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The Impact of Historical and Current Loss on Chronic Illness: Perceptions of Crow (Apsáalooke) People

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Abstract

The purpose of this research was to gain a better understanding of perceptions about the impact of historical and current loss on Apsáalooke (Crow) people acquiring and coping with chronic illness. This study took a qualitative phenomenological approach by interviewing community members with chronic illness in order to gain insight into their perceptions and experiences. Participants emphasized 10 areas of impact of historical and current loss: the link between mental health and physical health/health behaviors; resiliency and strengths; connection and isolation; importance of language and language loss; changes in cultural knowledge and practices; diet; grieving; racism and discrimination; changes in land use and ownership; and boarding schools. The findings from this research are being used to develop a chronic illness self-care management program for Crow people.

Keywords

Historical trauma; chronic illness; chronic illness self-management; American Indian; Native American; Crow Nation

Introduction

The Community

The Crow Reservation is located in the northwestern United States, in southeastern Montana, bordering Wyoming on one side. The Apsáalooke or Crow people have lived in this area for hundreds of years (Medicine Crow, 1992; Old Coyote et al., 2003). The Crow Reservation has high rates of chronic illness and unemployment (Montana Department of Public Health & Human Services, 2011). Members of the Crow Nation have also been subject to a long history of trauma and discrimination, yet they have survived and continue to hold traditional practices and values.

Colonization Experiences

The first official relationship between the United States government and the Crow Nation was in 1825 in a friendship treaty that was meant to establish relationships and allow for protection to settlers moving into the area (Loughman, 2002; Medicine Crow, 1992; Old Coyote, Old Coyote, & Bauerle, 2003). The Fort Laramie Treaty of 1851 established the boundaries of the first Crow Reservation. This treaty was also meant to provide supplies and rations for the Crow people; however, these were often spoiled, inadequate, or not received at all (Loughman, 2002; Medicine Crow, 1992). Through treaties, Crow land was reduced from 38 million to the current 2.25 million acres (Loughman, 2002; Medicine Crow, 1992; Old Coyote et al., 2003).

Through all of this, the Crow Nation worked to maintain friendly relations with the United States government. Crow chiefs spoke at a Peace Commission in 1867 at Fort Laramie (Oman, 2002). In the commission, the chiefs talked about the kindness and peacefulness that they had shown to the white men who had been through their area. They shared that they were not returned the favor and had been shot at by white men (Loughman, 2002).

In 1868, the Crow signed the second Fort Laramie Treaty (Loughman, 2002). This treaty confined the Crow to the reservation and placed them under stricter control by the government. The Indian agents assigned to the Crow Reservation tried to change the Crow people from their nomadic lifestyle to a farming lifestyle by limiting their hunting rights and pressuring them to establish permanent dwelling places (Graetz & Graetz, 2000). Joseph Medicine Crow (2006) described how a Crow elder shared that this change hurt the hearts of the Crow warriors. After the Crow Agency government boarding school was opened in 1883, parents were required to send their children to the boarding school or be denied their rations. Also in 1883, the first Crow child was sent to board at the Carlisle Industrial School in Carlisle, Pennsylvania (Montana Office of Public Instruction, 2010).

Chronic Illness

Chronic illnesses are defined as long-term illnesses with no known cure that often result in negative health outcomes such as preventable death, disability, lower quality of life, and greater healthcare cost (Centers for Disease Control and Prevention, 2014). High rates of chronic illness plague the United States. Of the top 10 causes of death across the country, seven are chronic illnesses (Heron, 2013). American Indians have among the highest rates of

any population for some chronic illnesses (Gallant, Spitze, & Grove, 2010). Not only do American Indians have high prevalence rates of chronic illnesses, they are also more likely to die earlier from them. In Montana, American Indians die on average 14 years earlier than their non-Indigenous counterparts from heart disease, 12.5 years earlier from diabetes, and 11 years earlier from cerebrovascular disease (Montana Department of Public Health & Human Services, 2013).

Historical and Current Trauma

Historical trauma can be defined as a traumatic event or set of events that have been committed by a group in control against a group of people who were not in control (Walters et al., 2011). A variety of terms are used to describe the outcomes of these events, such as “soul wound” and “historical loss” (Duran, 2006; Whitbeck, Walls, Johnson, Morrisseau, & McDougall, 2009; Yellow Horse Brave Heart, 2003). For this study, community members stated that they preferred “historical loss”. Walters et al. (2011) explored ways these terms have been used and applied in the research and theoretical literature. They organized the uses of the terms into four categories: as an etiological agent, as a particular response or syndrome to the etiological agent, as a pathway to transfer trauma across generations, or as a stressor that interacts with current trauma and stress (Walters et al., 2011). For the purposes of this study, we are using the term to refer to an etiological agent. We include events that occur at both the community and individual levels as well as events that have happened in the past and that occur in the present. For example, land loss through treaties has an impact at the individual level for the family or individual who lost land and also at the community level, through the signing of treaties and the establishment of reservations, which has an impact on the lifestyle of the tribe. There are multiple examples of trauma that occurred historically and continue today, including language loss and racism.

This paper will explore perceptions of the link between chronic illness and historical and current loss among members of the Crow Nation. We have not seen this link investigated in the existing literature, but an understanding of it is vital to developing culturally consonant programs to improve chronic illness management.

Relationship

This research was conducted through the Messengers for Health program, which began in 1996 as a partnership between the Crow Nation and Montana State University. A community-based participatory research (CBPR) approach was utilized, led by a community advisory board. The board began informally in 1996, was formalized in 2001, and has actively sought solutions to health disparities since. The nine members of the community advisory board are all enrolled members of the Apsáalooke Nation.

CBPR is a collaborative research process between researchers and community members. Through this community-based process, the partners decided to develop and test a translational intervention research project to improve chronic illness management with and for members of the Crow Nation. The community advisory board and the research team wanted to develop an intervention based on cultural strengths that exist within the community. In order to base the project in cultural strengths, it was important to gather

information from the cultural community members who are currently coping with chronic illnesses (Christopher et al., 2011; Israel, Schulz, Parker, & Becker, 1998; LaVeaux & Christopher, 2009; Wallerstein & Duran, 2006).

Methods

To understand what facilitates and hinders chronic illness management, 20 exploratory qualitative interviews were conducted with American Indian men and women on the Crow Reservation who have a chronic illness diagnosis. We received Institutional Review Board approval from Little Big Horn College, which is the tribal college on the Crow Reservation.

Alma McCormick, a Crow tribal member and executive director of Messengers for Health, conducted the interviews. Alma has a long history of conducting interviews in the community and has research ethics training through the National Institutes of Health Collaborative Institutional Training Initiative. There are a number of advantages to having a community member conduct the interviews, including comfort level of the participants (Christopher, Knows His Gun McCormick, Smith, & Christopher, 2005). Participants were able to set up a time and location that was convenient for them and were interviewed in their home, at the Bighorn Valley Health Center (BVHC), at a conference room in the local library, at the Messengers for Health office, or at the interviewer's home. BVHC is a community healthcare center that is focused on the needs of the residents of Big Horn County and is a community partner in our research.

A mixed methods sampling strategy was used, including a criterion strategy, and an opportunistic approach. The criteria for participating were as follows: (a) a patient of BVHC, who has (b) a diagnosed chronic illness, and who has been (c) identified by the staff at BVHC as an individual who could provide information on their experience of having a chronic illness. BVHC staff referred these individuals to the interviewer. There were 13 patients who were referred in the criterion process. The opportunistic participants were either self-referrals who saw recruitment material for the study at BVHC and contacted the interviewer, or were BVHC patients who were referred by participants recruited through the criterion process. There were four self-referral participants and three participants who were referred by other participants.

The participants were given the option to share their name or to remain anonymous; five participants chose to remain anonymous and 15 participants waived their anonymity. As discussed by Shawn Wilson (2008), many Indigenous communities believe that a person should be credited for their words and so we wanted to provide the participants this option. Participants ranged in age from 26 to 78 with an average age of 52. There were eight male participants and 12 female participants who had a variety of chronic illnesses including hypertension, chronic pain, chronic persistent hepatitis, chronic obstructive asthma, diabetes mellitus, hypertension, chronic kidney disease, alcoholic cirrhosis, and rheumatoid arthritis. Most of the participants had more than one chronic illness. Interview lengths ranged from 9 minutes 33 seconds to 1 hour 40 minutes 32 seconds, and the average length was 42 minutes and 3 seconds.

The interview questions were open-ended. This paper will focus on those questions that addressed perceptions of the impact of historical and current loss on acquiring and coping with chronic illness. For the purposes of this research, we used the term “historical loss” in the interviews instead of “historical trauma,” as our Crow research partners stated that “historical trauma” is considered an academic term while “historical loss” was more relatable. The research team also felt that it was important to include the effects of current loss, such as language loss and racism. Additional questions not explored in this paper focused on the participants’ experience managing their chronic illness and their thoughts on what should be done to help chronic illness patients on the reservation.

The questions related to historical and current loss were as follows:

- In what ways do you think historical and current losses such as land loss, broken treaties, boarding schools, language loss, and racism have had an effect on the health of our people?
- In what ways do you think these historical and current losses have affected people getting chronic illness?
- In what ways do you think these historical and current losses have affected people coping with chronic illness?

Analysis

All interviews were transcribed verbatim. The three questions were analyzed without software using thematic content analysis. The content analysis process is used to review the interview data and to develop themes (Creswell, 2014). For our process, the first, second, and fourth authors read the responses to the three questions and developed an initial list of themes. The fifth and sixth authors joined in a discussion to develop a final list of themes and subthemes, which the first author then used to code all of the transcripts. The fourth author then randomly coded 10% of the interview transcript pages, which were compared with the first author’s coding. Coding differences were discussed and a consensus process was used to develop a final list of codes. The first author then re-reviewed the transcripts for any additional or missed themes. Analysis of these questions and others was also conducted with the community advisory board and project staff using culturally appropriate methods (Hallett et al., 2016).

Results

Areas of Impact of Historical and Current Loss

When the interviews were read, we noticed that participants discussed similar responses across the three questions. Therefore, we analyzed the interviews across the questions rather than analyzing separately by each question. The following 10 areas of impact of historical and current loss emerged in the content analysis, presented in order of highest to lowest prevalence:

1. Link between mental health and physical health/health behaviors
2. Resiliency and strengths

3. Connection/isolation
4. Importance of language/language loss
5. Changes in cultural knowledge and practices
6. Diet
7. Grieving
8. Racism/discrimination
9. Changes in land use and ownership
10. Boarding schools

These areas of impact are discussed below. Quotes are shared to illustrate each area, including information on the quoted participants' gender, approximate age, and chronic illness(es).

Link between mental health and physical health/health behaviors—When sharing information on how historical and current loss have affected health, a large number of participants discussed the connections they saw between mental health factors and physical health or health behaviors. Mental health factors included stress, grief, depression, inability to forgive, bitterness, and resentment. They saw these mental health factors as leading to or causing physical health outcomes, including disease in general and specifically diabetes. They also saw the mental health factors causing health behaviors including self-medication and substance use and abuse. Many of the participants talked about stress and depression and how they impact the body. This participant mentioned how losses contribute to mental and physical health:

They just seem to not care anymore. You know ... like take care of themselves ... look after each other. ... I think that's because of all that [the losses], they've ... just kinda lost interest. (Female, 50, chronic pain syndrome, hypertension)

This participant commented on losses and how they led and lead to depression and other diseases:

They took a lot away, all within a short period of time. And it was a whole culture shock and I think that made a lot of people depressed ... it leads to other diseases. That's my belief. (Male, late 30s, hypertension and diabetes)

Resiliency and strengths—When the participants were asked about historical and current loss, some brought up the issue of survival. Participants described genocide and how American Indians have survived the multitude of genocidal acts that have been committed against them. They discussed specific acts against their tribal nation and acts committed against tribal nations in general. They shared specific strengths that American Indians, and Crow people, developed in response to historical and current trauma, including seeking knowledge and strength in general. This participant, and others, described a general strength that came out of surviving genocidal acts:

I think it affected them [Crow people] right away, but I think we learned to get strong and to just to be strong. It really made us strong in the mind and in the soul.
(Male, late 30s, hypertension and diabetes)

Connection/isolation—One impact of historical and current loss mentioned by many participants was connection, disconnection, and isolation. Participants talked about the importance of traditional practices of visiting and connecting as families and as a tribe. Many specifically mentioned that the decrease in these practices was due to changes in the social and political structure of the community as a result of colonization. One participant shared:

People are going distant from each other ... where it used to be, everybody used to, like, get together. (Female, early 50s, chronic pain syndrome, hypertension)

Importance of language/language loss—When answering questions about the impact of historical and current losses, participants talked about feeling frustration over the loss of language and a personal desire to know more of the language if they did not speak it. Participants also felt that the Crow people are lucky to have their language to the degree that they do. The loss of the language for some is connected to historical trauma that occurred in boarding schools and other assimilation policies and programs that impacted Crow people. One participant expressed this sentiment:

And we speak to them in Crow; they don't even know what you're saying anymore. And that's a big loss. And now the Crow language has completely changed from the old Crow language. (Male, early 50s, chronic pain syndrome)

Another participant shared:

When we go away to school, they tell us not to speak the Crow language ... because they, the English people that don't speak the Crow language, feel offended. And they feel that we should not speak our own language, but to always speak English. And so that takes some of the feeling we have—how proud we are of our language, it takes it away. ... And this is offending our whole body system. Because I feel it's a part of our life. (Female, late 70s, chronic kidney disease, diabetes mellitus)

Changes in cultural knowledge and practices—When asked about the impact of current and historical loss on health, participants discussed the loss of traditional practices, traditional medicine, and traditional activities. Participants discussed changes in communication patterns and relationships between older and younger generations and a negative change regarding role models. In the past, role models were people within the community, and now many role models are people outside of the community. Participants also discussed a decrease in tribal activities such as powwows and hand games. Finally, participants talked about changes in tribal political structure. They talked about how the past coup system, of chiefs being chosen based on their action in battle, is vastly different from the current political structure of voting for tribal leaders. Participants drew a connection between these changes and colonization experiences. We share two examples:

It's very important to have all of your cultural beliefs and customs intact. Makes a whole person. Otherwise you're missing something. (Male, early 50s, diabetes mellitus, hypertension)

They wanted assimilation of the people, and they're doing that. They're trying to get them to be completely where they're off the reservations and no longer part of their culture. (Male, late 50s, chronic persistent hepatitis)

Diet—Many participants discussed diet in response to questions on how historical and current losses affect health and getting and coping with chronic illness. There was talk about changes in access to traditional foods and lack of current access to healthy foods. There was discussion about the introduction of novel foods to Crow people and commodity foods. Commodity foods are those that are provided to American Indians through the federal Food Distribution Program on Indian Reservations. Participants commented that foods are often considered to be very low quality. This participant commented on commodity foods:

The commodities and all the corn syrup they fed us through our lives. That's got all the sugar, diabetes and stuff. Yeah. All the grease. They used to give us lard. White lard. I remember that ... white lard, gallon buckets of it ... that's what we cooked with, baked with. So you think about the fat in the hearts of people. The government—yeah. (Male, mid-70s, diabetes mellitus, hypertension)

Grieving—Many participants talked about historical and continuous and ongoing loss and the difficulty of overcoming that loss. Losses included death in families and the community, and there was also discussion of children who were removed from their families. Content under this area of impact crosses over into many of the other areas. One participant commented:

You know, when a family loses their loved ones, it's like they just give up on life, and its um, seems like they don't care. (Female, early 60s, diabetes mellitus)

Racism/discrimination—When asked about the impact of historical and current loss on health, participants discussed the impact of past and current racism and discrimination. This included racism that took place in medical, institutional, and governmental settings. There was discussion of the white man having power and of feelings of helplessness, injustice, and anger at being cheated. Participants also described the impacts of acts of genocide that were committed against American Indians. For example:

We were promised one thing. It was a lie. And we're affected by it today. (Female, late 40s, diabetes, chronic kidney disease, chronic pain)

This participant discussed current mistreatment by the government and its consequences:

It's terrible, the way they treat the people, and it's there today. You see it. You hear about it. Causing a lot of grief on a lot of people. They're wondering what's gonna happen, and you know, I think the ... government hasn't left the Indians alone yet today. They're still out there tormenting and taking the land from us, and doing what they damn well please. (Male, 50, chronic pain syndrome)

Changes in land use and ownership—Participants' responses to how historical and current loss affect health included past, current, and future changes in land use and land loss. This included reservation-era land loss, land loss and mismanagement by the Bureau of Indian Affairs (BIA) that is happening now, and anticipated land loss through future governmental acts. Participants talked about different uses of the land, and land being sold for money, for example:

All the good land is bought up by the white man ... the white man's taken everything that was really needed by the Indians. ... That superintendent of BIA just step in there and say, "Well, I can take this land back from you." And I had to turn it over to this white man. (Male, mid-70s, diabetes mellitus, hypertension)

Boarding schools—There were stories of personal experiences in boarding schools, and participants who talked about the lasting effects of boarding schools, including cycles of abuse. Crow children were like many other Native American children and were sent across the country to boarding schools. In later times there were also religious boarding schools and mission schools. Both the boarding schools and the mission schools were reportedly places of abuse. A participant shared:

And they sent me off to school. And I didn't want to leave my brothers and sisters because I loved them so much. But they sent me off to school, and what could I do but go. (Female, late 70s, chronic kidney disease, diabetes mellitus)

Discussion

Participants felt that there were historical and current losses that impacted the development and management of chronic illness among Crow people. There were many strong first reactions to the question of how historical and current losses have affected health, including: "It's affected the tribes tremendously," "It's made a huge impact," "Oh my goodness," and "Oh gosh, how could you ever get me started on that?" Many participants shared information from a broad perspective rather than describing a linear relationship between cause and effect.

These interviews were conducted to assist in the development of a chronic illness self-care management program for Crow people. Chronic illness self-care management includes the daily steps and choices individuals make to manage their chronic illness (Center for Managing Chronic Disease, 2011). There are various self-care management programs in existence; however, most programs were developed from a majority Western cultural lens and may be inappropriate to be applied in an Indigenous setting (Castro, O'Toole, Brownson, Plessel, & Schauben, 2009).

The information shared by participants led our team to underscore the importance of addressing the impact of historical and current loss in the development of our chronic illness self-management intervention. Warren, Coulthard, and Harvey (2005) saw a similar need when they applied a Western-developed chronic illness management program with Aboriginal people in Australia. The program they were applying did not address grief and

loss, and they stated that participants had grief and loss issues that were vital for them to address before they could focus on chronic illness management.

As the questions we asked were about the effect of current and historical loss on chronic illness, many of the responses, and thus the areas of impact, reflect deficits. We believe that directly addressing the impacts of trauma validates community members' experiences and difficulties and helps to initiate the development of healthy coping strategies. The intervention that we are developing based on the interviews uses key aspects of trauma-informed interventions, such as promoting a sense of safety, calm, self- and collective efficacy, connectedness, and hope (Elliott, Bjelajac, Falot, Markoff, & Glover Reed, 2005; Hefferon, Greal, & Mutrie, 2009; Hobfoll et al., 2007), along with community cultural strengths such as the language (*biiluukeilia*), clan system (*ashamaliaxxia*), a strong heart or resilience (*dasseitchiachuchek*), provision of advice and instructions for life (*baa nnilah*), and spending quality time with others (*itchik dii awa kuum*). Using these strengths creates a comfortable and safe place that allows information to be absorbed and encourages confidence in community members' ability to take action toward better health. Respecting cultural values creates a comfortable atmosphere to share information and feelings, which promotes growth and strengthens resilience. We believe that unearthing these deficits and addressing them with community strengths is a necessary step toward community healing.

Limitations

Several aspects limited this study. The interviews were conducted in English for the convenience of the university partners. For some of the participants, Crow is their first language and it would have been more comfortable for them to speak Crow. Our interview questions were focused on perceptions of the effects of historical and current trauma, rather than asking more direct causal questions. We chose to ask the questions in this way to be respectful and to aid in the development of a community-based intervention to improve chronic illness self-care. In this analysis, we were limited by the fact that we broke apart the interviews by conducting thematic analysis instead of keeping the stories whole (Kovach, 2010; Wilson, 2008). Our reason for this was that we were looking at only a few of the interview questions that were specific to historical trauma. Also, in our analysis, we did not focus on the connection between responses and gender or chronic illness condition. This was because our aim was to develop an intervention that could be applicable across the community.

Conclusion

Many Crow people perceive that historical and current loss has had an impact on their lives, especially in the areas of developing and managing chronic illness. In partnering with chronic illness patients in developing an illness management program, it is important to develop a component that will directly assist with impacts of historical and current grief and loss.

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