UCLA
American Indian Culture and Research Journal

Title
Foreword

Permalink
https://escholarship.org/uc/item/0wt8c4tt

Journal
American Indian Culture and Research Journal , 38(1)

ISSN
0161-6463

Author
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Publication Date
2014

DOI
10.17953

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Foreword

Kelly Acton

One of the most valuable lessons I learned about cultural capital came from my relationship with a Crow medicine man twenty-eight years ago. I was a young, new doctor, fresh from residency training in Philadelphia and recently had joined the staff of the Crow Indian Hospital in south-central Montana. Because I was the only doctor of internal medicine on staff, most of the patients with diabetes were referred to me. Mr. Old Bear was in his late sixties and had been to see me several times in clinic, but this particular visit was different.

"The Sun dance is coming up next month, and I am going to participate," he told me. "I want you to help me figure out how to do it safely with my diabetes." I asked what the Sun dance entailed. He described an arduous three days of fasting without food or drink while dancing in the hot sun in order to bring on a vision or to honor someone. As a spiritual leader in the tribe he had taken part in many Sun dances in the past, but he had not participated since his type 2 diabetes diagnosis. This year he intended to dance to ask the Creator to cure a close family member who had just received a grave diagnosis. I was alarmed. Nothing in my training had prepared me for this request. Yet I was convinced that the only practical and respectful thing to do was to help him navigate this activity as best I could. He had not asked for my permission or approval. When I told him this was just a little beyond my experience, he laughed. We agreed that he would come back in several days and we would then make a plan for his participation.

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I shared this story with my colleagues at rounds the next morning. Several were horrified, concerned about malpractice, and suggested that I forbid him to participate and refuse to have any further discussion with him about it. However, Tim, a "seasoned" member of the staff who had been there a full year longer than I, applauded my willingness to work with my patient to assist him to care for himself physically while following his spiritual path. Together we worked out a rudimentary plan, discussed and refined it with an endocrinologist from the nearest medical community whom we both respected, and crafted a list of safeguards and preventive strategies to follow. Mr. Old Bear was delighted. At our suggestion, he obtained permission from the Sun dance leader to drink a limited amount of water during the three days and to make other minor accommodations for his diabetes. He participated in the Sun dance without mishap and came to see me three weeks later.

"They don't teach you everything you need to know in that doctor school, do they," he commented, his eyes twinkling. I agreed. "That's OK," he continued. "You already have what you need here," he added, making a fist and gently tapping it over his heart. "You will figure the rest out" (tapping his head), "as you go along." And then he thanked me.

His words that day brought me back to something that I knew but had somehow forgotten among all the textbooks and sleep deprivation and tests that comprised my medical school training: the realization that I *could* listen to my heart *and* also be a good physician. I am sure he had no idea that his words that day set my career as a physician on a different trajectory. I learned to listen beyond the boundaries of my own experience, to respect that knowledge and wisdom comes in many forms and from very different sources, and to recognize that, in situations where biomedicine has little to offer, there are other sources and traditions that offer comfort and healing, traditions that are rich in cultural capital.

I worked in the Indian Health Service (IHS) for twenty-seven years. I learned many important lessons along the way, especially from those unsung heroes of Indian health—the community health representatives and public health nurses. They helped me to recognize the biomedical culture that I came from and how I needed to expand my working context to include other cultural perspectives and interpretations in order to be effective in Native communities. For thirteen of those twenty-seven years, I served as the director of the IHS Division of Diabetes Treatment and Prevention. During that time my staff and I built and oversaw the congressionally mandated Special Diabetes Program for Indians, which has funded more than four hundred grant programs in Native communities throughout the United States. This unique program has for the first time provided tribes with the resources necessary to target diabetes prevention at the local level. Native communities are

not only participants in this endeavor, but are also working as active partners alongside health care providers and administrators to design programs from the ground up. What has emerged is a rich, diverse, and complex approach that has allowed tribes to explore the use of their local cultural capital, social capital, and economic capital to address this major health disparity in unique, local ways and to begin a meaningful journey toward primary prevention in their communities.

As editors of *Diabetes as a Disease of Civilization: The Impact of Culture Change on Indigenous Peoples* (1994), Joe and Young examined how the environmental and sociocultural factors that US and Canadian Native peoples experience has contributed to the high rates of type 2 diabetes in these communities.[1] The anthology's authors chronicle the history of this epidemic in a way that had not been described previously in one place. They presented regional, specific experiences of tribes that served as important benchmarks for indigenous peoples around the world and helped us to understand the emergence of this epidemic beyond medical terms: they helped us to see and define it in terms of critical environmental and sociocultural changes.

In the present collection, Joe and Young are expanding our vision again. This time they are taking us on a journey that examines what is happening in Native communities beyond exhortations to "just eat less and exercise more" and, traveling beyond environmental and sociocultural contexts, examines how these communities are leveraging their "health relevant cultural capital" to uniquely address diabetes prevention.[2] As the authors point out, chronic diseases such as diabetes were not part of the cultural health history of tribes, and thus there are not names for these diseases in traditional languages, nor do traditional remedies exist to treat them. Naming is very powerful in Native communities. Assigning a label can often be seen as a naming ceremony: "you are a diabetic," or "you are an alcoholic." Too often the connotations of being labeled with a disorder are negative and incongruent with one's worldview. Duran, Firehammer, and Gonzalez have explained that helping an individual to understand the sociohistorical context of his or her disorder and using culturally appropriate metaphors assist the client to develop a new relationship with the disorder so that a new narrative can emerge that is liberating for the individual and his or her community.[3] Extending this concept further, I propose that helping communities themselves to understand this epidemic in terms of cultural capital and sociohistorical context, as well as using culturally appropriate metaphors, invites them to see diabetes in a different way. As with individuals, when communities develop a relationship with a disorder rather than *becoming* the disorder, a new story can emerge.

The social determinants of diabetes in general are gaining recognition and are increasingly documented in the research literature. These include social inequalities related to poverty, employment that is insecure and of poor quality, lack of social support and educational opportunities, poor literacy, and addictions that can result from all of these conditions.[4] The literature also describes additional social determinants of diabetes that are specific to Native communities, including land loss, loss of culture, and community trauma.[5] Intergenerational grief and stress are determinants of health that have received little attention in the study of diabetes. Some suggest that the current model for diabetes needs to be expanded to encompass both the underlying reasons for certain unhealthy behavioral choices such as overeating and less physical activity, and the health effects of stress, poverty, low self-esteem, social isolation, and personal and community trauma, all of which cluster in Native people. In addition, it has been suggested that scientists should study resilience as well as disease and how acknowledging the pain of personal and cultural traumas in the context of diabetes can be a healing process.[6] We also need to communicate the social determinants of health in ways that allow the general public to expand its views about "where health starts, not just where diseases end," as US Department of Health and Human Services Assistant Secretary for Health Dr. Howard Koh has said. And, as he also noted, "we are all interdependent and interconnected, and we all have promises to keep."[7]

Evidence supports exploring this approach. In the mid-1990s NIH researchers conducted a randomized lifestyle intervention pilot study in Pima Indians from the Gila River Indian Reservation in southern Arizona.[8] Individuals were randomized into two groups, a "Pima Action" group, or the intervention group, that participated in a conventional exercise and nutrition-based intervention program, and a "Pima Pride" group—ostensibly the control group—that took part in an unstructured program which emphasized small-group, self-directed learning about current lifestyles and the cultural history of the tribe. The remarkable findings from this study revealed that the "Pima Pride" participants (the control group) experienced *stronger benefits* in improving lifestyle behaviors, weight maintenance, and glucose tolerance when compared with their "Pima Action" counterparts (the intervention group). The authors could not explain these findings and in a subsequent paper concluded that "an indirect approach motivated from within the culture was more effective than a standard, proven lifestyle intervention" and speculated that it is possible "that social support has a more direct effect on diabetes control or perhaps influences glycemic control in ways that extend beyond our current paradigm of diabetes management."[9] In not only this but in other studies where health messages and lifestyle teaching are delivered in synchrony with a participant's cultural framework, researchers have noted that important effects

are achieved and have concluded that "the positive factors generated from within these cultures may have important social effects that are not measurable with standard approaches."[10]

It is very important to examine these issues, but we must be extremely careful and respectful in this work. Many well-meaning professionals who operate from culturally biased views of what are considered to be appropriate intervention strategies perpetuate "various forms of injustice and institutional racism by imposing helping paradigms that are often incongruent with the worldviews, values, beliefs and traditional practices" of Native people.[11] Mainstream, dominant-culture definitions of success and the expected benefits to the community often differ greatly from tribal expectations and definitions.[12]

So why should we care about cultural capital in the context of diabetes? Cultural capital has been described as how people (humans) engage each other (social capital) and their resources (economic capital). Cultural capital is created when values, traditions, beliefs, and language become the currency to leverage social and economic capital.[13] For action-minded leaders, cultural capital is the most important type of capital. It is the difference between creating an environment to maintain the status quo and building the foundation for making change.

As the authors of the Pima Action/Pima Pride study pointed out, unfortunately, their kind of study does not explain how social support or cultural pride translates into improved behavioral and/or physiological outcomes. However, these studies may highlight a need for new evaluation approaches and tools that can enhance our understanding of how change and improvements occur in minority cultures.[14] If we are to replicate effective programs, we need to know what aspects of an intervention were significant. Kumanyika and Agurs-Collins have asked, when we culturally adapt programs, whether we are presupposing that the aspects that make the difference *are* cultural.[15] Clearly, much more thought needs to be given to what these process measures are and how we assess them, and the results highlight the need for theoretical models of behavioral change that can accommodate cultural variables. Indeed, incorporating indigenous approaches to knowledge-concepts that go beyond "cultural competence" and partnerships with academic institutions may provide us with the ability to create new frameworks for understanding these results and to employ participatory methodologies that fit an indigenous framing of place, community, values, and culture.[16] According to Howard Koh, "Changing what we measure can lead to new directions in how we act," and he points out that in twenty-first-century public health, we understand that health is too important to be left to biomedicine and to the health sector alone.[17] He calls on us to take a broad social-determinants approach—that is, health in all

policies—involving a multi-sector approach and collaborations with nontraditional partners. That is why this *American Indian Culture and Research Journal* special issue "Leveraging Cultural Capital to Help Prevent Diabetes in Native Communities" matters.

In this latest collection Joe and Young have brought their rich understanding of cultural capital together with biomedicine to further the conversation by presenting these ideas and experiences from the perspective of Native communities. To borrow the words of Kumanyika and Agurs-Collins, the articles in this special issue provide evidence that "attempts to transfer clinical or medical models [to the study of lifestyle change], which are always set primarily within the culture of medical institutions and medical staff and which focus on individuals, are yielding in favor of approaches that are more appropriate in community settings and situations in which people interact in a different cultural context and in family units and social networks."[18] There is still much work to be done, however. Kumanyika and Agurs-Collins observe that if we fail to specify theoretical models or conceptual frameworks that include cultural factors and perspectives, then we might not even recognize certain powerful, spontaneous, and culturally based forces at work when we stumble on them through intuitive ad hoc program adaptations.[19] We can do better than this! We can go the next step, beyond the surface structure of cultural competence, and actually try to measure the cultural, historical, social, and environmental forces that shape health behaviors among indigenous people in order to better understand both the intervention process and the outcome. To accomplish this, however, we need a more profound understanding of what culture is and how cultural capital works.

Thank you, Jennie and Robert, for bringing us several steps closer to that realization for diabetes prevention in Native communities. I think Mr. Old Bear would be pleased.

Notes

1. This anthology looks at the impact of diabetes on several indigenous peoples, all experiencing high rates of type 2 diabetes. Changes in diet and increased sedentary lifestyle are discussed as two key risk factors. *Diabetes as a Disease of Civilization: The Impact of Culture Change on Indigenous Peoples*, ed. Jennie R. Joe and Robert S. Young (New York: Mouton de Gruyter, 1994).

2. Thomas Abel, "Cultural Capital and Social Inequality in Health," *Journal of Epidemiology and Community Health* 62, no. 7 (2008): e13.

3. Eduardo Duran, Judith Firehammer and John Gonzalez, "Liberation Psychology as the Path toward Healing Cultural Soul Wounds," *Journal of Counseling and Development* 86, no. 3 (Summer 2008): 288–295. See 290.

4. Alexander M. Clark, Kim Raine and Dennis Raphael, "The American Cancer Society, American Diabetes Association, and American Heart Association Joint Statement on Preventing

Cancer, Cardiovascular Disease, and Diabetes: Where are the Social Determinants?" *Diabetes Care* 27, no. 12 (December 2004): 3024.

5. Dawn W. Satterfield, John E. Shield, John Buckley, and Sally T. Alive, "So That the People May Live (*Hecel Lena Oyate Ki Nipi Kte*): Lakota and Dakota Elder Women as Reservoirs of Life and Keepers of Knowledge about Health Protection and Diabetes Prevention," *Journal of Health Disparities Research and Practice* 1, no. 2 (2007): 1–28.

6. Ibid., Lakota and Dakota elders, 21.

7. Howard K. Koh, "The Ultimate Measures of Health," *Public Health Reports* 126, no. 3 (2011): 14–15; quotation at 15.

8. K. M. Venkat Narayan, M. Hoskin, D. Kozak, A. M. Kriska, R. L. Hanson, D. J. Pettitt, D. K. Nagi, P. H. Bennett, and W. C. Knowler, "Randomized Clinical Trial of Lifestyle Interventions in Pima Indians: a Pilot Study," *Diabetic Medicine* 15, no. 1 (1998): 66–72.

9. Edward W. Gregg and K. M. Venkat Narayan, "Culturally Appropriate Lifestyle Interventions in Minority Populations: More than What Meets the Eye?" *Diabetes Care* 21, no. 5 (May 1998): 875–877; quotation at 875.

10. Ibid., 875.

11. Duran, et al., 292.

12. Michelle Chino and Lemyra DeBruyn, "Building True Capacity: Indigenous Models for Indigenous Communities," *American Journal of Public Health* 96, no. 4 (April 2006): 596–599.

13. Pierre Bourdieu, "The Forms of Capital," *Handbook of Theory and Research for the Sociology of Education*, John G. Richardson, ed. (Westport, CT: Greenwood Press, 1986): 241–58.

14. Gregg and Narayan, 875.

15. Shiriki K. Kumanyika and Tanya D. Agurs-Collins, "Response to Gregg and Narayan. Letters to the Editor." *Diabetes Care* 21, no. 5 (May 1998): 876.

16. Chino and DeBruyn, 597.

17. Koh, 15.

18. Kumanyika and Agurs-Collins, 876.

19. Ibid.