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Urban Dwelling American Indian Adolescent Girls' Beliefs Regarding Health Care Access and Trust

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Key Words

sexual risk behavior • American Indian • adolescent • qualitative research

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Abstract

Indigenous people, specifically American Indians (AI), have historically had a greater mistrust of the medical system compared to their White counterparts. The purpose of this paper is to explore the perceptions of AI adolescent girls living in an urban, Midwest area about health care providers, health care systems, and access to health care as related to sexual health care. Using grounded theory methodology, twenty 15-19 year old AI girls participated in talking circles and individual interviews. Two distinct themes emerged related to sexual health care: 1. AI adolescent girls trust their health care providers and the health care system; and 2. Access to health care is critical to practicing safe sex and obtaining information about healthy sexual practices. These findings are unique and may help health care providers and social workers providing care and support to the urban adolescent AI girl.

There is significant evidence that Indigenous people, specifically American Indians (AI), have a greater mistrust of the medical system compared to their White counterparts (Call et al., 2006; Canales, Weiner, Samos, & Wampler, 2011; Guadagnolo et al., 2009; Moreno-John et al., 2004). Previous studies have shown that AIs and other minorities who have a negative experience with a health care provider, whether it is a cultural mismatch between the patient and the provider or negative perception regarding care, had a greater mistrust of the larger health care system (Buchwald et al., 2006; Hunt, Gaba, & Lavizzo-Mourey, 2005). Health care included services provided at both American Indian health centers as well as general health care facilities. Yet, most of the articles that focus on AI perceptions of health care focus on patients with disease processes (e.g., cancer), adults or elders, and rural or reservation dwelling AIs. The perception of urban American Indian dwelling youth regarding sexual health care is not well understood.

Understanding perceptions of urban AIs can be challenging because of the relative heterogeneity of the group. Current estimates show fewer than 40% of AIs in the United States currently live on reservations or in rural areas and 31% of the AI population are youth under the age of 18 (Office of Minority Health, 2012). Despite the fact that urban dwelling AIs are the majority population, most of the research on AIs in the United States is conducted with large reservation-based tribes in the Midwest, Northern Plains, and Southwest.

The Indian Health Service (2013) concluded that urban dwelling AIs "share the same health problems as the general Indian population; their health problems are exacerbated in terms of mental and physical hardships because of the lack of family and traditional cultural environments" (para, 2). The Indian Health Service additionally states that AI youth are at greater risk for negative health outcomes, including teen pregnancy and often lack adequate health care services. Sexual health in particular is problematic for American Indian youth. AI adolescent girls contract chlamydia and gonorrhea at higher rates than their White and Hispanic adolescent counterparts. American Indian 15-19 year old girls contracted chlamydia at a rate of 4235.1 per 100,000 (2.9 times greater than their White counterparts and 2.1 times greater than their Hispanic counterparts) and gonorrhea at a rate of 501.9 per 100,000 (Centers for Disease Control and Prevention [CDC], 2014). Although the gonorrhea rate is lower than the national average, it is the second highest rate among ethnicities (second only to African Americans), 3.7 times greater than White adolescent girls, and 2.7 times greater than the Hispanic adolescent girl rate (CDC, 2014). Additionally, according to the National Campaign to Prevent Teen and Unplanned Pregnancy (2013), AI adolescents have a higher birth rate compared to the national average (34.9 per 1,000 compared to the national rate of 29.4 per 1,000). Given these clear disparities it is critical to understand how urban dwelling AI youth view health care related to trust of providers and access to care.

PURPOSE

In this paper, we explore the perceptions of American Indian adolescent girls living in an urban, Midwest area about health care providers, health care systems, and access to health care as related to sexual health care. The findings of this study are the result of a larger grounded theory study focused on sexual risk behavior of urban adolescent AI girls (Saftner, Martyn, Momper, Loveland-Cherry, & Low, in press). We will discuss recommendations for health care providers and systems that provide care for young, urban AI girls. In this paper, the terms *American Indian* and *girl* will be used to describe the participants. These terms are being used because this is the language the participants used to describe themselves and others.

METHODS

SAMPLE AND SETTING

Participants were primarily recruited from an American Indian urban health center in the Midwest region. The AI urban health center is a Title V center and receives the majority of its funding from the Indian Health Service and the U.S. Department of Health and Human Services. The director of the American Indian health center approved the research project as did the University institutional review board (IRB). Additionally, a certificate of confidentiality was obtained from the National Institute for Nursing Research due to the sensitive nature of sexual health questions asked in the data collection process. It is important to note that the American Indian urban health center uses the University as the IRB of record. This relationship was approved by the Indian Health Service and therefore additional IRB approval from the Indian Health Service was not required. Additionally, given the wide array of tribes represented in the study, the location of the study in an urban area away from traditional tribal lands and government, and the fact that participants were asked of their tribal affiliation and not membership, individual tribal approval was not appropriate.

Recruitment methods included posted flyers throughout the American Indian health center, referrals from the youth group and medical staff, and word of mouth. Participants included twenty 15-19 year old girls, who self-identified as AI, lived in an urban or suburban area, were able to speak, read, and write English, and if less than 18 years old had parental permission to participate.

DATA COLLECTION AND ANALYSIS

All participants and parents (of those under 18) provided informed consent/assent. Participants and their family members were offered a meal prior to data collection and participants received a \$30 gift card to a local retail store for participation in the

initial study and an additional \$20 gift card for follow up interviews. Participants were given \$5 to cover transportation costs (e.g., gas, bus fare, etc.) to and from the data collection site. Data collection included participant completion of a demographic form, an event history calendar, and participation in a talking circle or individual interview. Talking circle/interview questions focused on influences related to sexual behavior and decisions to have or not have sex.

Participants had the option of participating in a talking circle or an individual semi-structured interview due to the sensitive nature of questions. Talking circles are a traditional AI method of group communication that allows all participants the opportunity to speak. They have been used successfully in other AI research projects in rural and urban settings (Becker, Affonso, Beard, 2006; Haozous, Eschiti, Lauderdale, Hill, & Amos, 2010; Hodge, Fredericks, & Rodriguez, 1996; Picou, 2000; Strickland, 1999). In addition to the initial talking circle or individual interview, individual semi-structured follow-up interviews were conducted with eight of the original 20 participants for member checking, clarification, and further exploration of data and peer validation of the data analysis. Participants who expressed interest in further time with the researchers or whose ideas resonated with the themes that emerged were asked to return for a follow up interview.

All talking circle and interview data were audio recorded and transcribed by a professional transcriptionist yielding 478 pages of data for analysis. Additionally, 74 pages of memos from the primary author and AI research assistant supplemented the data transcripts. Glaser's constant comparative method was used for data analysis (Glaser, 1978). The primary author and second author, both experienced qualitative researchers, conducted the coding. The primary author initially coded all the data and the second author then verified coding and generated themes.

Open coding of the data (Level I) began data analysis. Level I coding involved line by line analysis of the transcribed data from the talking circles and individual interviews in order to identify the processes and contextual factors in the data (Glaser, 1978). During the research project, these processes/contextual factors or substantive codes were compared with other data, including the memos, and assigned to categories (Level II). Categories were then composed of coded data that appeared to form patterns or exhibit similar information. The categories were compared to other categories to ensure that they were mutually exclusive (Glaser, 1978).

After ensuring that each category was mutually exclusive, the categories were then reduced by comparing them to each other to determine how they fit in a higher order category. Reduction of the numerous categories occurred in order to identify the primary social processes or core variables that explained the social scene (Level III) (Glaser, 1978). Conceptualization of the relationship among the three levels of

codes occurred through development of the more theoretical Level III codes (Glaser, 1978; Hutchinson, 1993). The results presented in this manuscript encompass a major theme identified in the larger grounded theory model (Saftner et al., in press).

RESULTS

Characteristics of the 20 participants are listed in Table 1. Table 2 details the participants' reported tribal affiliations. Given the political and historical complexities of tribal membership and the concern for excluding participants who identify as American Indian but do not qualify for services and benefits, tribal membership was not asked. Rather, participants were asked to identify the tribe that they were affiliated with. Fourteen of the participants identified as a member of the Three Fires nation. This was an expected finding based upon the historical presence of the Ojibwe, Odawa and Pottawatomi people in the Great Lakes region. All participants currently lived in non-reservation areas within a large urban or suburban area. Most (90%) of the participants were full time students.

HEALTH CARE

In this study, health care was perceived by AI girls as an important influence on their sexual behavior. Two distinct themes emerged related to sexual health care: 1. American Indian adolescent girls trust their health care providers and the health care system; and 2. Access to health care is critical to practicing safe sex and obtaining information about healthy sexual practices.

Trusting providers. Trusting health care providers emerged as an important issue for AI adolescents in this study. Participants reported receiving sexual and routine health care services in a variety of health care settings from nurse practitioners, certified nurse-midwives, family medicine physicians, pediatricians, and gynecologists. Health care settings included an AI health care center, private medical offices, and non-profit organizations (e.g., Planned Parenthood). Ten participants received the majority of their care at the American Indian Health center, 8 reported primary care services at private or non-profit health care settings, and two received care at both the American Indian health center and other settings.

In this study, most of participants reported trusting their health care provider and the system where they received their care. Trust included trusting the care they received, trusting that their provider was being honest and nonjudgmental, and trusting that their visits were confidential. Participants believed that health care providers addressed their health care needs comprehensively and truthfully. An 18 year old who received care at a non-AI clinic said, "I feel like they'll provide me with what I need." A 17 year old who accessed care at the AI health center discussing the

certified nurse-midwife she saw for sexual health care asserted, "She answers every question, like every question I have, she answers it and I feel more educated when I leave. I trust her. I know she is telling me the truth." Another 16 year old who received care at a private clinic trusted her provider and felt that her provider protected her. She stated, "I know she won't tell my mom anything."

Another 15 year old who accessed care at the AI health center agreed that health care providers help adolescents stay safe and said, "They [providers] go into details and give you pamphlets or even if you want them to show you or you can go in to see a doctor and get check-ups or whatever." A 19 year old who received care at her University's health center and previously accessed care at a private non-AI clinic said, "I trust like general medicine." They thought health care providers provided sexual health care in a nonjudgmental way that respected individual autonomy. One 17 year old who received care at the AI health center said, "I never feel judged. I think that they support me because it's my decision and they know that it's my decision and it's gonna happen. They just try to protect me the best way they can."

Girls in this study believed that seeing physicians and advanced practice nurses improved their sexual health. An 18 year old who received primary care services at the AI health center explained how going to see a health care provider improved her own sexual health:

I definitely think it does [help] because they give you free condoms here and they tell you basically what, and knowing that someone else out there you know will help you understand, especially because you can get condoms and be safe.

Only three girls in this study reported an experience with a health care provider that they described as "negative." These negative experiences included receiving false information and feeling that the provider was ignoring their needs. Two of these participants received care at a non-AI health center. Yet, despite the negative experiences, two of these three stated that they trusted health care providers and felt comfortable seeking care for sexual health and primary care needs. The third participant who stated initially that she did not trust health care only received care from a non-AI health clinic. She said, "the only time I would go to the doctors is if something...was seriously wrong." However she continued by saying, "If I did talk about sex with my doctor I would trust them...and everything they say." This contradiction highlights the fact that although some AI youth may mistrust health care, they often times will trust the information they are receiving.

However, even though overall the participants overwhelmingly trusted their health care providers, many expressed discomfort with providers who were older or male. Although some girls felt comfortable talking to their family physician about

sexual health needs, other girls were comfortable with general health issues but not sexual health issues. One participant went to Planned Parenthood for birth control so she would not have to go to her family physician. She felt uncomfortable going to him since he had known her since infancy and he was much older than she was. Similarly, other participants felt more uncomfortable with male providers asking sexual health questions compared to female providers. Therefore, they tended to deliberately schedule appointments with female physicians or advanced practice nurses. One 16 year old participant who received care at a non-AI clinic said, "My doctor is like this old guy and my mom's doctor is some young lady." She later said, "I would go to the lady if I needed stuff for sex because I would be really uncomfortable with him."

Overall, the majority of those who received care from a trusted family physician or advanced practice nurse stated that they felt comfortable seeking care, especially services directly from the American Indian health care center. One 15 year old who accessed care at both the AI health center and non-AI clinics spoke specifically about the AI health center. She said, "Yea, I trust them...because I know them. I know all of them. I've been there ever since I was a little kid. And they all know me." An 18 year old who received care at the AI health center had a similar view and remarked, "A lot of people don't know some of the stuff they teach you here [at the center] or at any other clinic. They further your knowledge."

Those who accessed the American Indian health care center liked receiving care in an environment where their culture and beliefs were respected. They appreciated the cultural sensitivity of the providers and the fact that referrals to case managers, mental health and substance abuse care, and social workers could be made quickly within the center. They also spoke highly of the center's current focus on providing traditional healing methods to the array of services. Those girls who received care from outside settings did not discuss traditional health methods when reporting their beliefs on health care. Yet over half of them stated that they would be open to providers who integrated non-Western medicine into their care.

The majority of girls (both those receiving care at the AI health care center and those receiving care elsewhere) believed that health care providers can be trusted. Although the American Indian health care center offered traditional healing methods as a part of the routine care, those who received health care elsewhere did not believe that their care was lacking or inadequate. The participants receiving care at non-AI health centers were trusting of the settings that they received care in and more concerned about receiving truthful information from their provider than receiving care rooted in American Indian cultural traditions. Only two participants reported receiving care at both the American Indian center and alternative sites. Both participants appreciated the services at the AI health center but also believed that the health care they received elsewhere was adequate.

Like those who received primary care from the AI center, these girls appreciated the non-medical services that were offered at the center. The participants highlighted the youth activities, summer programs, and cultural events (e.g., Pow-Wows, Winter Solstice celebration) that made the center a good place to receive all their services: social, medical, and youth education.

Trusting health care providers and the general medical system was a phenomenon described by most participants. In contrast to the literature on the larger AI population, urban AI girls in this study felt comfortable receiving care from health care providers. However, they preferred those providers who were culturally sensitive and incorporated traditional AI healing into their health care.

Access. All participants in the study stated that access to care and information was critical for practicing safe sex and remaining healthy. Although many girls received information about safe sex and contraception from other sources (e.g., school, home, youth groups), most identified access to trusted health care providers as imperative to staying safe. Girls in this study believed that health care access was necessary for good sexual health. Many participants felt that having a health care center to go to when they needed birth control or condoms was a reason they practiced safe sex. When a 17 year old sexually active participant was asked whether she would be safe if she did not have health care access, she replied that she did not think she would have safe sex if the American Indian health care center she received care from did not exist. This was in part due to the low cost of services as well as various transportation methods to get to the center including bus, taxi, and shuttle service arranged by the health care clinic. The 17 year old said, "Having access to health care makes it easier to have safe sex... They...help me, teach me...tell how to practice safe sex." Another 19 year old said, "I take the bus, so if there wasn't an easy bus, I wouldn't come. But I have a grandma who always calls for the clinic's free shuttle. She likes that over the bus. So that helps too."

Other participants receiving care at the American Indian health care center agreed that the center made health care accessible by allowing for same day appointments and walk-ins as well as by accepting many insurance providers, including Medicaid. These money/insurance issues arose with multiple participants. The participants overwhelmingly agreed that receiving health care at low cost or no cost was critical in their decisions regarding health care, particularly sexual health. A 17 year old sexually active participant said:

Because people without health care they kind of feel like they have to pay for everything, so it's like what's the point. And then people like me, and l know I can get in for free so it's like I know I can go get a birth control shot for free every three months. So I know I can get it, so why not use it to my advantage?

Although many of the participants in the study sought health care at the American Indian health center, others received care elsewhere. One participant, age 16 and sexually active, felt that another clinic, Planned Parenthood, was critical for her sexual health. She said, "[Planned Parenthood] lets you kind of make your own appointments and stuff and I feel more independent." Another participant, age 18 and not sexually active, thought that the university health care providers at her college were the easiest to access. She particularly enjoyed knowing that services she received would be confidential and not reported to her parents. Participants valued health care clinics that made appointment scheduling easy, were accessible by multiple forms of transit (e.g., walking, buses, cars, shuttle service availability), and respected each girls' right to privacy.

Health care emerged as a way for young AI women to access services and get additional information about safe sex and reproduction. Most of the urban AI girls in this study trusted their health care provider and felt comfortable accessing services. Yet, this was particularly noted by the girls who accessed services from a health care center sensitive to American Indian culture. Adolescent AI girls prefer to seek sexual health care services from service providers that are trustworthy, accessible, affordable, and culturally competent.

DISCUSSION

Health care emerged as imperative for promoting safe sex and education with AI adolescent girls. Although many girls received sex education in other venues (e.g., school, home), the health care provider's office was a large source of information about health promotion and risk reduction. Adolescents believed that access to health care and provider trust were important influences on protective sexual behavior. Specifically, AI adolescents perceive having providers who are open to questions about sexual behavior, respect the adolescent's autonomy, and provide reliable instructions and guidance as necessary for sexual health.

Although previous studies have shown that AIs have a greater mistrust of the health care system and negative perceptions of providers, the results of this study did not support those conclusions (Buchwald et al., 2006; Guadagnolo et al., 2009; Buchwald et al., 2006; Hunt et al., 2005). This discrepancy could be related to the health care offices that served the participants. It is possible that AIs on reservations are less likely to feel that their visits are confidential given the tight knit community and structure of reservation based IHS clinics. In addition, although two participants experienced negative experiences with providers, all participants believed that the goal of the health care provider was to offer health education and provide ways for the adolescent to protect themselves. Those who were able to receive low cost medical treatment from culturally sensitive providers were more likely to be satisfied with the

health care system. Similarly, those who were able to easily schedule appointments, find transportation to the health care center, and believed that the services they received were affordable or free, reported being happier with their health care services. Despite the trust the participants had in the health care system and their providers, there was still a preference for same sex providers for sexual health visits. The majority of participants in this study stated that they would only choose a female provider for sexual health services and would feel uncomfortable seeking care from a male provider. Previous research has been mixed regarding gender preferences related to sexual health visits (Johnson, Schnatz, Kelsey, & Ohannessian, 2005; Plunkett, Kohli, & Milad, 2002; Shnatz, Murphy, O'Sullivan, & Sorosky, 2007). However, a meta-analysis by Hall, Blanch-Hartigan, and Roter (2011) found that female physicians are favored by younger patients. Further investigation into this phenomenon is necessary to understand if AI culture influences the selection of same sex health care providers.

Additionally, access to care is particularly critical given that those in urban areas often have increased difficulty receiving IHS care that is guaranteed to members of federally recognized tribes, have difficulty obtaining services due to not qualifying for tribal enrollment, or are members of tribes that are not federally recognized (Katz, 2004; Lillie-Blanton & Roubideaux, 2005). Given the large numbers of American Indians in urban communities, policy should focus on optimizing care for non-reservation AIs. Although urban dwelling American Indians often have access to private, public, and non-profit health care organizations that their reservation counterparts do not have access to, urban dwelling AI youth will often choose to access care at a culturally specific health care center if available. Given the history of forced relocation and migration of American Indians to urban areas, the Indian Health Service should examine resource disbursement and consider how to more fully support urban dwelling Native people.

In addition to barriers related to service access, access to transportation is a barrier that urban health care centers serving American Indians must acknowledge. The AI center used for recruitment in this study had mechanisms for community members to access care. The center is accessible by city bus (although participants still have to walk over 2 blocks to access the center) and will also arrange transportation to and from the center for prearranged appointments. However, community members often lack funds for the bus, do not schedule their appointments in advance and therefore cannot prearrange transportation, or do not have access to a personal vehicle. Most of the participants in this study had minimal access to a vehicle and relied upon family and friends for transportation. This was in part due to the age of many participants but also reflected the urban lifestyle and socioeconomic status of the participants. If a vehicle was available, it was often shared by multiple family members.

For those accessing services at a non-AI center, transportation was a larger complication. Although not directly asked in this study, multiple participants mentioned that it was difficult to find a ride from family members because they didn't want to reveal the purpose of the clinic visit (i.e., sexual health visit or contraceptive care visit). Therefore, it is critical for urban based health care facilities to consider how to make their site more accessible and consider options through insurance programs that will help provide transportation for health care appointments.

STRENGTHS AND LIMITATIONS

Strengths of this study included a population who sought care in various settings and data validation by an AI research assistant who was a member of the urban community. This additional layer of analysis provided colleague validation and assurance of cultural sensitivity and appropriateness. There were two limitations to this study. The first limitation was the inability to quantitatively generalize the results from this study to the larger urban AI adolescent girl population. Data for this study was collected in the Midwest. Most of the participants reported being affiliated with a Three Fires tribe, tribes traditionally located within the Midwestern region of the United States. Therefore, it is unclear whether the results from this study can be generalized to other urban populations in areas outside of the Midwestern United States. The second limitation to this study was related to recruitment of participants. The majority of the participants were connected with and recruited from their area's AI community center. Therefore, it is unclear whether these results would be applicable to AI adolescent girls who are not involved in their community AI center or have minimal connection to their cultural heritage.

FUTURE RESEARCH

Although there is significant evidence that American Indians living on reservation lands are mistrusting of their health care providers (Buchwald et al., 2006; Guadagnolo et al., 2009; Hunt, Gaba, & Lavizzo-Mourey, 2005), further research must be done to properly understand how urban American Indians view the health care system. Although rural and urban dwelling American Indians share many common cultural traditions, their physical location in different environments and the health care settings they have access to (e.g., IHS services, private medical offices, university health care settings) may impact how they view health care and whether or not they trust their providers. This study found that urban American Indian girls between the ages of 15 and 19 are trusting of the health care system and believe that their health care provider helps them make safe sexual health choices. However, it is unclear if older generations of urban dwelling AIs, those living outside the Midwest, and young males believe the same. Additionally, participants in this

study emphasized their comfort with a female health care provider. It would be important to explore these phenomena further. Additionally, the participants in this study identified access to transportation, access to appointments, and access to a preferred provider as barriers that could prevent them from seeking care. Further analysis of barriers related to accessing health care should be explored.

CLINICAL PRACTICE

It is critical for those working with adolescents from underserved or marginalized populations to consider culture when providing care. This is important particularly for those providers caring for American Indians in urban areas because this group is heterogeneous and cultural connectedness, knowledge, and traditions vary amongst individuals. Therefore, providers must first ask the adolescent about their own values and beliefs. It is imperative to ask the urban AI adolescent how they identify, how they view health care, and if they have any questions or concerns at the visit. Urban AI girls may identify with multiple races and thus their care will need to be approached from a unique perspective. For example, in this study, many participants identified themselves first as American Indian, but also cited their African American, Caucasian, or Hispanic heritage during the interview process.

It is also important for the provider to clarify their own knowledge on the culture and provide parameters for care. For example, if the adolescent prefers traditional healing methods be used in conjunction with their health care, it would be important for the provider to clarify this expectation and also provide information on the limits of their ability to provide this type of care. This will ensure that the adolescent feels respected and valued but that the provider is also able to work within the confines of their scope of practice.

Health care providers must strive to be culturally sensitive and responsive to the needs of the population in order to decrease sexual risk behaviors and improve the health and well-being of the population. Urban AI girls in this study trusted their health care providers and were usually willing to share personal information with them. They also desire accessible services in an environment that promotes trust between the patient and the provider.

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