid plus Indian Health Service (IHS) insurance was reported by 37.2% ( $n = 16$ ) of participants, while 16.3% ( $n = 7$ ) only had IHS, and 9.3% ( $n = 4$ ) had private insurance supplemented with IHS. The typical amount of time participants reported having cancer was around 2.42 years ( $SD = 2.19$ ).

## Data collection

Prior to initiating data collection, approval from the Institutional Review Boards was obtained by four institutions: (a) University of South Dakota, (b) Avera McKennan Hospital, (c) Rapid City Regional Health, and (d) Sanford Research center. Voluntary signed consent was completed by participants before they were enrolled in the study. The principal investigator (PI) of this project and two highly trained research assistants with extensive previous experience working and conducting research with AI populations and people with cancer conducted the research interviews. For recruitment, fliers were sent to cancer patients at each of the hospitals, posted at agencies in the community, announcements through the newspaper or public radio were made, and recruitment via word-of-mouth was done at local churches and agencies. Interviews were done where participants desired, and took place either at participants' homes, private conference rooms at either one of the hospitals, a local church, or a PI's office, from June of 2014 to February of 2015.

A qualitative semi-structured interview guide, developed through partnership with the CAB, was used. Questions included in the study guide were developed through quarterly CAB meetings. The CABs evaluated the interview guide, paying special attention to the phrasing of questions, and making sure questions were cultural appropriate. Participants answered the following questions: (a) "Tell me about accessing health care? Where were you receiving your care when diagnosed?"; (b) "What has been your experience of being treated for cancer?"; and (c) "What made you go to the doctor originally when you received your diagnosis?" The interviews, which were audio-recorded, were then transcribed by graduate students verbatim, and the interview length was between 30 and 120 minutes. Participants time was compensated with \$50, and participants were provided with an extra gift card for any travel or additional expenses. After being transcribed, the interviews were analyzed using NVivo data analysis software (QSR International Pty Ltd., 2015).

## Data analysis

To guide our data analysis, we used qualitative content analysis. For qualitative descriptive studies, this method is recommended because it facilitates the identification of inductive themes that come directly from the study findings (Milne & Oberele, 2005). Qualitative content analysis involves: (a) full immersion in the research findings through listening to interviews and reading the transcripts several times in order to conceptualize the research data in a deep and holistic manner; (b) coding of data line-by-line to identify central ideas; (c) the identification of 430 preliminary codes which we then categorized into larger themes and subcategories; (d) discussion with co-authors about these subcategories and clusters and to explore whether any notable differences existed between the different forms of cancer. The authors identified no differences; (e) the categories that emerged were then used to organize the codes further into understandable clusters, with a definition for each group; and (f) clusters with their related quotes were shown to respondents during member checking. All respondents were contacted at least three times by authors for member checks. Although around half ( $n = 21$ , 46.5%) of participants had phones that were disconnected, more than half of those in the study ( $n = 23$ , 53.5%) participated in the process. No changes or amendments were asked for by participants following these member checks. In addition to probing for clarity, conducting member checks and using inductive analysis, we further

promoted the validity and authenticity of findings by reflecting on possible bias and engaging in reflection and peer review with the different co-authors (Milne & Oberele, 2005). Respondents were given anonymous ID numbers to demonstrate the quotes and themes that are present across participants throughout the results section.

## Results

Women reported varied experiences with healthcare providers and the health care system when receiving their diagnosis of cancer and throughout their cancer treatment. These experiences included: (a) women's health concerns being ignored or overlooked; (b) lack of consistent and qualified providers; (c) inadequate healthcare infrastructure; (d) sub-optimal patient–healthcare provider relationships; (e) positive experiences with healthcare providers; and (f) pressure and misinformation about treatment. Perhaps most concerning is the finding that 37% ( $n = 16$ ) of women reported extreme difficulties in getting treated and tested for cancer.

### Women's health concerns being ignored or overlooked

Many women struggled to be heard, to be taken seriously, or to have their legitimate healthcare concerns addressed. Over 41% of participants ( $n = 18$ ) reported struggling to have their initial concerns about cancer taken seriously. As Participant 13 reported, “In the beginning they [healthcare professionals] ... would just say I had the flu or a virus, and just give me antibiotics and send me home.” Participant 9 echoed this experience:

They [healthcare team] just kept giving me pain meds and shoving me out the door ... I told them there was something seriously wrong. They told me that oh it was just because I was on birth control for too long ... I was fighting for two years before I got attention to see what was really wrong with me.

Women consistently reported having to convince their doctors that something was wrong. As Participant 3 described:

I wasn't gaining any weight and I kept telling the doctors over and over, I eat like a horse, but I'm not gaining no weight, and the way I eat I should gain some weight. At first, they didn't listen to me, so I went back again, and I told them, 'I keep telling you guys ...'

Participant 32 thought this interfered with her ability to catch the cancer early on and to possibly start her cancer treatment earlier:

No, and I was quite upset. I even wrote it in all my evaluations and everything that they [healthcare professionals] dropped the ball and didn't call me and how we could have caught it ahead of time. Now it was a full-blown cancer.

Women who were identified as having cancer early on usually reported finding out they had cancer through regular screening programs, highlighting the importance of these programs. As Participant 21 stated, “It was my yearly mammogram check-up. I have a mammogram once a year. And a pap.” This was echoed by Participant 4, “It was just my yearly check-up.” These findings indicate that women encounter substantial obstacles when receiving their cancer diagnosis.



### Lack of consistent and qualified providers

Additional challenges reported by participants (22%,  $n = 10$ ) included a lack of consistency in care providers, an insufficient number of providers, and inexperienced healthcare professionals. Participants identified these problems as being barriers for their cancer treatment. As Participant 10 explained:

Every time I go up to the doctor, it's always a different doctor, and I have to explain each time why I'm there. It's like they [the healthcare team] didn't believe me, like there's something wrong. I keep telling them there's something wrong, but they don't see nothing. So I did three ultrasounds and then finally the ultrasound tech is the one that suspected something ... But when I went back up there they [healthcare team] said he was busy that day ... That's why I made this appointment at [name of alternative hospital] because this hospital keeps giving me the run around. They [healthcare providers] say I have cancer but they're not really trying to treat it.

Several participants reported problems with not getting results or information because there was not a doctor available to provide it (they had work done by a physician's assistant or radiologist, who were not qualified to give them the results) and that they then had to wait a long period of time to get results. As Participant 14 related, "No [be]cause the physician said he can't tell me cause he's not my doctor. I have to see the one in Pine Ridge." Participant 12 described all her care providers as, "they're all interns." Participant 10 further elaborated on this issue stating that, "They [the physicians] stay for a week or two and then they leave. They constantly rotate like that. So it's really hard. It's not like one doctor." The lack of consistent and qualified providers was a notable barrier for many women in accessing cancer treatment.

### Inadequate healthcare infrastructure

Participants reported several infrastructure barriers to accessing cancer treatment. Some forms of healthcare infrastructure barriers were particularly common concerns for participants, being reported by 45% of participants ( $n = 20$ ). These included: (a) long distances to get to healthcare facilities, (b) lack of record-sharing between health facilities, (c) long waiting times between appointments, (d) poor health equipment, and (e) insufficient insurance coverage. As described by Participant 24, "At Indian Health Services. And their mammogram machine was broke down. It was broke down." Participant 1 reported a similar lack of resources, "Our hospital is so bad and such poor healthcare, they [the hospital] didn't have a doctor to do my Pap smear." For Participant 14, distance was an additional notable barrier, "About, um, anywhere from Pine Ridge where I live to Rapid is like a hundred miles." When asked about the length of time to receive treatment, Participant 14 stated, "Geez, about like three years."

Other participants reported difficulties in getting reimbursed for their treatment. Participant 24 described:

I asked Indian Health Service to help me out for, to pick up the 20% and they [IHS] said that this was not a life-threatening illness. And I said to them, I said, if this isn't a life-threatening illness, then tell me what is. Tell me what is.

Participant 14, echoed this sentiment, stating, “Poor people that don’t have private insurance, they’re stuck.”

Two participants specifically brought up the use of patient navigators. Participant 40 described how important her patient navigator was for her treatment:

Well, thank God, they have a navigator here, a nurse navigator. She’s a nurse practitioner ... And she kept all my appointments straight for me ... But thank God for her, she’s like my guardian angel, sometimes I just can’t cope.

These findings indicate that patient navigators may be one way healthcare systems can overcome some of these healthcare infrastructure obstacles.

### **Sub-optimal patient–healthcare provider relationships**

Relationships between cancer patients and providers varied with many women reporting both explicitly positive (43%,  $n = 19$ ) and negative (25%,  $n = 11$ ) experiences with their doctors and their healthcare team. Positive experiences were important for woman to be able to continue their treatment and included nurses and doctors spending the time to communicate with patients, and providing emotional support. Negative experiences included disrespectful and insensitive comments and insufficient communication with healthcare providers. Issues with confidentiality were salient for other participants, particularly because of the small community. Participant 13 stated that, “Whatever you tell them [healthcare providers] gets passed on.” Experiences of disrespectful communication from their healthcare providers were reported by several participants. Participant 13 relates her negative experience:

She [nurse] was in a hurry because it was almost time to go home. And I go, “What’s mastitis?” She goes, “Oh, cows and horses get that in their breasts. It clogs the milk ducts and that’s what you got ...”

Participant 2 recalled a particularly egregious incident where a doctor made an insensitive comment:

After I found out I was going to have to have the bag [colostomy bag] on forever, and he [the doctor] ... made a remark about, “How does [name omitted] even stay with you? How do you even have sex?”

Participant 3 recalled another one of these negative instances:

The doctor [acted] ... like act like he was scared! An Indian doctor. He’s from Blackfoot Indian doctor. He came in, act scared, he said um ... uh, you know why you’re in here for? I said yeah, do I have cancer? He wanted me to read what was in my chart. What biopsy they did ...with the medical terms ... I have never felt so bad. I didn’t mind me having cancer, all I needed was that doctor to be nice about it ... And so I left, I cried to her, my kids. The way I was treated by him.

Additional concerns reported by participants included feeling uncomfortable disrobing and being examined by their healthcare provider. Participant 6 describes this experience:



So it took me a while ... [I'm] uncomfortable having people I don't know ... to expose our bodies to just anybody. You know what I mean...having the doctor you know. Even now I'm still that way because ... [to] take your clothes off and ... I don't want to go back up there because it's so embarrassing and I'm tired of having them you know [look at her when naked].

Participant 14 similarly felt uncomfortable with this aspect of the relationship, stating, "I was not very comfortable with ... [the visits, because] I go see a male doctor."

Some women reported receiving treatment, yet they didn't know what the treatment was for, as was the case for Participant 14: "No, I don't know what this radiation therapy was for." For some patients, nurses would end up providing more of an explanation of the treatments than would the doctor. As Participant 6 related, "They [the doctors] didn't help very much with um like explaining so much... The nurse would tell me more about the situation. The treatment or whatever." Other women reported receiving information about their treatment but not about what came after. This experience was echoed by Participant 13, "They [healthcare providers] didn't explain in advance all the things that were gonna [going to] happen after the surgery. They just explained what was gonna happen at the surgery and not afterwards."

Even when given the opportunity to ask questions, as Participant 40 observed, not all women know what to ask:

Well, they [healthcare team] say if you have any questions you can always ask but a lot of times you don't know enough about what's happening to ask questions, exactly. I'm well educated, I was a nurse, but I didn't have to deal with cancer patients or dialysis patients.

Many AI women experienced negative and insensitive care and treatment from their healthcare providers. This was a source of considerable distress for many respondents.

### **Positive experiences with healthcare providers**

However, it is important to note that not all women reported negative experiences and insensitive and inadequate communication with their healthcare providers. This emphasizes the important role that receiving kind treatment from the healthcare team can play in treatment and recovery. As Participant 12 described:

I feel that they [healthcare team] are very caring, you know, beyond their profession. And I feel that, um, that I am important to them, and that, my recovery is important, and the treatments, everything is explained to me, and if I don't understand something, then they explain it in a way for me to understand it.

Participant 1 also reported a positive experience and described her doctor:

The doctor is excellent, and they communicate with me all the time, you know call me or you know check on me, and it went quick, 5–6 weeks.

Participant 11 echoed this:

She [the doctor] would come and we would think of a lot of questions that we would have and we would do a lot of research and we would ask the doctor and my sister would come and she would kind of help us make sense of all the medical terminology, and I think the doctor was really good in explaining the treatment procedures and how long they were and I was treated very well.

Participant 19 described the importance of providers acknowledging when they didn't know the answer to something, and working to find an answer, "One of the things I am glad about is both my doctors have never looked at me and go 'I don't know.' They've said, 'we'll find out if they didn't have the exact answer to a question.'" Participant 23 reported a similar positive experience with her doctor taking the time to listen and answer her concerns:

They [the doctors] really respect us. I think their time with us is supposed to be around 20 minutes, I can't remember, but when you go in there you feel like you're the only patient that matters. They are so attentive up there and I have never had one issue with any of my care up there. I always just appreciate it.

Participant 11 described the importance of her healthcare staff providing her and her partner with instrumental support, for example, food because of the long commute time they experienced to get to the facility:

They [healthcare team] would get him food or something to drink if he needed them because he would drive to Rapid City from here, from Pine Ridge. He would drive an hour and a half to come to the appointments with me ... and they treated us both very well.

These experiences highlight the importance of positive and sensitive care and treatment from healthcare providers.

### **Pressure and misinformation about treatment**

Women also reported medical staff pressuring them to have certain procedures they were uncomfortable with, healthcare providers providing treatment without their explicit knowledge, and healthcare professionals providing participants with inaccurate information about cancer, its causes, and treatment (20%,  $n = 9$ ). Participant 24 describes her experience being pressured to have her breasts removed:

That was the doctor up at Indian Health Service. He told me, he said, the best thing you can do ... [is to] remove both your breasts. Because you remind me of my mother. He said, 'Just remove your breasts ... You know then you won't have to worry about it no more' ... then I started crying.

Several participants reported being treated without knowing why a procedure was done. Participant 9 described:

At first, I did it because he [doctor] told me it was just going to be a laparoscopic surgery and um he ended up cutting me wide open right here. That is one of the reasons I was really mad, because I had all these thoughts running through my head, 'Why did they open me this way? Did it spread? Is it bad?' I couldn't talk. I couldn't ask questions at the time because I was in so much pain.

Participant 2 reported a similar incident:

What made me feel depressed was knowing that when something was wrong with me after the treatment, that there is one time that we went to the emergency room at the IHS and they were trying to give me an enema. It's like nobody would listen to me ...

Several women also reported receiving misinformation about cancer and its treatment. Participant 29 recalled her doctor telling her, "He [doctor] said cancer skips every generation, all your grandkids need to be checked." Participant 3 recalled a similar incident:

I'll tell you what Rosebud IHS told me. They told me that Native women are...well there's more cases of breast cancer here because of the Native women breast nursing. That's what they told me at Rosebud IHS.

Many woman reported feeling pressured to have medical treatment, and receiving insufficient or inaccurate information from their medical providers.

## Discussion

As these results indicate, participants reported a variety of barriers and challenges throughout their cancer diagnosis and treatment. These experiences included: (a) women's health concerns being ignored or overlooked;(b) lack of consistent and qualified providers; (c) inadequate healthcare infrastructure; (d) sub-optimal patient–healthcare provider relationships;(e) positive experiences with healthcare providers; and (f) pressure and misinformation about treatment. Women reported both positive and negative experiences with their healthcare providers and the healthcare system when receiving their diagnosis of cancer and throughout their cancer treatment. Not only did participants report experiences of doctors not believing them when they reported health problems, many women reported infrastructure barriers related to a lack of sufficient and consistent doctors, testing facilities, and hospitals within driving distance. Several participants also reported getting diagnosed through routine screening programs, highlighting the need for these programs. Considering the difficulty many women had in getting diagnosed, community education and screening programs are an essential need identified by these women.

Women also reported several challenges in the patient–provider relationship, and pressure and misinformation from the healthcare team about their cancer treatment. Women also indicated that having a supportive doctor or staff person was essential to their ability to navigate the healthcare system, and receive and continue treatment. Consistent with previous research showing the importance of consistent care (Haggerty et al., 2003) for patient well-being, women in this study similarly reported the importance of having the same care provider throughout their treatment. While some women are able to have the same care provider, other women experience discontinuity, which can affect the amount of trust and respect in the patient–provider relationship. Many women also reported insensitive treatment from their doctors, or a total lack of communication. Two women also indicated that they believed patient navigators may be one way to address some of their concerns, particularly those related to infrastructure barriers and the need for more information about their care

and treatment options. Other women had more positive experiences, stressing the importance and need for sensitivity trainings for healthcare staff.

### Limitations

This research uses self-report data. The sample is also not generalizable beyond its specific setting, since it only includes participants who are AI women from South Dakota. Although no differences were found across the experiences reported by participants with different forms of cancer, future research may further investigate whether the type of cancer affects the healthcare experience of AI women. Additionally, it is possible that women with more negative experiences were more likely to participate in the study, therefore biasing the results. However, the inclusion criteria (discussed in the methodology section) which aimed at recruiting all AI women with cancer, hopefully mitigated this possibility. Finally, the healthcare experiences of AI women with cancer may also be influenced by their specific tribe, and it is expected that tribal supports may impact healthcare experiences and will vary depending on region and the specific tribe.

### Implications for practice and conclusions

The findings of this study have important implications for those working with AI women in healthcare settings in general and for those working with individuals with cancer in particular. Results indicate that AI women experience a variety of obstacles, including identifying their cancer, in accessing healthcare resources, and in their interactions with healthcare providers. In addition to an increase in healthcare resources for AI woman, these findings suggest that healthcare providers need to undergo culturally-sensitive trainings to provide more sensitive and high-quality care for their patients. Consistent with previous research indicating that fewer AI individuals receive concordant cancer treatment compared to White patients, the findings from this study suggest that there is a need for AI-specific programs for cancer diagnosis and treatment (Javid et al., 2014).

Because of the need for culturally sensitive care, communities represent a promising resource for healthcare providers (Brown et al., 2015; Struthers & Eschiti, 2004). Communities may also be uniquely positioned to conduct cancer education and screening programs (S. R. Brown et al., 2015; Guadagnolo et al., 2009; Harris, Van Dyke, Ton, Nass, & Buchwald, 2016). AI women may also be more likely to participate in, and to have access to, screening programs that are run by their tribal community (S. R. Brown et al., 2015; Harris et al., 2016). However, despite this need, there is evidence to suggest that the medical community may not always be supportive or help facilitate community-driven programs (M. K. Canales et al., 2011; Guadagnolo et al., 2009; Harris et al., 2016).

Patient navigator programs (which can assist patients with understanding treatment protocols and options, financial and transportation issues and care coordination) are an additional promising area where community and health-care provider partnerships can be instrumental (Burhansstipanov et al., 2012; Harris et al., 2016). Although many AIs report preferring face-to-face contact during their healthcare treatment, AI individuals are increasingly reporting being open to other types of communication, such as e-mail and social media (Harris et al., 2016). This may be especially relevant for healthcare providers working with

individuals in rural areas where access to resources is limited (Gage-Bouchard, LaValley, Warunek, Beaupin, & Mollica, 2017). To address the geographic barriers women in this study reported, the use of “telehealth” programs among AI and AN cancer patients may be an additional creative option for linking geographically distant women and as a way to provide some of these needed healthcare services (Doorenbos et al., 2010). Though these programs may not mitigate all of the negative experiences reported by AI women with cancer, being linked to support persons and networks may begin to address some of the infrastructure barriers (e.g., not knowing where to get tested or how to get medication reimbursed) and may address the knowledge gap many women reported about their cancer treatment and care.

Patient navigator, telehealth, community education, and screening programs are all areas where social workers can play an important role. Indeed, social workers may be particularly well-suited to this task because of the discipline’s emphasis on social justice and the impact of macro, mezzo and micro factors on the individual (NASW, 2008). These results suggest that providers may need training in viewing health more holistically, compared to Western models that generally view health as the physical well-being of individuals (Brown, Harris, & Russell, 2010). This is contrasted with the AI view of health, where health is viewed as a relationship between an individual, their community, and all components of the environment (Brown et al., 2010; Cochran et al., 2008). Western models of health, even when applied by well-meaning practitioners, may still perpetuate destructive views of AI people if they do not incorporate more holistic understandings of well-being (Denzin, Lincoln, & Smith, 2008). Because of the legacy of historical oppression in AI communities, interventions must be specifically tailored and culturally-sensitive. Not only are AI women’s health needs in general under-researched, but community-informed and resiliency research about AI women’s health is rare (Gurr, 2014), making the results of this study especially important for those providing healthcare services for AI women in general, but particularly those with cancer.

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