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SPECIAL ISSUE

Indigenous Health & Healing Research

INSIDE THIS ISSUE:

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Page 23: Image from *La Medicina Maya: Pasado y Presente*, produced by Médicos Indígenas de Chiapas

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Cover photo: Ciruela, wild plums in Mexico and Guatemala. Meredith Parr, 2010

Lukanka

Lukanka is a Miskito word for "thoughts"

RUDOLPH C. RŸSER
Editor in Chief
Fourth World Journal

Our long-term commitment to revealing the contours, content, structure and efficacy of peoples' ancient knowledge systems has given exposure to ways of knowing and understanding of our material and immaterial realities with an emphasis on contemporary applications for explaining phenomena and solving problems. We are recognizing more and more how what has long been known and understood by the original peoples of the Americas and other lands becomes increasingly relevant to contemporary challenges. There are many knowledge systems such as Cartesian Rationalism, the Vedas in India, Toltecayotl in Mexico and Central America and Hammurabi rooted in ancient Persia. Reclaiming such knowledge systems to the world may produce new and useful ways of meeting the social, economic, political, cultural problems of the 21st century and beyond.

From time-to-time the Fourth World Journal features a Special Issue spotlighting a topic that demands attention, but with out the special focus would probably not receive a great deal of notice. More than two years ago, Dr. Teshia Solomon and I began a colloquy about the possibility of publishing papers produced from the Native Research Network's annual sessions. This US-based network was founded as an informal group of American Indian researchers (mainly concerned with health matters) in 1997, and has become a non-profit organization located in the State of Oklahoma that now includes American Indians, Native Alaskans, Native Hawaiians and Aboriginal researchers in Canada. After some discussion, Dr. Solomon and I came to realize that much of the research being conducted by indigenous researchers in North America tended to rely heavily on conventional research methodologies that emphasized reductionism—condensing complicated research questions to rather limited aspects of much broader problems. Learning that Dr. Solomon heads the Native American Research and Training Center at the University Arizona raised the possibility that a collaborative effort between the Center for World Indigenous Studies and the Native American Research and Training Center could create an opportunity for native researchers to publish the results of their work that relied on methodologies that depend on scientific approaches grounded in ancient knowledge systems predating the conventional sciences. Accordingly we agreed on the following: "This issue [of the Fourth World Journal] shall focus on indigenous health and healing research that points to effective approaches for applying traditional knowledge treating and reversing the adverse effects of chronic disease. We are hopeful

Meredith Parr, 2010

that researchers will have employed indigenous or "traditional knowledge inspired" research methods and will point their outcomes to the application of traditional healing techniques or methods to the prevention and treatment of chronic disease." We were pleased to find such studies among the NARTC researchers did exist, and now after a few years we are ready to release the results of our efforts.

All of the articles generated by researchers at the NARTC for this issue have been peer reviewed. We have been scrupulous in our efforts to thoroughly vet these studies and our editors find them to be significant in their outcomes. As Editor in Chief of the Fourth World Journal I am proud to be able to point to the high quality of these studies and their important results.

In *Health as a Proxy for Living the Good Life* **Dr. Gail Dana-Sacco** considers the meaning of "health" as understood in the language of the Wabanaki of Northeastern North America. Noting that expressions of health in the English language can be quite different than the meaning of health from the cultural and language perspective of non-English speakers Dr. Dana-Sacco examines the process of expanding the space for intercultural dialogue "returns indigenous health beliefs and practices from the margins to the center" so as to reveal the underlying causes of illness or injury. Though this study begins in the Passamaquoddy-Maliseet, it reveals pathways that have deep significance for cross cultural health and healing between all cultures.

Dr. Patrisia Gonzales writes in *Calling Our Spirits Back: Indigenous ways of diagnosis and treating soul sickness* that the ancient teaching in Mayan medicine hold the secrets of treating personal and community trauma—unresolved trauma. She notes with eloquent writing style, "Ancient Mayan symbols depict the gourd that retrieves the soul from *susto* in a pre-Columbian vase. Symbols, enlivened by ceremony, prayers and respectful acts, become medicine. They reflect memory, accumulated acts, and knowledge." Dr. Gonzales' narrative shows the reader how chronic disease can and does arise from *susto* or "soul loss" and that the methods of ancient teachings restore the balance from the state of imbalance rsulting from the "loss."

Storytelling is the "literature" of the ages extending as a cultural practice into the depths of human knowledge. **Dr. Janelle Palacios** examines in here essay *Traditional Storytelling in the digital Era* the use of contemporary digital techniques to record 3 to 5 minute visual narratives as vehicles for transmitting stories in the treatment of patients as a therapeutic tool. Considering that storytelling long played a role in health and healing, Dr. Palacios and her colleagues have opened a chapter in this ancient practice with the prospect of projecting its utility far into the future.

Dr. Priscilla Sanderson offers in her essay, *A Perspective of Diabetes from Indigenous Views* insights into how elders from different indigenous cultures understand the chronic disease of diabetes. Sanderson and her research colleagues consider storytelling as providing the complex tapestry that reveals cultural relevant understandings of health and healing that can prove to be useful for care providers serving indigenous people.

Dr. Rodney Haring and his research team write in *Increasing the Knowledge Base: Utilizing the GAIN in Culturally Sensitive Landscapes* about their findings introducing an indigenous perspective to the Global Appraisal of Individual Needs (GAIN) bio-psychosocial assessment instrument in an effort to demonstrate its usefulness in connection with indigenous populations. Probing the perspectives of indigenous peoples for themes, experiences and perceptions in different workgroups, Haring and his team find that storytelling helps improve understanding and communication in evaluations.

Dr. Paulette Baukol and her research team consider the relationship between activity levels among American Indian youth living in urban settings and those living on a Reservation and causal factors influence the onset of obesity and overweight. In their article, *Community Specific Daily Activity in Northern Plains American Indian Youth* Boukol examines the relative levels of physical activity as documented using the International Physical Activity Questionnaire. The Study evaluated 689 children in urban and reservation settings.

It is with pleasure and satisfaction that I extend to Dr. Teshia Solomon, Director of the Native American Research and Training Center at the University of Arizona my appreciation for her single-minded support of the collaboration between the Center for World Indigenous Studies – Fourth World Journal and her Center to produce this important Special Issue. Our editors and the many peer reviewers worked for more than a year to produce this issue and Dr. Solomon's cooperation and contributions played a large part in our success.

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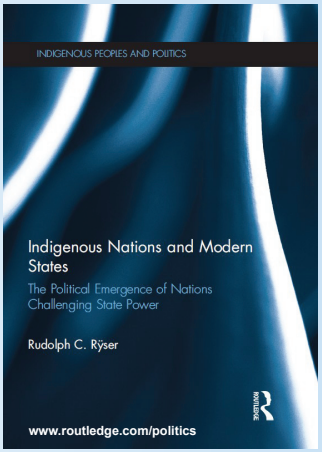

Indigenous Nations and Modern States

The Political Emergence of Nations Challenging State Power

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"Indigenous Nations and Modern States provides a refreshing, insightful ‚Äì and needed ‚Äì reframing of the international system, contemporary ethnic conflict, and the politics of indigenous peoples. This analysis facilitates a needed "un-thinking" of the inevitability, stability, and predominance of the unitary nation-state." *— Erich Steinman, Pitzer College*

"As states come and go, the Nations and Peoples persist over time, and the book gives a detailed description of the situation for the world,Äôs many Nations and Peoples. The book is an important contribution to both the survival of the Nations and Peoples of the Fourth World and to making the world a better place." *— G√∂ran Hansson, Former Chairman of the Unrepresented Nations and Peoples Organization.*

Selected contents

Introduction Emerging Modern Nations; Fourth World Geopolitics, Four Nations and the U.S.A.; First Nations and Canada; The Laboratory of Internal Political Change; The Laboratory of External Political; A World of Nations and States

Biography

Rudolph C. Ryser sits on the faculty of the School of Public Service Leadership at Capella University, and is an adjunct professor of History and Culture at the Union Institute and University. He is a 2011 Fulbright Scholar, Chair of the Center for World Indigenous Studies and the Editor in Chief of the Fourth World Journal.

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Health as a Proxy for Living the Good Life:
A critical approach to the problem of translation and praxis in language endangered Indigenous communities

Gail Dana-Sacco, PhD, MPH
University of New England

ABSTRACT

This paper explores and elaborates on concepts of health expressed in Passamaquoddy-Maliseet, an Indigenous language of the Wabanaki of Northeastern North America. I approach the translation of these ideas into English carefully, with strict attention to the indigenous frameworks within which they reside. Critically engaging the translation process to create dialogic space enables language community members to express ideas with the integrity of Passamaquoddy-Maliseet health ideologies remaining mostly intact.
In the praxis of translation by a community of speakers experiencing language endangerment, the complexity of indigenous language health ideologies emerges. Community members contemporaneously identify health problems and discuss healing, thus giving voice to the foundational process-orientation of indigenous ideologies. The critical approach to translation returns indigenous health beliefs and practices from the margins to the center. Explicit recognition of the active relational indigenous perspectives of health prompts critical reflection on the root causes of illness and injury.

Acknowledgment of the unique Passamaquoddy-Maliseet identity supports more conscious choices about the reclamation of definitional authority and collective community health.

Including language and translation as a means of power shifting in indigenous communities expands the critical applied linguistics discourse. Observations on the translation process and a full description of wolibmousu, living the good life, are revealed.

Introduction

Indigenous language documentation and conservation has become a more urgent project, as indicators of indigenous language vitality decline at ever more precipitous rates. In North America, 90% of the estimated 154 remaining languages are in danger of extinction (Manatowa-Bailey, 2007). While language preservation remains an important concern of scholars and Native peoples alike, achieving active spoken language fluency is the more primary task among indigenous peoples for whom language represents cultural survival (Kipp, 2000). These languages are the expression of distinct, place-based knowledge and belief systems essential to the survival of indigenous peoples inhabiting ancestral territories (McKinley, 2005; Meyer, 2001; Wilson, 2003.)

The translation of indigenous languages into English is routinely done, ostensibly with the goal of preservation and language revitalization. It is in the act of translation that a subtle and pervasive extension of the colonization process occurs. A critical perspective reveals the innocuous way in which indigenous-centered collective action is undermined and subverted through this process. Making space for indigenous voice through the translation process is essential to community transformation. The critical applied linguistics discourse

is thus expanded to include the translation process as means for power shifting in indigenous communities.

In this paper I explore and elaborate on concepts of health as expressed in Passamaquoddy-Maliseet, one of the indigenous languages of the Wabanaki of Northeastern North America. I approach the translation of these ideas into English carefully, with strict attention to the indigenous frameworks within which they reside. Critically engaging the translation process to create dialogic space enables speech community members to express ideas with the integrity of Passamaquoddy-Maliseet health ideologies remaining mostly intact. In the praxis of translation by a community of speakers experiencing language endangerment, the complexity of indigenous language health ideologies emerges.

Background

Critical applied linguistics

In defining the domains of critical applied linguistics, Pennycook (2001) discusses a critical approach to translation, concerned with "the politics of translation, the ways in which translating and interpreting are related to concerns such as class, gender, difference, ideology and social context"(pg. 13). Critical applied linguistics thus spans across both applied linguistics, defined as a researcher orientation concerned with the validation of theory; and the application of linguistics, concerned with practical solutions to language-related problems (Davies & Elder, 2004, pg. 13). The anti-hegemonic, critical applied, political stance, which practices an "ethic of difference" (Pennycook, 2001, pg. 14) can be used to interrogate all forms of linguistics.

The politics of translation begins to play out in language-endangered indigenous communities, when preservation efforts escalate. Scholars and practitioners focus on preservation in written, audio and video forms, engaging fluent speakers in these efforts. Preservation and revitalization are often distinct endeavors with spoken fluency the opportunity cost of preservation (Grounds, 2007). The scarce linguistic resources of indigenous communities are thus pressed into the service of translation for the purpose of preservation at the expense of active language teaching. More importantly, the way in which translation is accomplished preserves indigenous language in forms and formats inadequate to capture indigenous ideologies (Simpson, 2004).

The complexity of translation across language families from source languages into English demands attention to questions of reliability and accuracy. Specific cross-language translatability issues involve the verb-based syntactic constructions of many Indigenous languages of the Americas, which emphasize process over product (Bronson, 2002). The lack of translatability between indigenous languages and English, and the dominance of English, results in interpretations that favor the subject-verb-object construction of English, and its attendant predisposition toward individualistic cause-effect relationships. In marked contrast, Passamaquoddy-Maliseet and many other indigenous languages express dynamic interrelationships involving people and the larger cosmos within the construction of the language. When these languages are translated into English, indigenous epistemologies centered in the primacy of these interrelationships are compromised. Complex elegant verb forms are deconstructed and then reconstructed to create translations that more closely approximate categorical English forms. In this way, an

inconspicuous, rather sophisticated colonization process is advanced (Simpson, 2004). To fail to disclose the artfulness of translation is to participate in the de-construction and remaking of indigenous languages. Since these languages are in the process of revitalization and are being learned anew, indigenous epistemologies can easily and surreptitiously undergo substantive change through translation. New language learners unknowingly encounter a language that has been transformed to reflect the Western ideologies that reside in English.

The critical applied linguistic stance demands a deep questioning of the assumptions under which language is analyzed and translated, and how these processes legitimize and strengthen existing power structures. We must ask whose interests are best served by language preservation and conservation, and how well the act of translation actually serves indigenous language revitalization. Ensuring that indigenous epistemologies are accurately communicated advances an indigenous agenda that seeks to maintain cultural integrity in intergenerational language transmission (Manatowa-Bailey, 2007; Simpson, 2004).

Critical applied linguistics assumes that language is inherently political. Phillipson (1992) characterizes English linguistic imperialism as "the dominance of English…asserted and maintained by the establishment and continuous reconstitution of structural inequalities between English and other languages" (pg. 47). For indigenous peoples, the decolonization project includes reclamation of land and language as central to self-determination (Grande, 2004, pg. 117). When we recognize the politics of indigenous language revitalization, we confront the prospect that indigenous people will reclaim their languages, in spite of concerted and sustained efforts to eradicate them at the highest levels of government. The talk among tribal nations of self-determination and self-governance lacks substance without indigenous language reclamation. (Deloria & Lytle, 1984, pg. 251) Thus indigenous language revitalization is inherently a political process (Walsh, 2005), with power shifting at the core. This shift of power in the collective is essential to genuine transformation in indigenous communities.

Praxis and Transformation

Praxis, defined as "*reflection* and *action* directed at the structures to be transformed" (Freire, 1997, pg. 107), occurs in the translation process, when the objective of translation turns toward uncovering and articulating indigenous ideologies, and away from fitting indigenous language words and phrases into English constructs. The specification of indigenous beliefs and practices gives voice to language and ideologies that have been systematically and intentionally oppressed. Freire's (1997) dialogic theory of action holds that "(the oppressed) meet to *name* the world in order to transform it"(pg.148) cooperating and communicating through dialogue. Moreover, the essential narrative form and structure in which traditional indigenous teachings are embedded (Alfred, 1999) is privileged by qualitative inquiry methods that locate the interpretive project within an "emancipatory and transformative agenda" (Schwandt in Denzin 2000, pg. 202).

A critical perspective holds that language not only describes the world but also serves to construct and delimit it (Kincheloe & McLaren, 2000). A critical approach to translation requires the researcher to adopt a problem-

posing stance, routinely questioning the frameworks within which translation is negotiated. Critical evaluation of the forms and frameworks routinely applied in linguistic practice is essential to providing space for authentic representation of indigenous values and ideologies. Conventional linguistic constructs operative in the translation project are thereby challenged. Power shifts from the linguistic researcher to the indigenous communities struggling to restore indigenous languages, thus constructing a platform for collective action.

While collaborative fieldwork approaches acknowledge the importance of speaker insights in the analysis process (Yamada, 2007), the empowerment model is insufficient to shift definitional power to the speaker community. Training indigenous speakers in linguistics teaches deconstructive methods and devalues the contextual social construction of language in use. The linguistic fieldworker must critically evaluate the "Eurocentric grammatical traditions and theoretical assumptions" that underpin linguistic practice and engage in a process of unlearning (Gil, 2001). For Pennycook (2001) "the imperative to develop broader, more ethically accountable, and more transformative frameworks of knowledge in applied linguistics suggests the possibility not of peripheral critical work, but of pervasive critical work" (pg. 176).

Concepts of Health

While the meaning of health in English has been amply discussed in the literature, there appears to be scarce information on indigenous conceptions of health among North American Native Nations. The complexity of the health ideology, residing within the language of the Whapmagoostui Band of Eastern Cree has been explored by Adelson (1991), who reports that no direct translation for health can be found. Rather, *miyupimaatisiiun*, translated "being alive well," (pg. 231) is the closest approximation given for health. A physiological aspect of this concept involves eating Cree food, which provides physical strength, and enables effective participation in cyclical activities required to keep warm and maintain self-sufficiency through sustenance hunting activities. A spiritual connection and relationship with the land and the larger environment is noted as essential to "being alive well." Adelson (2000) proposes an integrative model of health, which takes into account individual, social, and environmental contextual factors grounding health beliefs and practices. An extended discussion of *miyupimaatisiiun* explicitly connects physical wellness to land, identity, and social and political well being.

Wilson (2003) finds that for Anishinabek First Nations people, the therapeutic landscape and its relationship to health is rooted in the concept of *mno bmaadis* translated as "living the good life." The relationship between the land and health is explored using the medicine wheel model of health as balance between the physical, mental, emotional, and spiritual elements of life. The land is characterized as part of Anishinabek identity, and the provider of all resources needed for survival. Spirituality and the use of native medicines are closely linked and spiritual practice is situated in the land. Wilson (2003) recognizes the importance of examining and appreciating the complex interrelationships involving identity and place and expressions of spirituality. This paper explores more fully the complexity of those relationships as articulated in Passamaquoddy-Maliseet through a research project I conducted in my home community.

Setting

I conducted the research in one of the east coastal Passamaquoddy-Maliseet communities with a 2005 census of 647 tribal members living on the reservation and 259 more nearby. An additional 1003 registered tribal members live off the reservation. The relatively remote location of this community in ancestral territory is an important factor in the survival of the language. Although endangered, the language is still spoken fluently in conversation by most of those fifty-five and over. The language is part of the Algonquin language family, with meaning and structure in common with its many sister languages spoken throughout the northern tier of the United States and Canada. Many tribal members of any age, who live in the community, speak or understand some Passamaquoddy-Maliseet. Fluent first-language Passamaquoddy-Maliseet speakers are very competent English speakers as well, who still operate within the cultural framework of their first language.

I am a first English language speaker and my fluency in Passamaquoddy is limited. Translation from Passamaquoddy-Maliseet to English was facilitated by my base knowledge and limited my lack of knowledge. I actively participated in the process of translation by asking particular questions and directing the inquiry. While my lack of fluency left more room for misunderstanding and misinterpretation, it also compelled me to be conscientious in trying to discover the full meaning of terms and concepts engaging fully in an iterative process of learning the language and its deeper meaning. The exploration of the meaning of words and concepts and how they are related became a dialogic process in which speakers expressed heightened awareness of the richness of the language. I came to believe that I should ask not what I could learn, but what was the language trying to teach me.

Methods

Ethnographic methods were utilized to identify and explicate concepts of health and decision-making in Passamaquoddy-Maliseet[1], and examine underlying cultural frameworks. The rationale and procedure for selecting participants, the development of the interview protocol, and details of data collection and analysis procedures are specified below.

Selecting Participants

I chose participants from the pool of community members whose first language is Passamaquoddy-Maliseet. I could not identify anyone in the community under the age of 50, who met these criteria. I first invited individuals who have demonstrated a commitment to language revitalization, or who have publicly expressed an interest in becoming a part of these efforts in the community. I expected that these individuals would be inclined to participate in the research project, given its potential to contribute to language revitalization efforts. Also those who teach or translate cultivate a deeper knowledge of the language. Because the social organization of the community is traditionally defined along extended family lines, I specifically included members of different family groups to get broader representation of health ideas and practices that might vary by family. Finally some individuals and families in the community are acknowledged to be stronger traditional medicine practitioners. I intentionally invited some of these individuals and family members to participate. All interviewees were chosen for their depth of knowl-

edge of the Passamaquoddy-Maliseet language and tribal health beliefs and practices.

I made the invitation to participate in person. Many had become aware of the project through an earlier presentation I had made to the Tribal Council. As I encountered prospective participants in the community meeting the criteria outlined above, I invited them to participate. Once individuals indicated an interest in participating in the study, I arranged to meet with them to obtain their consent and conduct the interview process. I recruited some participants by calling to ask if I could come to see them about a project I was working on. I went to their homes to discuss the project with them and sometimes obtained consent at that time, while arranging for a later interview appointment. The recruitment process was facilitated when I attended our annual cultural celebration lasting several days.

I successfully recruited two individuals who are considered master language teachers, and one person well known for deep knowledge of traditional tribal medicine. Another participant comes from a family where the medicine tradition is quite strong. I invited two other master teachers. While both were willing, neither was able to participate due to family health issues. Two other individuals well versed in tribal health practices, were asked to participate. One of these agreed but became unavailable due to family commitments.

I asked two couples for an interview, expecting that having a partner in the household, who is a Native speaker, would provide a higher Native language use environment. At the same time, I wanted to provide an opportunity for speakers to dialogue about the questions I asked in the interviews, as a means to support each other in developing responses. This strategy was also intended to widen the scope of participation to include most of the largest families in the community. One couple and one of the partners in the other couple participated.

In all, of the thirteen who were invited, eight gave interviews. Three other individuals, who are fluent Passamaquoddy speakers, provided some information within the context of another interview protocol for a related study, which focused primarily on tribal health decision-making processes.

All of the individuals who participated are considered elders at 55 years old or older. Passamaquoddy-Maliseet is their first language. No conversationally fluent speakers under the age of 50 could be identified. Although the community is small in number, individuals from several different families participated. Inclusion of different families is important in order to explore whether differences in health beliefs or practices can be identified by family group. All of the interviews took place in family homes. All of the participants are personally known to me.

Researching Within

My "insider" view as a tribal member, who has lived in the community and remains connected there can be considered a limitation as well as a strength of the study. The insider view provides a foundation and grounding in the community that significantly informs the research. Intimate community knowledge helps guide decision-making and can contribute greatly to the efficiency of the study. While my network of relationships facilitates quicker

access to a number of knowledgeable informants, those same relationships have a history that may limit disclosure in unknown ways.

Similarly my level of fluency in Passamaquoddy-Maliseet is simultaneously an enhancing and a limiting factor in the conduct of the research. Participants were enthusiastic about helping me complete the work required to finish my graduate program and they wanted to help me learn the language. I've worked with several of them over the years to support language revitalization efforts in the community.

I have disclosed much more detail about the rewards and challenges of researching within my own community elsewhere.[2]

Data Collection and Analysis

Data were collected through in-depth interviews, group interviews and documentary review. Six individuals gave in depth interviews. The individual in-depth interview allowed space for participants to develop and articulate their perspectives in a private, confidential setting. This approach enabled individual narratives to come forth reflecting the individual's own history and particular concerns. One of these individuals, a master Passamaquoddy teacher, gave one individual interview early in the project and another toward the end, and remained available for consultation throughout. Having this individual available for consultation on words and meanings throughout the data analysis helped me obtain clarification at opportune moments in my process.

Two group interviews, one with a married couple and one with three individuals, were completed. The couple interview was conducted to see if the dialogic process between long-time partners would produce synergy in response to the interview questions. I had already witnessed some individuals struggle with translation in the individual interview process and wanted to try to provide a more supportive environment for interviewees not accustomed to translating Passamaquoddy ideas and concepts into English. The second group interview of three individuals included a master teacher, an expert in traditional tribal health and contemporary health practices, and a community activist with a broad network of community connections. This interview was conducted after analysis of all the interview data, except the second interview given by one individual. The group interview was convened to further explore questions about relationships between words and concepts that arose from the initial data analysis. The dialogic process was important to the task of Passamaquoddy speakers exploring the language in more depth, and most challenging to me given my fluency level.

All of the interviews were given in both Passamaquoddy and English, with Passamaquoddy ranging from approximately 20-50% of each interview. The interviews were digitally recorded. Interviewees were offered a digital copy of their interview on CD upon request. I loaded the digital audio files onto my computer and my iPod so that I would have ready access to the data. I listened to each recording and referred back to them frequently while reviewing the transcripts and analyzing the data. All of the files were backed up on CDs and DVDs. The English passages were transcribed verbatim, with time markers recorded for the Passamaquoddy passages. I verified the accuracy of the English transcription making corrections as needed. I added

to the transcripts my phonetic rendering of all but the most lengthy (more than two or three sentences long) Passamaquoddy passages.

I employed a translator, a Passamaquoddy elder, to help translate the lengthy passages and words or phrases in the shorter passages that either were not fully translated by the interviewee or that I did not fully understand. Generally I understood the basic message, if not the nuances of all but the lengthiest Passamaquoddy passages. I asked clarifying questions, asked for direct translation in the moment, and/or utilized the translator after the fact. I listened to the recordings and noted the passages that I did not fully understand. I met with the translator and she listened to the passages I had identified, while I transcribed her translation in English. I then read back this translation and asked clarifying questions of the translator as I transcribed. I inserted the English translation of passages given in Passamaquoddy and differentiated them in the transcripts from the portions of the interviews given in English.

I listened to the individual interview recordings once again, while reading the transcripts, and highlighted words or concepts that needed further explanation or clarification, thus advancing the data analysis process. These words were discussed in the second interview with one of the key informants and in the final group interview, which was convened for the purpose of clarifying translations and exploring relationships between different concepts of health emerging from the analysis of the transcripts. I recorded reflective notes as well throughout the data collection and analysis processes.

Documentary sources, including dictionaries in electronic and print form (Francis, Leavitt & Apt, n.d.; LeSourd, Leavitt, & Francis, 1986; Nicholas & Francis, 1988) were reviewed to identify Passamaquoddy-Maliseet concepts of health, wellness, illness and injury on individual, family, and tribal levels. These materials were referenced in advance of informant interviews and throughout the data analysis process.[3] These sources were used to further explore relationships between words and concepts emerging from the interviews.

Transcribed records of interviews were evaluated, in concert with documentary evidence, to identify emerging themes. Analytical questions were noted throughout the data analysis process. Interview transcripts, field notes and memos were coded using NVivo7 software (QRS International, 2006). The initial coding scheme consisted mostly of free nodes intended to capture unique ideas and concepts.

Important ideas and relationships between concepts were explored through review of the coded passages of the transcripts. Dictionaries were reviewed extensively for related terms. Key informants were consulted throughout the process to enhance my understanding of terms and concepts. The second iteration of the coding scheme reflected the identification of important unifying themes and concepts within which the free nodes could more easily be grouped. The data was reviewed once again using the revised coding scheme to group passages. Passages were recoded as needed to account for proper placement in the revised coding scheme. The results of this analysis provided the framework for reporting and discussing the findings below.

Interview Protocol

The interview protocol addresses the ques-

tion of how ideas about health are expressed in Passamaquoddy[4]. I routinely opened the inquiry with general questions about the language and its use in the community. Next I asked about individual, family and community health in Passamaquoddy. I asked about illness, injury and community health concerns. The interview protocol included a section on tribal health decisions, and finally one on Passamaquoddy traditions. The questions were open ended, such as "When you think of health in Passamaquoddy, what comes to mind?". To prompt, I might ask, "Can you say something more about that?". In every interview, informants were encouraged to speak in Passamaquoddy and given the option to translate for themselves as they spoke, or after speaking for some time. I often checked in to see that I had the correct pronunciation or interpretation of words, phrases and concepts, repeating words in Passamaquoddy and clarifying meaning. I often asked for responses in Passamaquoddy, if they were given in English, but did not interrupt the narrative to do so. I might say "If you talked about that (something just discussed in English) in Passamaquoddy, how would you say it?" The prompting required to elicit Passamaquoddy varied by individual and within each interview.

Findings

Speaking the Language

Certain essential characteristics of Passamaquoddy-Maliseet emerge through the discussion of health. These ideas are invariably expressed as motions and processes, rather than static or abstract entities. *Wolibmousu* or *wolibmousuwogn*, commonly used to express the idea of health or healthy, can be translated as "living well," or "living the good life," with the first term referring to the action, and the second specifying the collective action. As one participant explains, "The health of the people would be ***a way of life***[5], you know, a way of life, how we survived, how we lived, how we communicated, you know, in community, in family, extended family…" A circular narrative style and repetition of words and phrases with slightly different inflections serve to emphasize and highlight messages. Native speakers recognize the complexity of the language as they explore conceptual frameworks related to health. The framework of the Passamaquoddy language allows for a great deal of creativity and improvisation as it is spoken. Through the translation process the elegance of the language is revealed. During the group interview while all struggle with translating from Passamaquoddy to English, one individual observes "…I've never heard the word sophistication with our language, but it's really a smart language."

Native speakers experience joy in speaking and hearing the language, "…no matter what he wanted to explain, they didn't listen to him, they spoke Micmac[6] to him, and eventually they started asking him where he was from, and then he started responding, ***in Micmac!*** And in ten minutes, they were all laughing, talking Micmac, the whole three of them, you know, and ***having fun!***" One individual describes how the sound of the language invokes peace and heals the body. "With the language, there is a physiological response when the language is used, and you have a lot of those receptors, leaving the gut, in the gut area, where they used to think they were all in the brain. And when the language is being used, those are activated. So a person's sense of wellness is enhanced. That joy is, you're happier, *when wolidahasu*."

Even in its most emphatic moments, the language with its relational and inclusive structures has gentleness, an obliqueness that creates an intimate and welcoming environment. Native speakers observe that discussions in English are sometimes more difficult or more disrespectful. "(I think when you speak in Passamaquoddy, you're more kind. You really are more kind. We have to talk to each other. When you speak in English you don't really talk.)"[7] Most Native speakers have never learned to write in Passamaquoddy and have only ever experienced it as a spoken language between people who are known to each other. Because individuals cannot be mentioned in Passamaquoddy without reference to their relationship with the speaker, the language provides for more intimacy in its structure, prompting the observation that "… in Indian I think it sounds more personal when you say *gil-un* (you and I), it has more meaning… I love you in Indian, it's much deeper." The depth of connection with others in the community, expressed through the language has important implications for the value placed on community cohesion.

Some insisted that in order to be healthy, we all have to speak the language, because instructions for healthy living are contained there, and cannot be divorced from how we conduct ourselves on a daily basis. "It's learning your language- having your language and trying to live your language based on its teachings; that's good health, to me, because it has all the teachings of what we're supposed to be." Native speakers refer to the positive physiological response generated by using the language: "When they speak Passamaquoddy (they're all laughing), the Passamaquoddy *mjellmulteenye* is free-er, more free. And if a person is free-er, they don't have to be sick. That's another reason (to speak the language), that sense of freedom. So there's a connection there."

Relationships

Taking care of each other and ourselves are essential elements of health. A concern with well-being in each personal encounter is indicated by the customary greeting, *Dun-gok*, (How are you doing?) and the customary parting remark, *Lunk-ay-us-in*, (Take good care.) Individual health is expressed as an active process. *When wl-ok-ay-us-id,* refers to someone who is taking good care of themselves. Intimate and satisfying relationships with each other and a sense of collective interdependence are viewed as foundational for health. Difficulties in close personal relationships are characterized as injury. Lack of attention to people who are in need is one result of old injuries to interpersonal relationships. One individual decries "not getting the attention from community, ***and*** family, due to an injury that already exists. People staying away… people not, you know, ***not loving each other*** in the moment." Physical illness is thus exacerbated by emotional distance.

Relationships with people who have passed on and intimate connections with the surrounding environment are described in the present as integral aspects of maintaining health. "When I take him in the woods, *enji-nuji-al-kul-dee-eg-chee-koog*, I think, he remembers the good feelings about being in the woods, *lee-da-hus mee-kwee-da-has-in wetchqwi-mdjee-gultee-eg edgi-week-wa-jay-ig when aloosed chee-koog,* and I think… that it heals him… cause it feels good to be in the woods. *Kee-ka-hoo-goon enji-nuji-al-kul-dee-eg-chee-koog.* One interviewee describes an active dialogue with a community member, who had recently passed on refer-

ring to connections between the land and the health of the people: "That's what I've been doing, to um, to… try to stay healthy, (talk to the people that are passed away) and um, every once in a while *ndlee bus-ken-eg-ee-kok* (I go to the place they are buried - graveyard) but every day I make it, no matter what, no matter what the weather, I force myself to go down to the shore, and have a conversation, (people that have died) to beg them, practically beg 'em to bring like a intercession for us, so that we can be healthy again."

Survival

The ability to survive well, to have all that you need, plenty of food, a warm house, and freedom from scarcity are all aspects of the good life. Observed personal characteristics indicate a better chance of surviving well. In individuals, *sugalumptu* is translated as healthy or strong, a physical characteristic which includes resiliency. *Sugalutpud* refers to someone stubborn or hardheaded and *sugalayu* to a difficult process. *Sugalugwastusid* can be translated to mean sturdy looking, rugged or wholesome looking. It implies a physical strength and capability for hard work. Having enough food to eat individually, as families and in the community are important elements of survival. *Woli-bmousu* recalls an earlier time when families relied on indigenous fish and game and natural foods harvested in season or grown in gardens: "And the (these) men catch a lot of fish and give it to the people. We eat well in the wintertime, we have rabbit, muskrat, deer meat, moose meat. We eat well. When I started going to high school, and when I started really *unsa-de when gloos-keep-in, gloos-kee-nug-wood mij-wogn,* eating not well or junk food. When we were going to school here, we ate well." *Gloos-kee-nug-wood mij-wogn* refers to fake food, not appetizing and having no nutritional value, food that is trying to trick you. Sustenance as it relates to *woli-bmousu* includes eating well, and eating more traditional indigenous foods, as well as being cared for in community, self-sufficiency, physical activity, spending time outside, and access to the natural landscape as a healing place.

Self-reliance on an individual, family and community level is viewed as healthy and beneficial in contrast to dependency on services provided by the tribe, the state or the federal government. "I think it helps us, to ruin ourselves of who we are, by having so much dependence, it's really crippling." In contrast, "…our language gave us independence. *Jewi-when-wdjew-kem-soo*, and it encompasses health, emotional health, physical health, and um… like some communities, my father would say *towi-wdjew-kem-sool-too-wg-nik,* they know how to survive, they know how to help themselves survive… they used to say that about us**,** *gil-wow-neet-owi-wdjew-kem sool-tee-bn* we'd say that about our family, said we knew how to help ourselves…"

Natural Cycle

Respondents often made reference to the cyclical nature of health and illness as a natural part of living. One individual acknowledged how the community is changing in this regard: "When people back then died, everybody just understood that they died because that's how our Creator intended it to be, and um, you deal with it appropriately, the way it was dealt with for generations, is that you try as much as you can to help those that are affected, family members, and um, and then after the funeral you move on. And now today, it's handled differently because of our health and

the way we look at health today, we look at health today like mainstream society looks at health." This comment refers to the displacement of traditional self-healing practices by medical interventions that favor over-reliance on others to handle the natural processes of grieving and healing.

Illnesses are recognized in Passamaquoddy-Maliseet as processes rather than conditions. As such, the illness does not define the person, but is a process occurring within the person. One person explains, "It's like, the person isn't the disease, you know? It's like, if I have a heart condition, it doesn't mean that I'm a heart attack walking around." The word *sugalene*, derived from the English "sugar" refers to diabetes, more specifically to the process of sugar troubling the body.[8] It's a state of being, not static, but rather a dynamic process. Illness is not attributed to physical causes alone. Individuals can make themselves vulnerable to ill health by failing to tend to distressed relationships. A person can never be well, if they have "unfinished business" with other people. The discussion of illness naturally moves to what a person must do to restore health. Peace and wellness are closely associated with health. One participant reiterates, "You can't be at peace or healthy until you take care of your relationships." Relationships must be put in good order before health can be fully restored.

Illness and injury are intertwined. The concept of injury is expansive, including physical as well as emotional injury. Physical injury is always described within the context of movement, never abstractly and always in relation to other people or objects. The structure of the language does not allow for the separation of the cause of injury from the site of the injury. The concept of injury also includes not having physical needs met, like not having enough to eat, or not having political favor sufficient to receive a fair share of community resources. Ill health is rooted in the lack of sufficient basic resources, which is also characterized as injury as described by one participant: "They didn't have enough *-mij-wogon* (food) growing up back then. That was a big injury to the body. So you bring on illnesses. *Ma debi-e-mij-wogon*. Not enough food to go around. *Muluks*…milk. People, you know went hungry, a lot. And that will cause injury. And bring on illnesses." One of the highest forms of injury is estrangement from relatives and other community members. "There's a lot of that now, a lot of injury, and when you get sick, a lot of people are sick because we are separated, families separated."

Medicine and Healing

General knowledge of healing practices and plant medicine still resides in families, but mostly in the elderly. One of the elders recounts, "[O]ur community people in every family had remedies I think that were passed on, by our ancestors, from one generation to the next, and I assume that they've been around for thousands of years." This knowledge has routinely been used for healing others as well as for self-healing. Many specialized applications, known only by certain individuals have been lost in their passing, although it is possible to recover some of that information through dreams "Anyway, there's a certain plant that she has to find. She saw the description of it in her dream, and she went and got it, found it in the woods, and she prepared it the same way, on the stove and drank it, and she got well…" The prospect of self-healing seems to have become more remote as this

knowledge is lost or forgotten, although many still believe strongly in the power of these medicines and resist making this information too available for fear of exploitation. A recent proposal to the Tribal Council to conduct a research project documenting traditional medicine practices by videotaping elicited strident objections by concerned community members, and raised important questions about collective tribal intellectual property.

Substance abuse was identified by several people as a primary health concern. One individual referred to abusing drugs as *tlyekoon pisun* "playing with medicine" or experimenting. Another term *twublawakon pisun*, is translated "misusing medicine or using it the wrong way." It's the overuse or incorrect use of medicinal substances that's harmful. These medicines are intended for healing purposes. Abusing them is harmful to individuals and to the community. Alcohol abuse is similarly acknowledged for its damaging effect. One of the participants associates alcohol use with stepping outside the community for the first time. "When we walked into the white man's world, we tried everything, we tried liquor, too. We started drinking when we very young; we started ruining ourselves."

Living the good life encompasses concerns with survival, sustenance broadly defined, living peacefully and taking care of ourselves, and each other. An abiding concern with separation from each other and its effect on the collective was often discussed. One participant observed that "(Wherever you go you have to keep a watch, you have to watch other people because you don't know them. In other places there's a lot of people that live together you don't know everybody and that's the way (this community) is starting to be. You don't know the person who lives across the street from you, you think you know them, but you don't.)" Participants consistently expressed a collective concern with living well, often discussing pathways to healing in conjunction with the topics of illness and injury. These individuals recall a time, not so long ago, when the community relied much more on themselves and each other for healing. They called for language reclamation and the revitalization of community as healing processes that could lead again to the good life.

Discussion

English Literacy and Power

It's hard to ignore the Anglo-centric view that English is indeed the language of choice, more complex, more difficult to learn, the language of commerce, hierarchical, abstract and politically positioned to ensure hegemony (Phillipson, 1992). Indigenous languages, many of which were never written, are thought to be inferior in every way. To be sure, "illiterate" has negative connotations. In fact, writing the language down can obscure the fine inflections and intonations that are critical to fluency and a deep understanding of Passamaquoddy-Maliseet.

From a critical perspective, the question is not what do we gain when the language is written down, but rather what do we lose in the process. The writing system commonly used for Passamaquoddy–Maliseet was first developed in the 1970s as a precursor to the dictionary project still underway today. The richness of meaning, the subtle inflection, the creativity and the precision of the language cannot be captured in dictionary form. Nor can we expect to understand the fullness of

health ideologies in English translations pulled out of context. In this study, we aim to understand how Passamaquoddy-Maliseet conceptualizes health through a process that engages community members in the inquiry, thus expanding language community awareness of the unique power and authority that resides in the language.

I concentrate here on how the politics of translation privileges Western ideologies expressed in English, over indigenous ideologies of good living, undermining the social construction of health and marginalizing indigenous health concepts.

Structural Considerations

One of the important observations of the research involves the complexity, the sophistication, and the elegance of the Passamaquoddy-Maliseet language. The precision of the language enables speakers to express ideas and feelings succinctly. Passamaquoddy-Maliseet expresses vibrancy and interdependence in its speaking. As Leavitt (1996), a linguist who has worked for years on Passamaquoddy-Maliseet projects, observes, "…space and time are continually reconstructed according to the speaker's location, so that personal identity is integrally tied to the space and time – both physical and social – in which the speaker moves. A language like English allows the construction of space and time without reference to a human presence. In Passamaquoddy an impersonal point of view is difficult to adopt" (p.13).

In Passamaquoddy-Maliseet the world is active and relational, visually defined and situated in the present. Processes have individual, family and collective impact. Accountability can be determined, but not blame. Generally, the language is less hierarchical, and less judgmental than English in keeping with the natural order of the world. In this study, careful attention to the scope of inquiry in a study of the meaning of health in Passamaquoddy-Maliseet creates space for the emergence of a complex ideology of good living. Living well encompasses ideas of survival, sustenance, collectivity, relationships and accountability. Good health then is the proxy for living well.

Ecology and Process in Health and Healing

Passamaquoddy-Maliseet draws attention to the centrality of dynamic processes in health and healing. The natural processes of death and regeneration are acknowledged as equally important and expected parts of the life cycle. The health of personal relationships is considered essential to collective good living, consistent with the interdependencies evidenced in the natural order of the universe. The loss of health and good living is attributed to the loss of community. The intimacy of a small close-knit indigenous community has eroded over time with changes in the population and erosion of the strength of the Passamaquoddy-Maliseet language, affecting how relationships are viewed and negotiated. The active process of translation in community facilitates the recovery of knowledge about healing, and supports the restoration of individual and collective efficacy in this arena.

Community members contemporaneously identify health problems and discuss healing, thus giving voice to the foundational process-orientation of indigenous ideologies. The critical approach to translation returns indigenous health beliefs and practices from the margins to the center. Explicit recognition of the active

relational indigenous perspectives of health prompts critical reflection on the root causes of illness and injury. Acknowledgment of the unique Passamaquoddy-Maliseet identity supports more conscious choices about the reclamation of definitional authority and collective community health.

Investigating these ideas uncovers the unique cultural identity of this indigenous community and enables more conscious choices about how to act to reclaim tribal definitional authority and support collective community health. The Cree and the Anishinabek are relatives of the Passamaquoddy-Maliseet, who are the subjects of this research. It should not be surprising, then, that the broad translation of the idea of health as "living well" in Passamaquoddy-Maliseet, usually expressed in the concept of *woli-bmousu* aligns closely with the *miyupimaatisiiun* and *mno bmaadis* ideologies expressed in these related languages.

Careful translation of health-related concepts residing in other indigenous language frameworks similarly provides ecologically situated-instruction for living well (Adelson 2000; Wilson 2003). Aspects of living the good life are consistent among three Algonquin-speaking communities, the Annishinabeak, the Cree, and the Passamaquoddy-Maliseet. These indigenous communities share the richness of a collective interdependent concept of health, which can transform approaches to health decision-making. Relationships between the conceptual frameworks expressed in these three languages and other indigenous languages globally should be more fully explored. The rich diversity of indigenous languages has common threads, which can be instructive for larger audiences, if articulated more broadly.

Limitations

This study provides a glimpse into the conceptual frameworks, particularly surrounding health issues, residing in the Passamaquoddy-Maliseet language and speech community. The study is limited by the experiences and the fluencies of the participants and does not fully represent the richness of the language. The dialogic process in which the researcher and the study participants explore the language together happens within the context of intimate community connections that cannot be replicated. The accuracy of the translation cannot be precisely measured. At the same time, the limits of our collective knowledge are pressed and expanded, as we grapple together with the challenge of how to bring forward indigenous knowledge and translate it into forms that will ensure its future.

Implications for Praxis

Health interventions that fail to consider the integrity of indigenous contexts for good living surreptitiously extend the colonization process in these communities and thereby subvert healthy living. The shift in definitional power to indigenous languages provides a foundation upon which indigenous-centered solutions can be developed and practiced. Individuals who work in indigenous communities are invited take a critical perspective on translation, to engage in reflexive research practice, and to help remove obstacles to self-definition of foundational concepts such as health in language-endangered indigenous communities. Doing so will pave the way for truly transformative dialogic health practice.

This research has global implications for making the wisdom embedded in indigenous

languages available to inform the healing of those communities and others interested in a more integrated approach to health.

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Endnotes

1. The research project included the exploration of decision-making concepts in Passamaquoddy-Maliseet, which will not be reported here. The larger project investigated health and decision-making as expressed in Passamaquoddy-Maliseet and how these ideas might currently be applied to tribal health decision-making.
2. See Dana-Sacco (2010) The Indigenous Researcher as Individual and Collective: Building a Research Practice Ethic Within the Context of Indigenous Languages, American Indian Quarterly, 34(1) 61-82
3. These textual materials employ a writing system developed by linguists that substitutes certain letters of the English alphabet for Passamaquoddy-Maliseet sounds that are different from English sounds. Although the texts were used for reference, the writing system was not used in the transcriptions.
4. Passamaquoddy and Maliseet are similar enough that the dictionaries currently in development all refer to one Passamaquoddy-Maliseet language. The languages are clearly differentiated in their speaking, with each having a different cadence and inflections. Each has place-based distinctions as well. The terms are used interchangeably.
5. Boldface indicates emphasis by the speaker of particular words or phrases.
6. Micmac, another of the Wabanaki languages, is very closely related and can be understood by fluent Passamaquoddy-Maliseet speakers.
7. 7 (English translation of spoken Passamaquoddy in parens)
8. Leavitt (1989) makes reference to Passamaquoddy names for health problems, recognizing the dynamic nature of the words, but translating sugalene as sugar suffering.

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Calling Our Spirits Back: Indigenous ways of diagnosing and treating soul sickness

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Susto: An Introduction

The bones will change, the blood will speak and jump, the winds may stir within us. These are all symptoms of *susto*, a soul loss or displacement of an animating force in the Indigenous bodies of Mesoamerica. The egg can cure it, a broom of plants. So can the earthen womb of the *temezkal,* the Nahuatl word for the Mexican Indian sweat bath. Sometimes a part of us is left in that place, the place where a disturbance occurred. Across time and place, we return to retrieve it, some disconnected part of ourselves. We may fit in a gourd, may accompany a fist of earth, or a glass of water, so that we can come back to ourselves. These are the teachings of my elders, Macehual Indigneous doctors.

Fig. 1. "Persecution of Indigenous medicine." Displacement of Indigenous medicine scene from La Medicina Maya: Pasado y Presente, produced by Médicos Indígenas de Chiapas

Ancient Mayan symbols depict the gourd that retrieves the soul from *susto* in a pre-Columbian vase. Symbols, enlivened by ceremony, prayers and respectful acts, become medicine. They reflect memory, accumulated acts, and knowledge. I transmit across different knowledges of the Indigenous Americas to connect this pre-Columbian Indigenous framework for understanding trauma with literature on unresolved trauma among American Indians.

> *…[When the Europeans arrived] They taught fear, they came to wilt the flowers. So that their flower would live, they harmed and sucked in our flower….*
>
> *(Yucatec Mayan Book of the Chilam Balam of the 1700s. See Florescano 1994, p. 105-106)*

The contemporary painted book (based on the pre-Columbian symbol system) by present day "médicos Indígenas," or traditional Indigenous doctors, of Chiapas depicts how traditional Indigenous medicine has endured various attempts by other knowledge systems to supplant Indigenous knowledges of plants, ceremony, and spiritual medicines. Much like the pre-Columbian symbolic language of the painted books, which serve as "visual testimonies" (Ojeda Díaz, 2003), the contemporary book is a painted script that details conflicting knowledge systems.

The visual narrative depicts more than shelves of pharmaceutical medicines and other

signs of authority related to biomedicine. The Christian pulpits and radio shows are sites of power where authorities preach(ed)* against traditional practices and ways of understanding and treating the causes of imbalance and illness. At the same time the educational system has emphasized the relinquishing of traditional markers of Indigenous identity for particular Mayan communities, such as discarding traditional clothing as part of modernization.

History repeats itself in the very fabric of Indigenous peoples. Another Native book in a series of Mayan colonial books, the *Book of Chilam Balam of Tizimin*, decries similar constrictions in the 1700s (in Carrasco 1990, p. 45).

> Your older brothers are arriving
> To change your pants,
> To change your clothes,
> To whiten your dress,
> To whiten your pants…

As signified by two healers of other Indigenous traditions, who are imprisoned for use of the sacred mushroom and peyote, this image is a visual testimony of the trauma of de-Indigenization and imposed belief systems that have impacted Indigenous medicinal knowledge all across the Americas. Earlier Mayan peoples chronicled this process in the 1700s: "They Christianized us, but they pass us around from one to another like animals. God is offended by the suckers" (in Florescano, 1994, p. 105).

And yet, the ability to endure as conveyed through the signs and symbols of Tzeltal and Tzotzil Mayan peoples in the Indigenous doctors' painted book reflects how Indigenous healing systems have persisted to the point that they now they speak back.

Traumatic histories of Native peoples results from the loss of relationships "with their daily world (Duran and Duran 1995, p. 32)." The depiction of usurping paradigms and its effect on Mayan traditional medicine are specific examples that reflect what Duran and Duran describe as an acute response to colonization.

> *… a postcolonial paradigm would accept knowledge from different cosmology as valid in their own right, without their having to adhere to a separate cultural body for legitimacy.… the past 500 years have been devastating to our communities; the effects of this systematic genocide are quickly personalized and pathologized by our profession via the diagnosing and labeling tools for this purpose. If the labeling and diagnosing process is to have any historical truth, it should incorporate a diagnostic tool that reflects the effects of genocide. Such a diagnosis would be 'acute and/or chronic reaction to colonialism.' (Duran and Duran, 1995, p. 6)*

Native American scholars have termed this process of cumulative, complex, and collective wounding across generations, resulting from colonization, as "Historical Trauma" (Brave Heart-Jordan, 1995). Symptoms of historical trauma can include depression, unresolved grief, trauma replicating behaviors such as violence against oneself or others close to you, and psychological numbing (1999 interview with Eduardo Duran). A growing body of research has shown that the survivors of trauma experience physiological changes in their brain messaging systems

(van der Kolk, 1994). Much of the literature on the relationships between this complicated trauma and illness in American Indian and other Indigenous peoples have used concepts of illness and disease that largely derive from the biomedical model. While these studies are useful in understanding the impact of trauma, recent studies on American Indian populations are connecting trauma to Indigenous ways of understanding unresolved grief and sentiments related to loss of land, and loss of relationships and values that provided a healthy cohesiveness in the daily lives of Indigenous peoples (Whitbeck, Adams, Hoyt, and Chen, 2004). "Acculturative stress," with the accompanying depression and sense of marginalization, foments the continuing effects of Historical Trauma, note Duran, Duran, and Brave Heart (1998): "While historical trauma includes acculturation stress, it goes much deeper and encompasses the aftereffects* of racism, oppression and genocide" (p.65). Depending on the specific historical context of Indigenous peoples, the process of historical trauma has often occurred during numerous stages of drastic changes in which Indigenous peoples often lost the social structures and the traditions that provided the stability to cope with the rapacious effects of colonization.

One surviving framework still in existence within certain systems of Traditional Indigenous Medicine (TIM) offers an Indigenous-informed coherence for understanding the impact of trauma—the concept of *susto* or soul loss, fright or trauma (Gonzales, 2012). While the literal translation of *susto* means fright, the term refers to a variety of responses that reflect the experience of soul displacement, a strongly experienced event that stirs emotional or mental distress, and trauma. I employ a transdisciplinary approach across time and space, connecting American Indian scholarship on Historical Trauma with the scholarly archive and case histories about *susto* among Indigenous peoples of Mesoamerica. I also incorporate oral tradition with lived practices and my own experience as a practitioner/community health promoter of traditional medicine. The inclusion of *susto* in the Diagnostic and Statistical Manual of Mental Disorders (DSM) as a "culture bound syndrome" now means that this classification is referred to by clinicians, researchers, policy makers, and health insurance companies in the United States. While the concept of a culture bound syndrome is arguable because many illnesses from mainstream U.S. society are also bounded by cultural frameworks, its inclusion in the DSM-IV-TR provides an opportunity to examine *susto*—and its traditional treatments—as a framework that may advance an understanding of various imbalances relevant to trauma among Indigenous peoples. I explore how TIM makes sense of the impact of traumatic events on the human body through the Mesoamerican framework of soul sickness, or *susto*.[1]

My work intersects with medical semiotics, which uses signs and symptoms to interpret and diagnose illness and states of wellness. Medical semiotics may include the "vital signs" that medical doctors agree upon in assessing a particular health condition; semiotic analysis may also include how symbols are employed to communicate authority, such as doctor's white lab coat. Symbols in Indigenous knowledge systems not only help to create meaning but also are part of an

[1] Other ancient cultures from Europe and Africa also have concepts similar to *susto* but my concern is how soul loss is expressed in Indigenous healing systems. These concepts often synchronized with each other during the colonization process into numerous manifestations of curanderismo or curing philosophies.

Indigenous science that includes TIM (Cajete, 2000). An Indigenous semiotics recognizes that symbols, when situated within the context of ceremony and sacred relationships with life giving forces, reflect and transmit the aliveness, agency and intelligence of life. Such symbol systems result in transforming the human condition not only because they serve to create meaning in peoples' lives. From the vantage point of many Indigenous cosmologies, they become imbued with the sacred powers that transform life. I conduct a semiotic analysis of the Indigenous symptoms and signs of illness associated with *susto* and its treatments, examining signs that are embedded in events and a series of acts that create units of experience. However, rather than use the medical gaze to interpret signs that "tells something about health and disease to somebody" (Maiterud, 2000, p. 603), I employ the framework of TIM of contemporary Mesoamerica to provide another reading of signs of distress of the human spirit. Many concepts and diagnoses are signs in and of themselves as they are part of a system of symbols that constitute agreed upon actions and meanings. For instance, "stress" is a recent conceptual framework that carries with it various associations, symptoms or signs that provide an agreed upon way to describe human experience. Depression is also a category of illness that is determined by a wide range of symptoms that may include a sense of hopelessness and worthlessness to fatigue and poor concentration and sleep disorders, all related to how people view life or how they view themselves.

In working with intergenerational-trauma among Native American populations, Duran and Duran (1995) and E. Duran (2006) apply the term soul wound. The concept of *susto*, based on enduring pre-Columbian frameworks, can include soul wounding, soul loss, and soul displacement resulting in a profound trauma or *susto profoundo* (Rodríguez, 2008) that can settle in the body. Traditional healers hold that this deep untreated trauma may "mature" into chronic illnesses, such as diabetes and depression. Such concepts are part of knowledge systems that may conceive of the Indigenous body in ways that are distinct from that of allopathic meaning systems, providing different etiologies to "dis-ease" and imbalance among Indigenous-origin peoples. Various American Indian concepts of the "soul," also recognize various manifestations of dynamic "vital principal" with a different kind of agency from what is currently acknowledged in the biomedical model of physiology (Hultkrantz, 1997).

Indigenous peoples from the Americas continue to rely upon cultural resources and healing knowledges to address "ethno-stress," traumatic occurrences, soul wounds and their implications for intergenerational wellbeing (Cajete, 1994; 2000). While these approaches are distinguished by their ecosystems, cultural patterns, languages and life ways, there are shared values and approaches which allow me to provide examples of how *susto*, as an etiological framework, can advance an understanding of traumatic responses—and traditional treatments—based on Indigenous ways of knowing, diagnostics and treatments as expressed in these healing systems.

Mexican Scholar Guillermo Bonfil Batalla (1996) argued that "Mexico Profundo" or a profound Mexico emanating from the depths of Indigenous being and knowing has persisted even among people without acknowledged Indigenous markers. Many scholars concur that these Indigenous ways of knowing have been maintained through traditional medicine. As we shall see from the lens of TIM, the pro-

cesses of genocide, de-Indigenization, gender oppression, poverty and the loss of land, culture and identity, present a complex syndrome of loss in the depths of the Indigenous being. Exploration of Mexico Profundo across time and space illustrates the possible implications of *susto profundo*.

The historical record shows how Indigenous peoples articulated and conceptualized different kinds and causes of soul loss, including the various levels of violence wrought by colonization. Mayan prophets have left a record in their own words in the *Book of Chilam Balam* (in Florescano 1994, p. 100): "Castrate the Sun, that is what the foreigners have come to do." The book (which dates from at least the early 1700s) reflects Mayan knowledge keepers' assessment of colonization's impact on their times: They lamented the bringing of sickness, when there was "no smallpox."

Indigenous healing systems from these cultures maintain methods for diagnosing and treating soul loss, or the displacement of part of the human spirit or vital force from the body as a result of a traumatic event or a strongly felt experience. Known as "*susto*" in Spanish, or fright or soul loss in English, this soul wound has been diagnosed and treated by Indigenous peoples with knowledge and methods that predate colonization of the Americas. From Mexico to the Southern Cone, Indigenous peoples who spoke unrelated Native languages believe in some concept of *susto* (Rubel, 1964) in which part of the human spirit may become disassociated from the body because of a trauma or a strongly experienced event. Since pre-Columbian times, Indigenous peoples from these ancient civilizations have held that the soul or various aspects of the spirit could wander, become detached or be captured as part of soul loss or soul intrusion. This "soul," variously known as the *tonal* in Nahuatl or the *chu'lel* among some Maya, is fundamental to understanding how a disturbance of the soul affects the health of Indigenous peoples of Mesoamerica. This soul is not necessarily the Occidental or Judeo Christian concept of the soul and can include concepts of vital forces that detach from the body and may be associated with cosmologies that influence human nature.

Though documenting Indigenous knowledge for the purposes of conversion and persecution, colonial records indicate how medicine people exercised ways of treating and addressing soul sicknesses. *Susto* among pre-Columbian Nahuas was referred to as *nematili* while its cure entailed calling the spirit back—*tonalzatzilia* (Aguirre Beltrán, 1963; López Austin, 1988). Colonial records contain prayers calling upon the assistance of tobacco to find and attract the wandering *tonal* or vital force of a child, showing the treatment's pre-Columbian origins. Such prayers were conducted by the *tetonaltique* to restore the *tonal* or *tonalli*, an irradiating vital force or internal sun. Colonial recordings of prayers (de Sahagún, 1950; de Sahagún & Garibay 1958; Ruíz de Alarcón, 1629) document invocations in which the healers look for the *tonalli* to "reconcile" the human spirit.

> *I have come to seek his tonal, his fortune, fate, star whatever may be: where can it have gone, where is it detained…I must bring it (de Sahagún, 1629, p. 172 in Foster, 1951.)*

The pre-Columbian *tetonalmacani* was the title given to someone who restored the *tonalli* or what today is referred to in Spanish

as *soplo*/enspirited breath or *alma* /soul but which originally referred to a life-force that resided in the head among the pre-Columbian Nahua. This understanding of the *tonal* persists among Indigenous peoples. For the Huastec, it is *ehetal and* for the Zoque, *kojama*. While among the Chinatecos, *susto* is evident when the vital substance *bi* leaves the body (Zolla & Pinzón, 1994). While there is great variation to how Indigenous peoples conceive of this idea, Timothy Knab (2004) in his documentation of dream medicine among the Nahua of San Martin in the Sierra of Puebla, Mexico, argues that the *itonal* is more complex than being the soul-breath, as it has also been described. It is a life force that can be displaced from the body, needs heat and the sun to survive, and survives after death. Among the Nahua of San Martin, the *itonal* requires living both with a good heart and in accordance with the ancestral teachings, thus raising implications for Indigenous people who have become disconnected from their ancestral ways or whose hearts are wounded and imbalanced by the violence resulting from inequality, internalized oppression and self-hate. Among some traditional Nahuas the *tonalli* may be strengthened with food imbued with the Sun and by establishing a good and direct relationship with the Sun (oral tradition). How might the disconnection of Indigenous people from their land base and the growing of their own food affect this life force?

Susto as an expression of various cultural healing systems has been well documented by scholars: Whether studying Zapotecs in Oaxaca or Mixteco farm workers who attributed their *susto* to the exposure to pesticides in the United States or Latino's concepts of *susto* or that of Nahuas in various stages of "acculturation," most of the studies found that respondents from these populations understood or employed the concept of *susto* (Baer & Penzell, 1993; Murguía Peterson, & Zea, 2003; O'Nell & Rubel, 1980; Rubel, 1960; 1964; Weller et al., 2002). Despite variations in the symptoms of *susto* or distinctive treatments, many scholars concurred that these populations shared a general notion of *susto* (Gonzales, 2012). My concerns here are the Indigenous expressions of this framework.

The numerous Indigenous words for the treatment of *susto* with what is known in Spanish as a *limpia* or *barrida*, a therapeutic cleansing or sweeping ceremony, also reflects the robustness of this practice. For instance, the *limpia* rite is called *ochpantli* or *tleuchpantle* in some Nahuatl languages; *hoku* among the Otomí, *kutsúrhentani* (Purépecha); *lak-pati* (Totonac); *metzel* (Tzeltal) and *naksugaba* (Zoque) to name a few (Zolla & Pinzón, 1994).

Susto Profundo and Contemporary Diagnostics

There are various diagnoses in Mexican traditional medicine (MTM) that can be part of *susto* or can stand alone as an ailment.[2] Symptoms of *susto*, which may vary with the people's cultural teachings, can include anxiety, *nervios* or nervousness, listlessness, fatigue or loss of vitality, loss of appetite, diarrhea, acute intestinal imbalances and apathy. Additionally, strong sentiments, such as mortification, embarrassment and shame are considered cultural diagnoses, are treated with prayers that may specifically address these maladies. These diagnoses have been the traditional ways that

[2] People can become sick from venting too much anger (*muina*) and get stomachaches and headaches or become sick from their nerves (*nervios, ansiedad*). When one becomes very angry or has a strong "impression" or "sentiment," the person may become physically "open" to, or subject to, the airs or *aires* that can attach or inhabit the human body through energetic points in the body and create internal wind.

Mexicans described symptoms now categorized under the label of depression. Even today, depression is not necessarily a term that many traditional Indigenous Mexican peoples use to describe deep grief, sadness or a sense of unsettledness, saying simply, "No me siento bien." I do not feel good. Or they will refer to a traditional concept of imbalance, such as having *susto* or *nervios*.

A Nahua prayer for treating *pipinahuistli* or embarrassment as well as feelings of "turbulence" are documented at the *Museo de Medicina Tradicional* operated by the state of Morelos, Mexico. In Nahua traditional medicine, *pipinahuistli* can produce symptoms that include diarrhea, vomiting, rashes or pain in a part of the body that becomes afflicted with the embarrassment that has concentrated itself in a particular location. The traditional healer addresses the *vergüenza* or embarrassment, asking where and how it was begotten, in a cantina/bar? Because of "a big nose?" The traditional healer prays in either Nahuatl or Spanish, using salt that is applied to the afflicted part of the body. The use of salt is associated with the pre-Columbian female power of transformation known by various names, including Ixcuina, which transforms what is no longer useful and can be depicted with cleansing brooms used in *limpias* or purification rites.

Mirroring the assessment of many traditional healers, Rubel (1964) acknowledged a form of *susto* caused by the distress over the loss of expected social roles. Numerous scholars have analyzed the underpinnings of *susto* as physiological responses to stress and how symptoms associated with *susto* can be understood by temperature changes, stress hormones, and biological functions (McKeever Furst, 1995). However, it is important to note that the notion of stress is a relatively new one among Indigenous peoples in much of the continent and not necessarily a generalized concept outside of Canada and the United States.

While Indigenous people have nuanced words for the various dimensions and categories of *susto*, in Spanish it is also described by various sources of infliction. Variously called *susto*, *susto meco*, *espanto* (including *espanto de chaneque*, a deep fright caused by air spirits or malevolent/overpowering spirits), *espanto de sueño* (deep sleep fright from being awakened abruptly), *espanto de agua* (fright caused near bodies of water or by water spirits) many of these cultural diagnoses reflect the pre-Columbian patterns that recognized the impact of fright or trauma on the human body spirit, as well as on a living universe and spirit beings that can be offended or that are so powerful that they can overtake a human being's vulnerable life force. A living force that leaves the body can be captured by spirits or places of great power because of a vulnerable state of life that may be caused by sickness, a weak life force or a troubled state of mind. However, while the potential ultimate consequence of an extreme *susto* may result in death, many cases of *susto* refer to a range of experiences in which a part of the human spirit is separated from its structural whole without a fatality, but resulting in other serious consequences.

The diagnosis of "*susto pasado*" reflects the concept of the extended or prolonged impact of trauma. This knowledge from oral tradition has been recorded in the literature (Avila, 1999; Trotter & Chavira, 1997). In one study, Mexican Americans attributed their diabetes to past *susto* from two to twenty years earlier (Poss & Jezewski, 2002). Many *curanderas* and

curanderos or traditional healers from Mexico hold that diabetes can be the result of some earlier form of *susto* that went untreated. One example of how *susto* is a distinct etiology is its comparison with the diagnosis of depression. From the logic of MTM, *susto* is not depression but can cause symptoms associated with allopathic definitions of depression if left untreated. Elders say that *susto* can become lodged in a particular body part, causing breast cancer, heart disease or spur the onset of diabetes (oral tradition with Indigenous doctors and midwives such as Don Aurelio Ramírez Cazarez, 2005; Doña Enriqueta Contreras, 2002). *Tonalhuicac* is a Nahuatl word that can describe a recent strong *susto* or a *susto pasado*, one that happened in the distant past, such as in childhood, requiring a ceremony (2010 oral tradition with Macehual knowledge keeper Paula Domingo García.) When this occurs, it is said, "te fue tu espiritu. Te alejó." Your little spirit left, it got away from you.

Susto: Pre-Columbian Treatments in the Present

Susto is often treated with a conjunction of elements that can include a ceremonial sweeping or rubbings with the four elements of life that are based on hot and cold as well as the plants from a particular ecosystem and in ceremonial positions and configurations such as the four directions. Because people are interconnected, they transfer energy to each other, in an exchange of both positive and negative aspects. The interchange of energy among human beings can be affected by bad thoughts or negative projections against another.

Additionally, people may be prescribed the sweat bath or in the Nahuatl language, the *temezkal*, to be heated with rocks to sweat

Fig. 2. Image of traditional Indigenous limpia employing a lizard: "In Tepahtiani - La Curadora de Gentes" Illustrations copyright © 2009 by Martha Ramírez-Oropreza

out the infirmities. Teas are used to calm the spirit, move the airs, and to settle the stomach and nerves in conjunction with massage or plasters that feed the body-spirit. (The lodge is a persisting Indigenous approach to address emotional disturbances with numerous American Indian programs employing the sweat lodge as an intervention in drug rehabilitation or as an Indigenous component of counseling). Sahagún recorded the pre-Columbian practice of conducting the *temezkal* for people who had been in physical fights or suffered an affront. At the Atekokolli clinic run by Nahuatl traditional doctors in the state of Morelos, Mexico,

the *temezkal* is administered for people who have a strong *susto* or who need to be deeply rebalanced emotionally (2011 interview with Aurelio Ramírez Campos). Certain plants are also administered based on their ability to treat *susto* that is lodged in a particular place in the body, such as in the spine, or in the eyes, which is called *susto de vista* or fright in the eyesight (2005 interview with Don Aurelio Ramírez Cazarez). The practices to rectify *susto* can include medicinal baths and teas, sweat baths, ceremonial sweepings and rites involving the four elements of life (constituted from air, water, earth and fire) and relationships to place. One ceremony that has a multiple variations involves "calling the spirit back" from the place of the traumatic occurrence.

Susto: Ceremonial Curings

Various purification ceremonies are conducted to address soul loss, soul intrusion, or soul displacement and they vary greatly in their ceremonial layering. The treatment tells us as much about the cause as the causal sources of *susto*. Prior to many *limpias*, a *platica* or conversation may transpire as the health seekers explain to traditional healers why they have not been feeling well. This aspect of traditional healing can be understood as a form of narrative medicine in Indigenous healing systems. The ability to talk out the problem is sometimes part of the healing and may be considered as a reflection of the element of "air," for as the words leave the person's body, the illness is carried in their breath out into the air. The concept of having winds or "*aires*" also reflects how emotions foment internal "winds" or strong sentiments. The practice of having the people respond to being called back into their bodies can also be considered a traditional understanding of the power of cognitive medicine in which the patient should be an active participant in their own recovery. Additionally, as they speak, they employ the property of air/breath as part of the traditional therapeutics. There is a sense of "reconciliation" with his or her own spirit or making peace with an event or another being that may be in keeping with the pre-Columbian concept of reconciling the spirit.

Numerous Indigenous peoples in Mexico and the United States practice variations of the ceremonial *limpia* called *levantando la sombra*, or the raising the shadow/calling the spirit back. I have learned dozens of variations of this *limpia* through oral tradition as part of my instruction as a *promotora* of Indigenous medicine. In these protocols, the spirit is called back from the place of a traumatic occurrence. When a person cannot return to the site, the traditional healer or family elder may return to the place of the event and gather the *tonalli*, or the spiritual aspect that has detached from the person, in a jar or gourd. Offerings may be left in exchange for the release of the spirit from the place. In a further nuance of soul loss, ceremonies to protect a child's spirit from being overpowered and thus taken or dislodged while in a home, near a spring, a sweat lodge or strong environment are forms of preventative medicine to guard against soul displacement, which portend deadly consequences for newborns and babies (Mak, 1959; Zolla & Pinzón, 1994). The ultimate consequence of a severe *susto* left untreated may be death for adult or child.

When *susto* is released, pungent sulphuric fumes, reminiscent of the pre-Columbian characteristics of the *ihiyotl* or inspirited aspect of the liver that emits a gaseous property, may fill the healing space as the body releases *susto*.

Some healers attribute this smell to the release of dense negative powers that have attached to the body. The body may be filled with chills and coldness and tremble, similar to the pre-Columbian response of "shuddering" as a sign that the *tonalli* had returned. In these healings, we have called the spirit back and person has responded, "*Estoy aqui, ay vengo*." I am here, here I come. The ceremonial, ritualized rubbing and sweeping allows for the stress, negative thoughts and energies to be swept off and open the way for restoring equilibrium.

Susto: Some Case Studies of Curing Traditions

> *The spirit is released from a living earth and the site of traumatic occurrence.*

In the 1960s, a Chinanteco child contracted *susto* after being punished at school. His mother conducted a *limpia* at the schoolhouse where a teacher hit her son on the hands. The child contracted *susto*. His mother took the clothes he wore to school that day and went to the place where he sat and spoke to the earth to release his spirit:

> *I come in the name of curer Garcia who at this time is unable to come. I come this time and this time only. It surely was not your intention to dispossess him of his spirit. Goodbye, I will return in four days to advise you as to his condition and to do whatever is necessary (Rubel, 1964, p. 276).*

She swept her son's clothing on the earth to retrieve his spirit and then took a fistful of earth to conduct other prayers at home. A traditional healer then conducted a ceremony

Fig. 3 Post-conquest image of Tlazolteotl-Ixcuina, presiding force of regeneration and limpia purification rites. She holds a broom of herbs and such brooms are often employed today in limpias. Florentine Codex Vol. 1, figure 12. University of Utah Press.

with his clothing, including wrapping the child in blankets and laying him on a cot where a brazier of hot coals were placed underneath. The healer, after the child's recovery, went to the schoolhouse to give thanks to the earth for releasing the child's spirit and in ceremony bid farewell to the spirit of the place (Rubel, 1964).

Signs important in the treatment include: inflammation in the body, clothing and personal articles, furniture, the earth and site of the occurrence.

The method of treatment includes key steps and interrelated processes:

1. Relying on framework that allowed the parents to understand the impact of stress on their child: this framework included an understanding of a living place; that the clothes held the sickness and could be used to undo the illness.

2. A relationship with a traditional healer.

3. Access to the school or place where the imbalance or event occurred.

4. The agency and power of the parent/mother to conduct the ceremony.

5. Recognition of the aliveness of the place as active participant in the healing and container for the imbalance.

6. Recognition that an aspect of the human body-spirit remains in clothing and material and immaterial items that come into contact with a human being.

7. An understanding of nature and spirit as inter-related.

Retrieving the spirit in a receptacle.

In another example from the Mixtec people of Oaxaca, a boy was diagnosed with *susto* that resulted from a fight at school (Mak, 1959, pp. 128-129) resulting in the inflammation of his right eye (a strong sentiment can open one up to wind-related ailments or *aires* and this inflammation is of a cold nature associated with *aires*). The mother went to the spot where the fight occurred and made an offering to the earth for his spirit to be released. The boy's mother formed a cross on the schoolroom's dirt floor and poured pulque on the cross and made it into mud. She sprayed the boy's shirt with the pulque, speaking to the boy's spirit: "Arise enter into your chest [shirt]." She moved the shirt around to different spots where the boy might have been and said, "Arise, let's return to our house, Temu [the boys' name], don't stay here. You got angry with your pal and you fought together. Perhaps you suffered badly inside, both of you, fighting in a fierce place. Don't stay here because this isn't where you live." She then addressed the spirit of the place and said, "Don't be angry and kill my child." She returned home and continued the ceremony. The child's spirit was returned and reintegrated from the bowl of pulque containing the child's spirit.

Key signs: inflammation as an expression of a strong sentiment lodged in the eye as a result of "*aire*," clothing that carries the child's spirit and the trauma of the event, the narrated prayer of calling the spirit back; the making of the sign of the cross in the mud.

Key events in the curing process:

1. The spirit has been displaced.

2. The parent is empowered to act.

3. The parent has access to the space to do ceremony and cultural curing rites.

4. The clothes and the earth/place are treated as alive.

5. For rebalancing of the human being with a vital aspect of the self that has

become disconnected, the earth is spoken to and addressed.

6. The ceremony involves a process of reintegration.

Susto: Group trauma

The following account from a Huichol elder from San Andres Cohamiata, Jalisco, suggests how an entire group became at risk when a group of children died (Vargas Becerra, 1999, p. 213). Huichol children became sick and died after they were ordered by certain elders to ignore ritual protocols and overturn ceremonial tables because of strong rains. One elder recounted to Vargas Becerra how she, her child, and their animals fell ill as a result. Despite allopathic measures to cure them, their maladies were only relieved after offering songs, paying respect to caves and offering waters from outside sources, which restored the health of the community.

Key signs: sickness and even death of community members, including animals as part of the community, songs, paying respect to places of power.

1. The trauma is triggered by an imbalance with the environment created by ignoring ceremonial accords.

2. The trauma affects various groupings of a community, both those distant and those people with close involvement to the event.

3. Animals are also part of the community that is affected.

4. The local ecology also carries the *susto* and may be an agent in emitting the *susto*.

5. Human and community balance is restored with offerings and acts that initiate a new harmony with the environment/natural world.

These accounts, spanning forty years, demonstrate how the ceremonial curings are persistent cultural resources, enabling Indigenous peoples to interact with places in accordance with their traditions. Parents are agents in their children's healings as are individuals who, in their health seeking behaviors, turn to resources within their social network and local ecologies. *Susto* is recognized as having an elliptical effect on the person's social and physical environment and the power of place has agency in creating imbalance or restoring it. The environment is impacted by illness and is part of the rebalancing of human health. It can be an important sign in both diagnosis and treatment of *susto*. Nor are these interventions a thing of the past, since many Indigenous communities continue to perform ceremonies for their physical spaces to avert negative influences. In the 2007 documentary *Way of the Warrior*, scholar Tom Holm noted that part of the post traumatic stress of some Native veterans of the Vietnam war was their remorse over having desecrated the Vietnamese landbase. The previous accounts from other Indigenous peoples suggests Indigenous understandings of how the environment holds trauma, and its potential role in releasing trauma from human-land relationships.

Susto: Adaptations of Enduring Knowledge

This framework of bringing balance to a human being is applied to more than the trauma of a car crash. The literature shows *limpias* used in cases of domestic violence, or witnessing violence. In fact, the first detailed treatment of *susto* recorded by anthropologists involved a Pokoman woman of Guatemala who was hit with a rock from a philandering husband (Gillin, 1948; Lincoln, 2001). In this article, Gillin termed *susto* "magical fright," a definition that many scholars apply today in their analysis of *susto*.

Indigenous midwives have shared numerous treatments with me as an apprentice midwife to address *susto* among pregnant women, where *susto* affects the mother-baby as a unit. While they do not use the term disassociation, many of the *curanderas* and midwives speak of *susto* inhabiting Mexican migrants, with their beings split. As the midwife Doña Enriqueta Contreras instructs: Their bodies are North of the border, while their spirits remains South of the United States. So Indigenous healing systems continue adapting the theories surrounding *susto* to the conditions of today.

Accumulation of the Intolerable

When N. Scott Momaday offered the idea that American Indian people held a "blood memory," he provided an Indigenized way to speak of a memory contained at the cellular level. Examples of TIM help to explain how such a blood memory goes beyond constructs of biological determinism. Among the Quichua, the idea of *pena* or an "accumulation of intolerable sorrow" resonates with both the concept of *susto* in Mexico (Tousignant, 1984, p. 383) and new literature on historical trauma. In *pena* or *llaqui*, a strong suffering is experienced in the heart, "the blood jumps in the veins of the heart and reaches the head, the feet and the hands to produced much emotional sadness and crying" and causes numerous symptoms (Tousignant, 1984, p. 386.)

When elders have explained the physical signs of *susto,* they have instructed me on how the blood changes, as do the position of the bones, as a result of a *susto*. In fact, not only does blood carry memory, the blood also "speaks," according to the Mayan *pulsadores* (pulse readers) of Tenejapa, Chiapas, who can detect the deeds of the ancestors through their subtle readings of the blood. The expert *pulsador* is a traditional healer who diagnosis and cures through working with various pulses or energetic channels in the body, similar to meridians in Asian acupuncture. Thus, the body is imprinted with various signs of soul wounding, demonstrating another variation of "blood memory" that has been evoked as a sort of inter-generational source of memory (Struthers & Lowe, 2003) among Native Americans north of the U.S.-Mexico border.

I have been part of *limpias* with great ceremonial complexity that addressed soul loss from violent encounters and murder as a result of Nahua peoples defending their natural resources. *Limpias* are a cultural resource used to treat *susto* wrought by land takeovers, massacres, rape, murders, and beatings. Mayan elders include *limpias* as some of the ceremonial processes by which Indigenous people in Guatemala have coped with the *susto* of recent genocide. But Don Alejandro Cirilo Perez Oxlaj (1998 interview) also attributes violence and poverty as key structural sources of *susto*. The following account from a Guatemalan human

rights observer describes the role of *susto* in the death of a boy.

> *His mother and neighbors calmly explained that he had died of sadness. His father had left the day before to the United States out of economic desperation, and his departure had been absolutely devastating for the boy – to the extent that he never woke up…Death by emotion is not uncommon here. In listening to friends' recounting the genocide "susto" – fright— is often given as an explanation of loved ones' deaths following the actual army-led measures…(Buckley, 2007).*

Just as some Quichua factor in colonization as part of the accumulating sorrow (Tousignant, 1984), *susto* provides a distinct framework for understanding the impact of trauma and other disturbances of the spirit. *Susto* and related aforementioned Indigenous etiologies are more than somatic occurrences (Marcos, 2006; Tousignant, 1979). They are not "magical" illnesses and carry their own internal logic as part of coherent meaning systems with expansive concepts of the body, nature, spirit and place. They help to explain how Indigenous peoples understand their vulnerabilities to illnesses and diseases. These frameworks are often invisible or hidden from providers of allopathic medicine. Many Indigenous peoples migrating to the United States are re-infusing these Indigenous theories into the burgeoning communities that are viewed as either Indigenous or Latino and who have maintained, to varying degrees, Indigenous forms of healing in what is termed *curanderismo*, or curing philosophy. Additionally, *limpias* provide not only an Indigenous method for rectifying various imbalances, but also are a cer-

emonial and energetic framework for restoring wellness based on Indigenous ways of knowing and experiencing the cosmos within and near human bodies. Both the Indigenous etiology of *susto* and the treatments for this soul illness may lead to innovative interventions based on enduring ways of knowing the Indigenous body. As researchers continue to document the effects of inter-generational trauma on Indigenous populations, measures should include Indigenous frameworks, such as *susto*, which are centered on concepts that are distinct from concepts of stress and depression.

Conclusion

Employing etiologies that emanate from Indigenous healing systems can produce new ways of thinking about the effects of stressful occurrences on the Indigenous body based on cultural tradition. The body is viewed as having more than one vital force. An aspect of the vital force can become detached from the body, creating various imbalances in mind, body, spirit and the environment. A vivifying force not recognized in Western anatomy has agency and can become separated from the body without necessarily causing death and is part of an Indigenous sign system that helps makes sense of trauma. Untreated *susto* rather than stress can be attributed as the underlying source of depression, fatigue and chronic diseases, such as diabetes. Similarly, inequality and cultural losses can also be the cause of this soul illness. As I have shown, the etiology of *susto* is expanding to accommodate the contemporary experiences of Indigenous peoples. Additionally, the treatment of *susto* is dynamic and entails more than typical counseling interventions prescribed for trauma. Traditional treatments may entail an intricate and/or intimate relationship to place as part of the

therapeutic intervention that involves restoring balance and reintegrating various aspects of human existence with the physical and social environment. These healing systems operate with diagnostic tools and treatments that may respond to the effects of colonization, providing culturally grounded strategies to treat the effects of intergenerational trauma, soul loss, and the soul wound of historical and contemporary trauma. Further research is needed that examines the effects of trauma with culturally specific conceptual measures based on Indigenous knowledges that frame trauma from the distinct lens of each Indigenous people. While *susto* operates within different contexts and healing systems, a growing number of mental health practitioners are incorporating MTM as part of their treatments. *Susto* can help conceptualize how even recent trauma, reinforced by the inter-generational traumas experienced by Indigenous peoples, impacts them in individual and collective ways, including their ecologies.

If the Indigenous spirit is to be called back, how far does the call go? To which sites of trauma do people return? What pieces of earth or gourds of water might be brought to them, what spirit medicine and ceremonies might be offered so that their spirits will recognize these victims of the many Wounded Knees, Long Walks, mass graves and massacres? And how might Indigenous peoples experience life differently as a result?

About the Author

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Traditional Storytelling in the Digital Era

Janelle Palacios, CNM

ABSTRACT

As a population, American Indian and Alaskan Native people have poorer overall health status when compared to other Americans. Due to a history of colonization and continued marginalization, a movement to bring forth traditional knowledge and practice, while reaffirming power over how a people are researched, has evoked a new orientation to researching wellness among indigenous people. The aim of this article is to situate the oral tradition of storytelling in the digital era as a research technique and intervention that can help Native and non-Native investigators meet American Indian health needs.

KEY WORDS: *Native, American Indian, Indigenous, Storytelling, Oral Traditions, Digital Storytelling, Health Care, Culture*

INTRODUCTION

As a population, American Indian and Alaskan Native (termed American Indian, Native, and indigenous throughout this article) people have poorer overall health status when compared to other Americans. American Indians have lower life expectancy and die at higher rates than other Americans from tuberculosis, alcoholism, diabetes, unintentional injuries, homicides and suicides(Indian Health Service, 2011). American Indians are situated within a colonized history filled with genocide, assimilation and acculturation. Researchers contend that the history of colonization and continued marginalization, evident by inadequate education, disproportionate poverty and discrimination in health care services (Indian Health Service, 2011), are the source of American Indian health problems (Brave Heart, 1999, 2003; Brave Heart & DeBruyn, 1998).

Conducting research with the American Indian population has proved challenging both due to historical atrocities and subsequent distrust bred through unethical research practices. Native people have been researched to death. Until recently, researchers conducting studies have not acknowledged (or known) the significance of American Indian history. Understanding Native people's encounter with historical atrocities bestows a deeper awareness for the context situating health and illness (J. F. Palacios & Portillo, 2009). Who knows the effects of living a colonized history? Those who live it.

A movement to bring forth traditional knowledge and practice, while reaffirming power over how a people are examined, has evoked a new orientation to researching wellness among indigenous people. The purpose of this article is to consider the usefulness of digital storytelling, positioned within a tradition of oral storytelling, as a research approach to enhance understanding and wellness in Native communities. Drawing upon current contributions of Native researchers, it will be suggested that incorporating an indigenous perspective to knowledge formation (oral traditional storytelling) with advances in technology (digital media and immediate dissemination) will help improve Native health. The information

is expected to be of value to both Native and non-Native investigators aiming to work with Native communities, and the Native communities hoping to partner with academic researchers.

DECOLONIZING RESEARCH

Historically, researchers have betrayed American Indian people. Whether it is the misuse of blood product among researchers, the detrimental report of sexually transmitted infections of a community that effects their economic viability, or the report of widespread virus that breeds fear among those surrounding the infected community (Davis & Reid, 1999), the power wielding hands behind research can make poor choices that have lasting damaging effects. A recent example of mistrust is when the Havasupais initiated a lawsuit against Arizona State University researchers for misusing blood samples taken from tribal members. In addition to brewing mistrust, American Indian communities resist research because partaking in the project consumes needed and non-existent resources (e.g. access to reliable transportation or gas), results are infrequently shared with the participating community, findings rarely improve local services in the community, benefits of the study seldom reach the community, and American Indians are tired of being guinea pigs (Burhansstipanov, Christopher, & Schumacher, 2005). Overall, the need for more appropriate research approaches with Native communities remains.

Even though measures have been taken to be culturally sensitive when conducting research with American Indian communities, there remains an unequal balance of power between the researched and the researcher. Recognizing the consistent exploitation of indigenous communities made by colonization, marginalization and investigations, a movement was started to recapture the power lost to these bodies. Indigenous scholars have their "own way of doing things" that consists of their own set of knowledge (Dunbar, 2008). In her book Decolonizing Methodologies Research and Indigenous Peoples, Linda Tuhiwai Smith(Smith, 2001) explains how "new ways of theorizing by indigenous scholars are grounded in real sense of, and sensitivity towards, what it means to be an indigenous person," (pg. 38), helping indigenous people make sense of their reality.

Our realities often involve living in multiple worlds. Linda T. Smith is careful to point out that decolonization is not about casting off our inherited Western theories and ways of knowing, but really is about recalibration. To pursue indigenous epistemology is to center *our* indigenous concerns and worldviews, and having our skills aid us in our pursuit from our perspectives for our own purposes. Naming research within her Maori community, Kaupapa Maori or Maori research was intentional for Linda T. Smith (2005). Employing their own term and language to name what was important to Maori, privileges Maori knowledge and ways of being. In Smith's view, echoed in her indigenous roots, importance is placed on the process (2001). Recovering stories of our (indigenous) past is linked to language revival and thus our (indigenous) epistemological foundations. Reframing research within a Maori conceptualization helps support social change and replacing power into the community's hands. Finally, Smith suggests that indigenous investigators working with their communities may be more sensitive to the needs of their community as they themselves rely upon the relationships fostered and must live with the consequences

and implications of the findings (2001).

While working with American Indian communities has been noted to be difficult given the previous stated reasons, successful projects are collaborative (Burhansstipanov et al., 2005; Davis & Reid, 1999) and include culturally patterned methods for engagement (Strickland, Squeoch, & Chrisman, 1999). Heeding the return to what we know and what our communities know will further provide successful collaborations by expanding upon culturally appropriate ways of pursuing research, but also honoring and supporting American Indian self-determination. Since the Indian Education Act of 1972 and the Indian Self-Determination and Educational Assistance Act of 1975, American Indian people have had the right to determine their educational priorities for their communities, and often this has included storytelling (Inglebret, Jones, & Pavel, 2008). Storytelling, as an indigenous practice and philosophical orientation to the world, holds emancipatory potential for positively effecting change in our Native communities.

INDIGENOUS EPISTEMOLOGY

American Indian Worldview

To a degree, generalizing the vastly diverse American Indian cultures, of which there are 566 Federally recognized tribes (Indian Health Service, 2011), is engaging in a Western practice of reduction. While there are great differences even between two bands of the same tribe, there are also common worldviews held by American Indian people. By virtue of a shared colonized history, similarities among American Indian people have emerged far more vividly in contrast to differences. The use of humor when faced with grief or hopelessness, or running on Indian Time are two examples as a source of common identity.

It is common for American Indian people to orient themselves as an extension of a broader collective such as their family, community, and creation/universe (Delgado, 1997; Lowe, 2002). Often greed and individual pursuits are shunned and ostracized as the supremacy and cohesiveness of the group is maintained (Lowe, 2002). Living life means having respect for the interconnectedness of all things- animate and inanimate (Buehler, 1992; Delgado, 1997; Lowe, 2002), and the orientation to life is meant to be holistic, interconnected, and relational (Buehler, 1992; Struthers & Peden-McAlpine, 2005). Harmony is conceptualized as being in balance with the self, others, community, and surrounding world which also includes a spiritual sense (Lowe, 2002). Time is understood and practiced in a cyclical pattern that is ever changing and fluid, rather than stationary (Lowe, 2002). Seasons change only to cycle back. Birth, life and death occur cyclically (Struthers & Peden-McAlpine, 2005). Much importance is placed on the present*ness*, rather than the future, for the future can be affected by what is done in the now. The journey is not a future destination; rather the emphasis is on the journey, in being and toward becoming (Lowe, 2002; Struthers & Peden-McAlpine, 2005). This is not to say that Native people do not reflect on the past nor consider the future. One can look to findings by Native investigators to see that the generational pain from historical atrocities remain ever present in the community's mind and lived experiences of suicidal ideation (Strickland, Walsh, & Cooper, 2006), or that parenting actions of today and yesterday alike affect the wellbeing of future generations and thus steps are being

taken to help promote the future community's wellness (J. Palacios, 2012).

Values highly regarded by American Indian culture are those that respect endeavors to support their relational and interconnected worldview. Struthers (2005) shared a list of American Indian values that include: respect, generosity, wisdom, spirituality, stewardship of the earth, humility, honor, cooperation, identity, oneness, balance, harmony, and connectedness. As an example of connectedness and sense of duty and commitment to one's family, community and larger universe, the potlatch custom of giving gifts along Northern West Coastal American Indian communities was and continues to be conducted not only to redistribute wealth, but out of generosity. While committing to a sense of oneness, or connectedness among the community, attendees honor the traditions of old in a culturally appropriate way of caring for the collective through gift giving, feasting, singing and dancing (Easterson, 1992).

In contrast, the Euro-American worldview places an emphasis on the success of the individual. Family and community are important, but do not take center stage, as is common of the American Indian worldview. The self is viewed broken into parts: physical, emotional, mental, and spiritual; whereas, the self is integrated and perceived as a unit of the whole in the American Indian view. While time is cyclic and fluid with a focus on the present*ness* in the American Indian world, time has a destination and future goals are set as time is lived forward within the Euro-American worldview. Additionally, differences can be found in how one views their relation to others and their environment. American Indian worldview holds the self and community in relation to the larger world/universe and the emphasis is to work along natural rhythms, versus holding one's self in stark contrast, sometimes in an oppositional stance against the world/universe, with the intent to tame or change the world to one's desires as in the Euro-American worldview (Delgado, 1997; Lowe, 2002).

American Indian Epistemology

Differences between each cultural worldview can be seen in orientation to research. Historically, for the biomedical sciences the pursuit has been focused on the absolute truth through objectivity. Indigenous scholars, similar to postmodern/post-structural scientists, view the world as one, which is filled with multiple truths and ways for understanding. Rather than focusing on the outcome, importance is placed on the process. Methods of collecting knowledge tend to be linear in the Euro-American tradition of research. For communities who are culturally oriented to a circular view of time and being in an interconnected way, applying Western methods may prove challenging and unnatural. Success for the researchers, in conducting research in Native communities, most likely can be found in selecting those methods that are flexible and can be shaped into cultural patterns aligned with the American Indian worldview (Dodgson & Struthers, 2005; Strickland et al., 1999).

Storytelling as a Tradition and Method

All cultures possess stories. Stories help us articulate understanding. The world cannot be understood without telling a story, for we make sense of lives and realities through lived experiences that are organized in story format (Inglebret et al., 2008; Wyatt & Hauenstein, 2008). Beyond artistic expression and enter-

tainment, stories are often our first teachers of the world. The value of stories as a pedagogical method is well recognized (Bergman, 1999; Haigh & Hardy, 2011; Inglebret et al., 2008; Iredale, Mundy, & Hilgart, 2011; Kirkpatrick, Ford, & Castelloe, 1997; Lee, 2011; Meyer & Bogdan, 2001), wherein cultural values, morals, laws, practices, and beliefs are taught and transmitted to future generations. Stories have the power to provide understanding, inspire empathy, and motivate problem solving. Indigenous scientist Felicia Hodge (Hodge, Pasqua, Marquez, & Geishirt-Cantrell, 2002) summarized the powerful function of stories:

> *Stories show ancient social orders and daily life, how families are organized, how political structures operate, how men hunt and fish, and how power is divided between men and women. They demonstrate appropriate behaviors; teach social rules and expectations, how to live harmoniously with others, being responsible and how to be worthy members. (p. 7)*

Stories move beyond folklore (Mabery, 1991), integrating science and art into knowing. As a part of AI oral traditions they exemplify relational ways of being and encompass time. As Struthers (2005) suggests: "Oral tradition naturally accommodates the essence of the past, the present and the future," (p. 1271). Stories are ever changing, like the flow of the river, but they do not forget where they have been and collected knowledge over generations is made accessible to present and future generations (Hodge et al., 2002; Struthers & Peden-McAlpine, 2005). In addition to accessing our cultural practices, values and beliefs (Inglebret et al., 2008; Mabery, 1991; Struthers & Peden-McAlpine, 2005), stories provide a bridge connecting us to our ancestors and their realities affirming group identity (Hodge et al., 2002; Inglebret et al., 2008; Struthers & Peden-McAlpine, 2005) and providing wisdom and experience that may help us identify solutions to community problems (Mabery, 1991; Meyer & Bogdan, 2001). For example, Maybery (1991) points out that motivation to identify solutions for healing his Diné community illnesses (e.g. substance use) can be found in Diné stories, for the story provides methods to understand and access the Diné worldview and philosophy.

Storyteller and listener are important components for the significance of the story. The interaction between the storyteller and listener is a shared experience (Carr, 1996; Hodge et al., 2002; Kirkpatrick et al., 1997; Werle, 2004), invoking inspiration, empathy and understanding. Often, stories change slightly from one telling to the next. The fluid malleability of stories, as they are reshaped and refitted, speaks to the power stories have in addressing community needs (Erdoes & Ortiz, 1984). What is important one year may change the next given situated differences in the socio-political climate. Lessons learned from stories may not always be direct, especially in traditional American Indian storytelling. Usually, repeated telling of the storyline, despite modifications, herald different levels of understanding from the audience, reflecting different levels of readiness for the listener heeding messages (Inglebret et al., 2008; Struthers & Peden-McAlpine, 2005).

Both as a tradition and research approach, storytelling displays a wide array of functions. As a tradition that facilitates cultural indoctrination, storytelling strengthens group cohesiveness through a unified identity and implicit adherence to a set of agreed upon practices

that are reinforced through story. As a research approach facilitating knowledge gathering, storytelling appeals to our relational mode of understanding while inspiring problem solving. Storytelling holds great potential for individual action, and greater potential for changing destructive community norms when individuals act collectively in harmony.

Storytelling as Emancipatory

The seamless ability to simultaneously impart knowledge, inspire, and generate problem solving capacity demonstrates the monumental influence story has in our lives. For the individual, storytelling centers their experience and knowledge at the forefront of importance. In the telling of a person's story, the study participant is viewed as a whole person; the story honors their humanness and personhood, the listener, if open, is left with an understanding of values and beliefs affecting the participant's decision making, and power imbalances are uncovered (Anderson, 1998; Kirkpatrick et al., 1997; Werle, 2004). For a brief moment, the listener walks in the shoes of the storyteller.

Investigators have found storytelling to privilege historically marginalized populations. Among women, storytelling respects their knowledge recognizing them as experts in their own experience, and grounds women's health care in women's lives (Banks-Wallace, 1999; Chinn & Kramer, 2008; Grassley & Nelms, 2009; Im & Meleis, 2001). Among African American women, the liberating cathartic effects of storytelling are found to be helpful in finding meaning in their own lives, bonding with others over storytelling, validating and affirming one another's experiences, allowing them to vent frustrations, resist oppression, and educate others (Banks-Wallace, 1998).

Indigenous scholars are charged with the task of sharing authentic indigenous narratives that illuminate the social, cultural, and political organizational patterns that reveal ontological and epistemological dilemmas (Dunbar, 2008). By drawing upon our traditional stories and storytelling orientation to understanding, Native and non-Native researchers may find paths to help us decolonize our lives and heal our communities (Hill, 2006; Lee, 2011; Meyer & Bogdan, 2001; Smith, 2001). Asserting our unique Native epistemological and ontological orientation to the world changes indigenous scholarly practice which in effect transforms how indigenous scholars think (Dunbar, 2008). Such action moves us to 'telling stories in the field as opposed to telling Van Maanen's (1990) stories of the field,"(Dunbar, 2008). In our relational sense of being and understanding, we are moving the ways of knowing and what is known to the forefront, thus honoring and respecting our indigenous worldviews and philosophies.

Both the liberating potential and traditional use of storytelling, as a research technique, intervention, and a source of community knowledge, intersect through stories as people make sense of themselves and their world. Additionally, through storytelling, parallel life experiences are shared among community members which creates a common experience and reference point of understanding (Inglebret et al., 2008), that supports the community's sense of cohesiveness and contributes to change.

STORYTELLING IN THE DIGITAL ERA

Digital storytelling holds promise for helping communities and individuals change while employing traditional ways of knowing.

Traditional Storytelling in the Digital Era

In our current era, we can access information rapidly and digitally. There are multiple definitions for digital storytelling. Digital storytelling and indigenous digital storytelling have been used as documentaries (Iseke & Moore, 2011). For the purpose of this article, digital storytelling will be defined as a short 3 to 5 minute visual narrative replete with still images, video, text, and audio recordings that shares a compelling story (Gubrium, 2009), which is often based upon a lived experience-although not always. Although there is no data yet on how many people use digital media, we know from an online survey of K-12 teachers (N=500) that 91% use some form of digital media, in place of DVDs or TVs, on a regular basis for instructional use (Public Broadcasting Service LearningMedia, 2012). This signifies the power and importance digital media has gained. Some recognize digital storytelling as a form of participatory visual research, cousins to picturevoice, or photovoice (Lorenz & Kolb, 2009), and it has increasingly been used for social justice (Blue Bird Jernigan, Salvatore, Styne, & Winkleby, 2011; Toussaint, Villagrana, Mora-Torres, de Leon, & Haughey, 2011). Short video quips that evoke an emotional response hold potential for inspiring change. The therapeutic value in sharing stories with an audience has been noted through various health-focused studies. Digital storytelling has been used by patients to educate other patients (Iredale et al., 2011) and health care providers (Anderson, 1998; Banks-Wallace, 1999; Christiansen, 2011; Hunter, 2008; Kirkpatrick et al., 1997; Schwartz & Abbott, 2007) about the illness experience, to demonstrate the humanness behind a disease (Kirkpatrick et al., 1997), and to inspire individual (Chin, 2004; Sandars & Murray, 2009) and institutional changes (Blue Bird Jernigan et al., 2011; Stacey & Hardy, 2011).

Digital storytelling has some limitations. For youth who used digital storytelling to share feelings and personal stories of illness online, there was concern for online safety, the audience's reaction to the story, and the potential for the storyteller experiencing embarrassment about their story being shared (Yu, Taverner, & Madden, 2011). There appears to be potential for misunderstanding of the participant's intended message when sharing their completed digital work, and backlash from the audience regarding the content and/or message. Knowledge that the digital footage will be shared with a wide audience may impact the participant's storyline and images. Additionally, the community may raise concerns of the digital content,

Despite these concerns, digital storytelling has consistently been shown to spark introspection, raise awareness, and evoke change. But these changes are largely reflective of the dominant socio-cultural Western world, facilitating change among individuals but not communities. How can digital storytelling foster change among those who have been historically colonized and continually marginalized?

Digital Storytelling as Emancipatory

Like its mother, traditional oral storytelling, digital storytelling can foster liberation from the dominant socio-cultural world that continues to marginalize the marginalized. By creating the digital story, the storyteller has control over what is important to tell. African American youth have used digital storytelling in school as a literacy method to showcase their experiences in producing stories that reflected their home speech communities and values (Hall, 2011). In this example, youth found digital storytelling to re-center their

racial and gendered selves, allowing placement of their story in the forefront of knowledge and experience, pushing the discursive classroom boundaries to establish their own space of meaning and experience.

As a collaborative project, digital storytelling can inspire change among multiple layers connected to the story. Skouge and Rao (2010) found that for small rural diverse Pacific island communities, digital storytelling was transformative for the subject of the story, those who work on digital production, and the audience. In their digital story of a young wheel chair bound college woman's limited access to her dorm and campus, it was noted that all involved working on the digital story were affected through the process of creating the digital story, and that problem solving was facilitated (Skouge & Rao, 2010). These experiences with digital storytelling demonstrates that the process of creating the digital story can incite change among involved for the good of the story subject. Likewise, a collaborative research project with a rural California tribe used digital storytelling to identify problems to healthy food security (Blue Bird Jernigan et al., 2011). After showing digital stories to demonstrate the lack of low cost healthy food options to the community and key stakeholders, institutional changes were introduced (e.g. expanded fresh produce options at the market, installing electronic benefit transfer machines at the local farmer's market, and introducing food choices targeting people with diabetes), which promoted changes in individual shopping habits. In this study, changing community norms and raising awareness were viewed as viable options for supporting improved individual health behaviors.

Currently, there are ongoing American Indian centered digital storytelling efforts on both local and national levels. Locally, the woman-owned, indigenous-focused consulting and digital storytelling company nDigiDreams LLC (www.ndigidreams.com/about.html) has collaborated with tribes, tribal colleges, state universities, non-profits, national organizations, small rural communities and individuals to focus on health, education, policy and cultural preservation (nDigiDreams, 2012a, 2012b). Northern Arizona University (http://nativedigitalstorytelling.blogspot.com/) has pursued an interdisciplinary and intergenerational project pairing elders with youth to created digital memories of how their culture is tied to the land in their project entitled, "Intergenerational Native Digital Storytelling Project," (Piner, 2011). The National Library of Medicine has sponsored "Native Voices: Native People's Concepts of Health and Illness" (http://www.nlm.nih.gov/nativevoices/) which is a myriad of short digital clips, images, interactive pages, and text to explore the interconnectedness of wellness, illness, and cultural life for those indigenous people living in the United States (U. S. National Library of Medicine, 2012) Funding opportunities for these programs are largely private grant based resources focusing on cultural preservation, though as digital storytelling gains popularity, it is conceivable that funding opportunities will broaden.

The very nature of digital storytelling, telling a story though use of digital media, lends itself to provoking deep reflection, which may lead to a transformative action. Research has found that reflection and action have been elicited from not just the audience, but those who work on the story production in addition to the subject of the story (Skouge & Rao, 2010). Digital storytelling, like oral traditional

storytelling, is transformative and has a place in the future for generating change not just on a community level, but also on a global level.

Digital Storytelling's Usefulness for Research with Native Populations

While the format benefits from our advancing technology and the audience grows wider (even global), digital storytelling is rooted within our enduring storytelling tradition. Most of the research on digital storytelling has demonstrated its ability to honor the individual's story; however, recent work on food security within an American Indian community has illustrated how the community's voice can be heard (Blue Bird Jernigan et al., 2011). While modifying the community as a whole was posited by the study as likely to facilitate individual behavior changes (Blue Bird Jernigan et al., 2011), recognition of the community's influence in individual health behavior changes both demonstrates the keen understanding of American Indian culture, but also the flexibility digital storytelling encompasses. More than one truth is attainable. In the above example, the community's truth and experience were sought. Both the multiple truths possible, dependent upon the digital storyteller's point of view, and the ability to give voice, parallel American Indian values of respecting one's voice (and not speaking for someone) and the possibility for multiple true views.

Digital storytelling provides ample space for both individual and communal voice. For both the individual and community, digital storytelling allows the story to unfold in such a way that the audience is drawn into the story. The story-maker, using their lived experience to demonstrate a point or share a meaning, calls upon a shared understanding to demonstrate their point to their audience. The audience in turn has the potential to connect with the story. This delicate dance between the storyteller and the listener demonstrates how digital storytelling draws upon a relational and interconnected sense of understanding and being, reflective of the American Indian philosophical worldview. However, there is potential that the audience, grounded in their own cultural context, may not understand the message, or the importance of the varied layers of understanding within the story. Iseke and Moore's (2011) collaborative work on indigenous digital storytelling with First Nation Canadian communities has yielded practical insight into the challenges related to editing the community's voice (by way of editing the digital story), to fit a finite time limit, and to pare down the story so that it is more universally understood. Competing concerns on behalf of the community, investigators, and mainstream funding agencies, can be tricky to negotiate and careful consideration must be taken to ensure success.

Digital storytelling, like the American Indian orientation to time, is process oriented. Researchers have pointed out that the creative process behind digital production is just as or more important than the empathy and understanding culled from the audience reveal (Skouge & Rao, 2010). Moving through the world with the cultural/philosophical view that one is being, always on a path to becoming, mirrors the deep reflective journey one takes in creating the digital story. One must have a compelling meaning or story to share and one must engage in self-editing as images, music and words are carefully chosen to represent a specific idea. The digital storytelling production journey is also a journey of being and becom-

ing, of understanding and changing.

DISCUSSION AND IMPLICATIONS

Storytelling in the digital era incorporates some aspects of traditional oral storytelling, including an oral narration. Rather than relying upon the images conjured from one's imagination, the storyteller directs the audience's attention to those images and sounds selected, thereby narrowing the field of relation. One's attention is held captive by the audio and visual content at hand. Digital storytelling is challenged by the time and cost taken to produce a story that can be retold in the same manner, rather than an ever-changing oral story that can be immediately changed according to the audience's needs. Although the digital story is malleable, depending upon the resources, it is more fixed in time compared to oral stories. It is unclear if this more static aspect of digital storytelling affects the potential for teaching and inspiring change. However, the degree of accessing a digital story far exceeds that of oral stories in light of immediate forums for posting digital media (e.g. YouTube) and the various programs in process of helping individuals and communities create stories (e.g. nDigiDreams,(nDigiDreams, 2012a) Native Voices,(U. S. National Library of Medicine, 2012) and Intergenerational Native Digital Storytelling Project (Piner, 2011). Although the audience is limited to those who have access to online forums, as people join the online community there is a sense of a globalized online community. Whether or not this community is cohesive has yet to be demonstrated. However, as Iseke and Moore (2011) warn, wider access to indigenous digital stories and the Euro-American cultural milieu surrounding digital storytelling, places pressure upon Native storytellers to conform a non-Native story structure (e.g. telling a story with a more direct message) that changes the uniqueness found in Native storytelling.

There is a potential for great abuse in telling a story. There are significant concerns regarding the content of the story, authenticity, whose voice is privileged, and who it will be shared with. Digital media has the power to capture what words may fail to express and actions that are incredible. For example, the voice of the storyteller who chooses to showcase illicit adolescent substance use in a small community may provoke a strong negative reaction from the community who risks a damaging reputation and public consequences for a community wrought with problems. The issues of whose voice prevails in the story, and how the story is told and unfolds will need to be addressed. It is uncertain if this vital dialogue will take place and how it will be enforced. Today as in yesterday, there are unspoken, but known "community copyright" materials. Certain songs or stories (often from divine origin) are bequeathed to individuals and families who then entrust their gift to trusted family members. While it is unlikely that tribes or families who "own-the-right-to-share" a song or story in public settings will legally pursue copyright infringement, awareness must be raised among those who are unaware of this generally unspoken rule, so that the community and families are respected. As technology moves the role of storyteller upon anyone who has the means to craft a digital story, the ability to vet stories that are represented as true may diminish. The sheer volume of stories, the way it is crafted, and the inability to access resources to document authenticity are potential obstacles preventing corroboration. Finally, some stories are not meant for the wider public, but are held in trust for sacred ceremonies or special

gatherings, this is an issue of trespassing across sacred cultural knowledge. Often this is to protect the audience who may not understand the implications and power behind the words or songs, and it is a breach of faith, trust and respect for these stories and songs to be used outside of their prescribed time and setting.

The process of digital storytelling mirrors the American Indian worldview of being and becoming. As Skouge and Rao (2010) have found, the process of digital storytelling is just as important as the outcome, for people change through the very process of creating the product. This process, similar to oral storytelling, echoes the relational, interconnected American Indian worldview. Connections to people and environment are made through the process of piecing together the story. One sees the photo images, one can see the digital footage, one can hear the careful worlds selected for the story's narrator, and one can integrate all of this information into their understanding, making connections to the images, spoken words and message.

Digital storytelling advances the health sciences for Native and non-Native researchers and Native communities seeking to link with academic partners by identifying a culturally congruent method and intervention that may prove successful in improving some American Indian health needs. In addition, digital storytelling provides a route, rooted in traditional oral storytelling that legitimizes an American Indian epistemological and ontological view of the world. Iseke and Moore (2011) point out that telling the community's story helps in, "negotiating social priorities and contemporary needs, expresses community viewpoints, and safeguards community values and norms," all the while facilitating communal understand of their political issues, affirming connection to their First Nation culture and legitimizing their indigenous knowledge (p. 21).

Both ethical and methodological considerations remain. The focus of this article is on the use of digital storytelling as a research approach and intervention for improving American Indian health concerns. The American Indian community may show concern in the digital story's content, as the reoccurring exploitive history is fresh in their communal consciousness. Reactions from the surrounding non-Native communities are likewise a concern emanating from the American Indian community. It is unclear what the ramifications are for Native communities, but history has shown that research has the potential for exploitation. Investigators must continue to practice sensitively, and understand that negative aspects (e.g. substance use) of the community may surface in the story. Investigators, both Native and non-Native, may find their work halted or indefinitely postponed, and their collaborative research relationships in jeopardy in these situations. In an effort to nurture the community partnerships, it will be essential that investigators facilitate a conversation with their partnering community on these more challenging prospective detrimental aspects, and provisions may be made in the researcher's community collaborative agreement. Community oversight is warranted when editing digital stories, for the community must live with the consequences. Further research is needed to determine the impact of digital storytelling on improving American Indian health and wellbeing. As a research approach that is culturally aligned to Native oral traditions, digital storytelling holds potential for great success. There is the issue of which health concerns are better suited for digital storytelling.

Finally, using digital storytelling as a research approach for collecting data will require additional logistical and scientific contemplation. It is unclear if some health concerns are better suited for digital storytelling than others. Little has been voiced in the health care literature as to the process of creating a digital story among individuals, groups and communities. Additionally, the costs versus benefits and methods for evaluation have likewise not very well addressed.

CONCLUSION

The health of our indigenous American Indian communities is out of balance. We must look to our cultural heritage and ancestors for ways to help heal the disharmony within our communities. Drawing upon the knowledge stored in our oral traditions and understanding the storytelling method is critical to secure our community's wellness. With rapid technological advancement, digital storytelling offers a complementary method for us to make our own. Our traditional storytelling methods can be adapted to the digital era. Through digital storytelling we can give privilege to our knowledge and experiences. Uploading our insight onto online forums can help educate the larger world of our health needs and strengths, but can also facilitate growing awareness within our community through the process of creating the digital story. Drawing upon our indigenous heritage, in this postmodern/critical theory era, the time is ripe for us to pick from our indigenous epistemologies the tools from which to foster wellness and healing among our communities. Lying dormant in the cupboard, waiting for the right season, right night, right situation, right time, is one of our most treasured tools- storytelling. The time is now, the present, in our being and as we are becoming, to gather our stories and learn ways to enhance wellness within our communities. Let us encourage our communities, while poking around in the cupboard, to pick up that old cell phone, the video camera and grandma's photo album and get to work on their digital story.

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About the Author

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A Perspective on Diabetes from Indigenous Views

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ABSTRACT:
Six elders, representing six different indigenous cultures, three of whom have academic appointments, were asked to provide their perspectives on diabetes addressing etiology, risk factors, increasing prevalence and co-morbidities. The rapid increase of this chronic disease has impacted the systems of care and financial management within Indian Health Service, the United States healthcare system established for federally-recognized American Indians and Alaska Natives. Indigenous people of North America not only have the highest incidence of diabetes in the world but also are experiencing early disease onset with rates increasing in those < 18 years of age. Giving voice to the very people affected by this disease is critical to develop a culturally relevant solution. Using a storytelling method and qualitative analysis, four themes emerged from the elders' perspectives: a) before contact with Europeans, diabetes was not found among the indigenous peoples; b) outside influence on food choices and activity patterns have been major factors in the rise of diabetes; c) disconnection from cultural roots yielding a state of imbalance or loss of harmony is manifest in negative health outcomes, such as wide-spread diabetes; and d) hope that a solution lies in the core values and knowledge of indigenous cultures. These narratives and themes can be used to guide the practice of non-indigenous health care providers working with indigenous people.

Introduction

Type 2 diabetes, a devastating chronic disease, has reached a crisis level of concern for indigenous families in the United States and their healthcare providers within the Indian Health Service (IHS) healthcare system. O'Connell, Wilson, Manson, and Acton (2012) reported that "approximately 1 of every 3 IHS dollars spent on treatment was for services for adults with diabetes" (p. 304). Diabetes contributes to life-long disabling conditions such as neuropathy followed by amputation, retinopathy, end-stage renal disease, stroke, heart attack, and poor wound healing. The epidemic rates of diabetes and these co-morbidities among the indigenous peoples of North America, known federally as American Indians/Alaska Natives (AI/ANs), yield a substantial financial burden to the IHS, Medicaid, and Medicare (Indian Health Service [IHS], 2010). In addition, co-morbidities among AI/AN elders are also a growing concern due to the need for increased hospitalization, doctor visits, medication and 24-hour care (Goins & Pilkerton, 2010). The director of Indian Health Service, Dr. Yvette Roubideaux (2002) asserts:

> *American Indians and Alaska Natives continue to experience significant dispari-*

[1] Navajo, Northern Arizona University; [2] Navajo, Retired Applied Indigenous Studies Department Northern Arizona University, [3] Mayan, Resident Elder, Applied Indigenous Studies Department, Northern Arizona University; [4] Hopi, Resident Elder, Applied Indigenous Studies Department, Northern Arizona University; [5] Oglala Lakota, Assistant Professor, Dental Hygiene Department, Northern Arizona University; [6] Yaqui, Professor Applied Indigenous Studies Department, Northern Arizona University; [7] Mississippi Choctaw, Assistant Professor, Applied Indigenous Studies Department, Northern Arizona University; [8] Associate Professor, Mel and Enid Zuckerman College of Public Health, University of Arizona; [9] Assistant Professor, Health Sciences Department, Northern Arizona University; [10] Chair and Associate Professor, Health Sciences Department, Northern Arizona University

ties in health status compared with the US general population and now are facing the new challenges of rising rates of chronic diseases. The Indian health system continues to try to meet the federal trust responsibility to provide health care for American Indians and Alaska Native despite significant shortfalls in funding, resources, and staff. New approaches to these Indian health challenges, including a greater focus on public health, community-based interventions, and tribal management of health programs, provide hope that the health of Indian communities will improve in the near future. (p. 1401).

The U.S. Department of Health and Human Services, Office of Minority Health (2010) reports AI/ANs are 2 times more likely to have type 2 diabetes and die from diabetic complications than are non-Hispanic whites. See Tables 1, 2, and 3 from the Office of Minority Health (2010 with secondary citations noted (Barnes, Adams, Powell-Griner, 2010; Schiller, Lucas, Ward, & Peregoy, 2012; Kochanek, Xu, Murphy, Miniño, & Kung, 2011).

Table 1. Age-Adjusted percentages of persons 18 years of age and over with diabetes, 2004-2008

	American Indian/Alaska Native	White	American Indian/Alaska Native to White Ratio
Men and Women	17.5	6.6	2.7
Men	18.2	7.2	2.5
Women	16.2	6.2	2.6

Source: Barnes, P.M., Adams, P.F., & Powell-Griner, E. (2005), as cited by the U.S. Department of Health and Human Services, Office of Minority Health. (2010).

Table 2. Age-Adjusted percentages of persons 18 years of age and over with diabetes, 2010 (National Health Interview survey, NHIS)

American Indian/Native American	Non-Hispanic White	American Indian/Native American to Non-Hispanic White Ratio
16.3	7.6	2.1

Source: Schiller, J.S., Lucas, J.W., Ward, B.W., & Peregoy, J.A. (2012), as cited by the U.S. Department of Health and Human Services, Office of Minority Health. (2010).

Education and promotion of healthy choices, such as regular exercise and consumption of whole-grain products, vegetables, fruits, and low-fat milk and meat products are needed to avoid this life-long chronic disease (Tuomilehto, Lindstrom, Eriksson, et al., 2001). In addition, environmental change to support healthy choices in indigenous communities needs to be addressed such as building *walkable* residential areas and walking trails that incorporate level surfaces and lighting to promote regular, safe physical activity. Cultural perceptions and understanding of the onset, progression and impact of a disease should direct the design, implementation, and evaluation of prevention activities within indigenous communities (Teufel-Shone, 2006). In North America, 565 Indian nations are federally recognized (U.S. Department of Interior, 2010a, 2010b). Each of these nations represents more than 500 tribal cultures, languages, traditional customs, and beliefs. To enhance the quality of life for individuals at risk for and diagnosed with diabetes and co-morbidities involves community commitment and resources, culturally relevant health promotion education, and respect for cultural explanations of the disease process within each tribal culture.

Table 3. Age-Adjusted Diabetes Death Rates per 1000,000 (2009)

American Indian/Alaska Native	Non-Hispanic White	American Indian/Alaska Native to Non-Hispanic White Ratio
34.0	18.4	1.8

Source: Kochanek, K.D., Xu, J., Murphy, S.L., Minino, A.M., & Kung, H-C. (2011), as cited by the U.S. Department of Health and Human Services, Office of Minority Health (2010).

Identifying how various Native American cultures explain the onset and course of diabetes is an important first step in developing appropriate strategies to mitigate the disease and its impact on indigenous peoples. To provide the context to culturally grounded explanations of diabetes requires an understanding of the impact of historical contact with Euro-Americans on contemporary adjustment of lifestyles, including food access, food choices, and activity patterns among indigenous people. Clearly, the development and much needed prevention and treatment of diabetes are complex processes that involve individual, family, and community behaviors. Understanding how indigenous people fit the progression and symptoms of diabetes into their worldview of the natural life course of change and balance can inform ethical practices for both clinicians and public health practitioners working with native peoples. Within many cultures, one role of the "elder" is to relate and preserve the traditional ways of thinking.

Methodology

The Applied Indigenous Studies (AIS) with Northern Arizona University utilizes traditional knowledge scholars in classroom oral teaching (Trujillo, 2011). This paper is a documentation of oral traditional knowledge that AIS Department have used throughout the years (Trujillo, 2011). The AIS traditional knowledge scholars (Ms. Maybelle Little,

Mr. Bob Lomadafkie, and Ms. Maria Marina Vasquez) with AIS faculty (Dr. Octaviana V. Trujillo and Dr. Karen Jarratt-Snider) and Dental Hygiene faculty (Ms. Maxine Brings Him Back-Janis) discussed traditional oral concepts of diabetes. The discussions with elders and faculty took place from October 2009 to January 2010. The co-authors chose a phenomenological approach from key informants' lived experiences of diabetes in an oral and written storytelling format. The key informants agreed to provide culturally informed explanation of diabetes and its impact from their perspective. The key informants' perceptions were purposefully informal to facilitate their writing and telling their stories from their perspective (Hodge, Maliski, Codogan, Itty, & Cardoza, 2010). Subsequently, the stories are provided with minimally editing to allow the word choices, relationships and thoughts of the elder to emerge. Some concepts may appear to conflict with Euro-American medical perspectives but this discordance is critical to understanding misunderstandings and unclear communication between non-native providers and native patients.

Procedure

Initial contact was made by the lead co-author with Northern Arizona University's traditional knowledge scholars and Native American faculty with Applied Indigenous Studies and Dental Hygiene. Faculty enrolled in six different indigenous nations: Diné, Hopi, Mayan, Oglala Lakota, Yoeme (Yaqui), and Choctaw, agreed to participate. Next, the lead co-author conducted follow-up meetings, telephone calls, and email messages to lead a dialogue about how diabetes is perceived in their respective cultures. Each of the elders and faculty members were asked to write their perspective about diabetes. An invitation was sent to elders and faculty members about the availability of Wiki to add their writing and to view the progress of co-authors work.

Participants

Participants were recruited as elders and faculty members affiliated with Northern Arizona University in the Applied Indigenous Studies Department and Dental Hygiene Department.

Data Review

Three of the co-authors (Sanderson, Teufel-Shone, and Bounds) reviewed the written stories. Based upon this review, themes were identified by consensus among the co-authors (Teufel-Shone, Irwin, Siyuja, & Watahomigie, 2006).

Results

Demographic characteristics

One male and five females submitted their perspectives in writing. The age range of the 6 participants was 52-79 years of age (mean age was 63 years). Of the six, four were raised in reservation or indigenous communities and two were raised in an urban setting. All reported being raised traditionally; four reported being fluent or semi-fluent speakers of their traditional language, and five reported siblings or parents with diabetes often suffering secondary complications, e.g. renal failure and amputation. One elder reported having "borderline diabetes."

Background: Diabetes on the Navajo Nation

The federally recognized Navajo Nation is the largest American Indian reservation in the U.S., encompassing 27,000 square miles across parts of three states: Arizona, Utah, and New Mexico, with a population of over 250,000 enrolled members (Navajo Nation, 2011). The Diné (Navajo) people are believed to have migrated into the southwestern U.S. approximately 1,000 years ago. In the mid-19th century, the U.S. cavalry forced many of the Diné from their lands on "The Long Walk" to Fort Sumner in New Mexico. Many Diné died en route and during the four-year imprisonment. After the 1868 treaty with the U.S., the Diné returned to their land, and today, they continue agricultural and shepherding practices commensurate with the desert environment of the Southwest (Indian Health Service [IHS], n.d.].

Diabetes is a significant problem on the Navajo reservation. In a comparison of diabetes prevalence among indigenous peoples worldwide, Yu and Zinman (2007) reported a Navajo diabetes mellitus prevalence of 16.5%, higher than that among the Pima of Mexico, but lower than the prevalence of diabetes among tribes in the Dakotas, Oklahoma, or southern Arizona. One study of Navajo adults 45 years of age and older, however, found 40% of participants with diabetes (Will et al., 1997). Navajo youth are also at risk: in 2001, a study of 15- to 19-year-olds identified one in every 359 Navajo youths with diabetes (Dabelea, DeGroat, Sorrelman, et al., 2009).

One of the critical components of reducing diabetes and co-morbid conditions in Diné communities and among other tribes is addressing economic disparity. In her address to the Committee on Senate Affairs, Dr. Melvina McCabe, President of the Association of American Indian Physicians, challenged Congress to consider the influence of the structural environment on diabetes:"Without electricity, how do we store our insulin appropriately, how do we store healthy foods such as fresh vegetables, fruits, eggs, milk. In Indian country, canned goods can be a staple because of the lack of electricity" (McCabe, 2010, para 17).

Bah Ray, Holben, and Holcomb (2012) defined *food security* as "ready availability of nutritionally adequate and safe foods for all people" (p. 93). In their sample, 43.2% of Navajo women were living at some level of food insecurity and this status was associated with increased rates of diabetes. Echoing the message of Dr. McCabe, these authors argue for improved economic conditions, including access to and affordability of healthy foods, as an essential means to reduce the diabetes epidemic (Bah Ray et al., 2012).

Storytelling: Dine' (Navajo) Perspective, Ms. Maybelle Little

> *There are two sides to Dine' Ways of Knowing -- on a beautiful safe side of the (now) Glittering World and the Dark World of Negativity. Strictness is involved with warnings about wrongdoings; taboos must be followed for prevention of serious life-threatening illnesses and errors due to misbehavior. Individuals must be aware of Powerful Foreboding Forces (from the Dark World) that deal with illnesses and other negative actions and event in the Glittering World. During Creation Times, Four Monsters: Hunger, Poverty, Diseases, and Old Age symbolized by decrepit Females, were allowed to live; each Monster begged the Warrior Twins for their lives because each Female promised to teach generations of learners how to prevent their living ways*

from what we know as the sad and sick human condition(s) that afflict populations today. The Four Monsters taught taboos to be heeded: During Creation Times, Four Monsters: Hunger, Poverty, Diseases, and Old Age symbolized by decrepit Females, were allowed to live; each Monster begged the Warrior. Using the example of diabetes –

1. ***Hunger** would result if individuals became lazy and did not take care of their field crops on Earth. This part of the food taboo refers to the behavior of over indulgence in foods and lack of exercise. We are taught that there are healthy foods to be had; but we do not search for these foods and we do not exercise our bodies to prepare for fieldwork like we should.*

2. ***Poverty** would surely follow if no one cared for and respected Ways of Knowing for success in the immediate earthly environment. If ailing diabetics do not follow the teachings of Ways of Knowing dealing with healthy thinking, poverty will issue its affects -- medical costs, food costs and ill feelings that attack the body.*

3. ***Diseases** that affect Perfect Health, the non-visible Sexual Transmitted Disease (STD) types appear as the price to pay for over-indulgence in human misconduct. The obvious illness caused by diabetes seems to flare-up with deep-seated negative eating habits of daily food intake – taking too much of one nutrient and too much of others (some that may have no food value).*

4. ***Old Age** is a part of Life that no one can overcome; however, it can be a Gift of Life if this Power is used in positive ways according to the Dine'. Today's physical ailments most likely are viewed as something that is bothering the human thinking capacity and could be due to negative thoughts and fears of the individual or other sources of negativity. Dine' healers and diagnosticians may be called upon to try to find the cause of physical ailments. Healers and diagnosticians are costly for their assistance with health problems. These Dine' healers try to return to the state of harmonious understanding Life Ways for the patient and his/her state of mind.*

Background: Diabetes on the Hopi Nation

The Hopi Nation is a federally recognized sovereign nation, occupying approximately 2.3 thousand square miles in northeastern Arizona (Hopi Tribe, 2010). The indigenous population of the Hopi Nation is 6,943 (Arizona Department of Health Services, 2012).

The Hopi people are descended from the Puebloan culture of the Southwestern desert. Farming continues to be an essential part of life, both practical and spiritual, especially the cultivation of corn. "The Hopi way of life is the corn -- humility, cooperation, respect, and universal earth stewardship" (Hopi Cultural Preservation Office, 2009b). Although garden plots belong to the Hopi women, the entire family works them, planting vegetables and fruits, including corn, squash, and melons. This provides an opportunity to connect in multiple ways with Hopi children: "as one

Hopi gardener said, 'This is not about growing vegetables; it is about growing kids'" (Hopi Cultural Preservation Office, 2009a). It also sustains family, culture, and community. By educating school children and community groups, the Hopi Office of Range Management/Land Operations strengthens traditional understandings and uses of native plants, as well as protecting the wild plants from mismanagement and loss (Flora, Livingston, Honyestewa, & Koiyaquaptewa, 2009).

Since the appearance of commodity foods and the adoption of more sedentary lifestyles, obesity has become epidemic on the Hopi Nation. In a study of this trend, Eisenmann, Arnall, Kanuho, and McArel (2003) found that 47% of Hopi school children were either overweight or obese. Since traditionalism in Hopi people has been found protective against health risks and chronic disease (Coe et al., 2010), it seems critical that Hopi children learn how to return to the traditions that have kept the Hopi people healthy.

Storytelling: Hopi Perspective, Mr. Bob Lomadafkie

> *A different Indigenous lifestyle was practiced before white man came to this continent. Eating three meals a day (breakfast, lunch, and dinner) with huge food portions on each plate are behaviors of a post-contact environment. However, some traditional cultural lifestyles have continued and some have diminished due to outside influences. Presently, Indigenous Nations are bringing back traditional lifestyles that have not been practiced for many years. These behaviors and beliefs include awareness of physical exercises like running, walking, and addressing poor diet and nutrition. For example, in the old days, the Hopi people would run up the cliffs and this practice is being revitalized in contemporary times. In addition, feasting after harvest continues to be a celebration for villagers. This brings together people for this cultural event, sharing the moment, belief system and social gathering. Contemporary Hopi people are also eating more "greens" like vegetables (brussels sprouts, lettuce) and less prepared foods (microwave frozen meals, McDonald's Restaurants) and red meat (steaks). To be diagnosed with pre-diabetes or diabetes, is challenging but with family and community support, the person diagnosed with diabetes is there for their family to offer strength and foundation for current and future generations. The first convenience store in Hopiland was a trading post. The trading post sold white flour, sugar, and Spam®. Spam is a local favorite. However, no fresh vegetables and fruits were sold to local people. Hopi families had to travel many miles to Winslow or Flagstaff, Arizona to shop for fresh vegetables and fruits.*

Background: Guatemala's Maya Population

Guatemala is a Central American country adjacent to Mexico, Belize, Honduras, and El Salvador, and encompasses approximately 42,000 square miles. Over half of the population is comprised of indigenous descendants of the Maya who live primarily in rural regions of the country, and at least 24 indigenous languages are still spoken, such as K'iché and Mam (U.S. Department of State, 2012).

Our indigenous elder providing the Mayan perspective, Ms. Maria Marina Vasquez, hails from the western highlands near Huehuetena-

go. Knowing something of her land of origin is particularly important in the context of understanding diabetes and other health challenges of the Mayan people. Guatemala's civil war (1960-1996) disrupted and sometimes annihilated entire communities, often in the highland regions. More than 200,000 Guatemalans, mostly indigenous civilians, were massacred or 'disappeared,' and tens of thousands more suffered torture. Reparations for injustices have begun, but remain incomplete (Amnesty International, 2009).

Guatemala's public health system, too, was disrupted during these years, and adequate national health surveillance data for indigenous people are still lacking. For example, in a study of diabetes and other chronic diseases in Guatemala, indigenous people comprised only 2% of the sample population, though most others were of mixed race. Overall, the prevalence of diabetes in this sample was 24.5% of the population over 20 years of age (Pan American Health Organization [PAHO], 2007). In a later sample of residents of metropolitan Guatemala City, however, the prevalence of diabetes among those over 19 years old was 7.3%, but information on indigenous ancestry was not noted (Barcelo et al., 2012). The collection and report of diabetes prevalence among indigenous populations remains a significant omission from surveillance efforts, and yet it is a key to diabetes prevention and care.

Migration as a means of escaping the violence of the war in Guatemala has also indirectly increased the risk for diabetes among Mayan populations. A comparison of rural Mayan and Maya-American children, for example, suggested that the health of these second-generation immigrants to the U.S. improved overall. Health behaviors adopted by Maya-Americans in the U.S., however, has resulted in significant increases in overweight and obesity, putting them at a higher risk for diabetes than their Guatemalan counterparts (Smith, Bogin, Varela-Silva, Orden, & Loucky, 2002).

Storytelling: Mayan Perspective, Ms. Maria Marina Vasquez

The belief is that diabetes came after contact with the Europeans more than 500 years ago. Before contact with Europeans, Indigenous peoples did not have diabetes. There is an interest by this co-author of finding out what type 1 and 2 diabetes are that western medicine has been researching for many years. There is no cure that has been found for diabetes type 1 and 2. After many generations of Mayan people eating refined foods introduced by Europeans, the belief is that many Mayans are diagnosed with diabetes that result from genetic defects, accidents, or psychological trauma. Presently, many Mayan people are diagnosed with type 2 diabetes due to their modern-day lifestyles. This disease contributes to historical trauma that Mayan people experience from forced assimilation to European lifestyles.

In the old days, Mayan people had a very different eating habits and nutrition than what they eat presently. They ate more healthy foods like: wild berries, wild game, cactus and wild greens to supplement their diets. Perhaps the Indigenous peoples of this land used the appropriate technology (using what was available in their area) for their survival and well being. They had to run after wild game for protein and at the same time they were exercising their

body. They had to eat simple meals during season changes from fall to winter, and would eat less portions of food to ensure that food was prolonged in storage. Presently, this is not what is happening. However, food always has been the center of social events and continues in modern kitchens (refrigerator, stove, cupboards, dishes). In the old days, there were no refined sugar to be used for coffee, tea, or preparing desserts to satisfy their sweet tooth. The Mayan people used honey and wild berries to help make their food taste better with natural sweetness. After contact with the Europeans, there was a cultural shift, which introduced white flour, sugar cane, grapes (uvas) and alcohol to Indigenous peoples. This resulted in new sweets and changed their eating habits, from wild game to canned meat and powder potatoes that are eaten today. This includes lack of exercise. Presently, there is high stress related to living in two worlds (white and Indigenous ways) and training to get all of the commodities of today. Globalization has contaminated the remote towns of this co-author's beloved country. The Mayan medical history and tradition will be discussed next.

Before the arrival of the Conquistadors in the beginning of the 16th century there were two general forms and levels of Indigenous medicine: elite healers or popular medicine and Shamanism. Popular medicine was reserved for the practices of studied elites. Once the elites reached the level of highly trained healers they formed part of the social class, which had access to the written word, and the systematized information of the Mayan people. They were then able to train the popular masses. The medicine that they used had a great deal to do with astrology because it was important to the healer to know facts about the patient based on his or her astrological alignment such as the person's date of birth which had a great influence on the rest of his/her life and propensity towards particular patterns of diseases.

The knowledge of astrology, writing, herbology and surgical techniques are a few examples of the kinds of specialize information that the patient could receive from the elite healer. One of the popular levels of knowledge was less specialized and less systematic, though it was inscribed by the same cosmo vision and understanding of health and disease as the elite medicine. The most popular tradition was the herbal and ritual medicines, which confirmed the relationship of personal health to the agricultural cycle and natural and supernatural forces. The popular understanding and practices have remained firmly imbedded in the traditions of Mayan people. They were preserved and assimilated with concepts and practices from the colonial Spanish medicine (new medicinal plants from Europe). Like many cultural systems, traditional medicine has undergone constant changes. As traditional ways of knowing encounter new factors, new ways of knowing replace ancient Maya concepts with concepts and words from European colonization or from modern medicine incorporating them into the Cosmo vision. For example, Mayan illnesses can be classified into four groups: (1) Organic illness, (2) Illness produced by contact with other people, (3) Illness of divine origin brought about by supernatural forces, and (4) Illness related to the individual's astrology [the role of destiny].

In general, Mayan people across Latin America know that traditional and indigenous medicine comes closer to a complete view of illness, integrating social, cultural, and psychological and historical factors; at the same time, developing and understanding the patterns of particular diseases. The Mayan people had wisdom and understanding of health, healing and the appropriate technology to eat healthy until the European contact and eventual colonization of the Indigenous people to the new world. Perhaps if this is taken care of now, this disease will not be an issue for the next generations. The next generations can go back to eating healthy foods like Mayan ancestors. As a Mayan woman from the Highlands of Huehuetenango Guatemala, this co-author has seen in her family the eating habits of today. Since moving to the outskirts of the city, for the past 50 years, the co-author's family has been diagnosed with diabetes. The co-author's four family members believe their diabetes resulted from a specific trauma that has happened to each of them. Western medicine diagnosed them with diabetes within a couple of months after their specific trauma. They believed that their use of refined foods has also contributed to diabetes. As a recommendation to help prevent diabetes is eating pinto beans, nopales or prickly pear cactus pads and tunas or prickly pear cactus fruits. The co-author drinks this beverage a couple times a month to avoid this disease: pineapple, celery, and fruit.

Background: The Oglala Lakota Tribe of the Great Plains

The Sioux or Lakota people is actually composed of multiple bands, such as the Oglala Lakota. Prior to the westward expansion of Euro-Americans, the Lakota inhabited large areas of the Great Plains. Like other indigenous people, the Lakota suffered violence and massacre, possibly the most notorious of these, the Wounded Knee Massacre, a consequence of gross cultural misunderstanding and the U.S. cavalry's attempt to disarm and subjugate the tribe. The Lakota were forced to move north, and most of the 70,000 registered Lakota today inhabit reservations primarily in North and South Dakota, the largest of which is the Oglala Sioux Pine Ridge Reservation (American Indian Heritage Foundation, 2012).

The American Indian participants of the *Strong Heart Study* from North and South Dakota, included the Oglala Lakota of the Pine Ridge Reservation. Among these participants, 36% of men and 47% of women were obese, and the overall prevalence of diabetes in this population was 32.5% (U.S. Department of Health and Human Services, National Institutes of Health [NIH], 2001).

Storytelling: Oglala Lakota Perspective, Ms. Maxine Brings Him Back-Janis

An area that may hold the key in the dialogue of oral health disparities and diabetes is centered on the voices of the tribal people perspectives. Significant in this dialogue are nutritional challenges due to limited access to fruits and vegetables. Because of the remoteness of many tribal communities an ample supply of fruits and vegetables is not available and this creates a challenge when the recommendation is to have these foods as part of one's regular diet. This access issue continually challenges tribal communities to forgo eating healthy diets of nutritional rich foods,

which was very much a part of traditional diet in the past. Among the Lakota, the traditional practices of digging thinpsinla (turnips), picking chunpa (choke cherries), and papa (drying buffalo meat) have lost their appeal to many which has led to less healthy dietary habits that exacerbate the diabetes epidemic among our tribal people. Additionally, tribal people continually express issues with access to prevention services within their communities. It's critical for individuals with diabetes to routinely be seen by a dental hygienist every three months for preventive care and monitoring of oral health status, however accessing these dental hygiene services at tribal and Indian Health Service clinics is limited and poses a challenge for many tribal communities. There are often not enough dental hygiene providers to service the people. In a recent study in a tribal community (Brings Him Back-Janis, 2011), numerous barriers to accessing dental care were expressed by individuals in the community. For example, the study revealed, 'Approximately 90 percent of the participants had at least one decayed tooth. Although most adults have thirty-two teeth (twenty-eight when the wisdom teeth have been removed), approximately 50 percent of the adult participants in the study had twenty-seven or fewer teeth. A full 10 percent of the adults we screened had fewer than sixteen teeth remaining. A number had no teeth at all. We also found high rates of gum disease. Because oral health has implications for total health and is linked to other conditions such as heart disease, premature birth, and infections, these data have many implications for the well-being of my people. (page 3).

Background: The Yoeme (Yaqui) People of Arizona and Mexico

The Yoeme's first contact with Europeans occurred in the 16th century, when Spain invaded what is now Mexico, capturing the Yoeme as slaves, establishing Catholic missions, and mining silver on sacred lands. Many Yoeme were killed or forced to relocate, ultimately into Arizona, to escape violence and massacre. Finally, in 1939, the Mexican government recognized the Yoeme people and their rights to land. It was not until 1978, however, that the Pascua Yaqui Tribe of Arizona became a federally recognized tribe, awarded 202 acres in southern Arizona. Today, there are approximately 10,000 members living in Arizona and more in Sonora, Mexico (Pascua Yaqui Tribe, 2009).

Originally, the Yoeme depended upon hunting and had strong, respectful ceremonial obligations to the natural environment, particularly to the deer and flower world. The deer dances (pahko'olam) and songs continue these traditions and remain an important part of Yaqui life, honoring the survival of the Yaqui people (Delgado Shorter, 2003).

A Euro-American lifestyle, however, has increased the risk for diabetes and other factors contributing to cardiovascular and other chronic diseases among the Yoeme, in both the U.S. and Mexico. The overall prevalence of diabetes among the Pascua Yaqui Tribe in Arizona is 35-39% (men and women, respectively), and there are dramatic differences across older age groups (Aickin et al., 1995). Approximately 42% of women 35 to 44 years of age were diagnosed with diabetes, but prevalence jumped to 92.9% among those 55 to 64 years old. In men, the increased

prevalence was significant, though less dramatic [44% and 61.5%, respectively] (Aickin et al., 1995). In Mexico, Rodríguez-Morán and colleagues (2008) compared the impact of factors of western acculturation on cardiovascular risk factors in a sample population of Yaquis and the more remote Tepehuanos Tribes (20-65 years of age). For diabetes alone, the difference in prevalence was 18.3% among the Yaquis and 0.83% among the Tepehuanos, most significantly associated with the higher intake of saturated fats in Western diets.

Storytelling: Native Language, Traditional Knowledge for Diabetes Prevention: Dr. Octaviana Trujillo

Historically, in our relations with the immigrants groups to North America, indigenous tribes faced the prospect of total extinction as the cost for maintaining the life ways we had known from time immemorial. The only viable alternative to annihilation was establishing some sort of relationship with the government and coexistence with the rapidly encroaching United States national society. This set the framework for the subsequent shaping of both the orientation and the content of "Indian health care" from that point until recent times. Federal policy and national social pressure has had a tumultuous effect on the very existence of our Indian communities. Regardless of the specific nature of any actions on the part of the U.S. toward indigenous communities, the implicit goal was—at its most benevolent—the complete cultural assimilation of Native America. Although this original implicit goal has never been realized, the vitality of our native health has been severely compromised in the ensuing cultural adaptation of indigenous peoples to the rapidly changing social dynamics surrounding them in their native communities. Indigenous Native American tribes are increasingly challenged to meet the demands of an economically driven, technology and research-based decision making world. These demands warrant creative solutions and innovative strategies to ensure that tribal communities maintain balance between the interplay of mainstream and tribal forces.

Tribal leaders readily understand today that no longer can any society function in isolation, as their communities are interdependent with one another, with other cultural minorities, and with the dominant national culture as well. Tribal communities are expanding their role in the competitive arena of a market-driven economy. To address this situation, they are investing millions of dollars in health care. New sources of funding, including gaming and interest-bearing investments, afford tribal communities the purchasing power that historically was not available. Health care is a primary benefactor of the proceeds from this industry as tribal communities increase their investment in their members' health, as well as institutional programs, which serve their communities. Native Americans share many health care needs in common with other groups.

On the individual level, they need to have access to the same institutional benefits as others in order to pursue their own personal health well-being goals. On the community level, education facilitates the development of capable and skilled professionals to occupy decision-making positions within tribal government and indigenous

organizations. Tribal schools and colleges, particularly, attempt to integrate indigenous cultural practices and value systems within the mainstream—that is, national culture—education milieu. Although public institutions in general are becoming more responsive to the needs of minority and indigenous communities in terms of their access to the benefits of quality health care, they have not been so responsive with regard to traditional native health care beliefs and practice. Due to the unique nature of Native American tribal communities vis-à-vis other ethnic communities, this persistent lack has an additional community impact. This is directly related to our relatively small populations and their unique cultural aspects that distinguish them from all other groups, including other minority populations. By nature, indigenous communities lack the much greater degree of migration of new people and resources into the community from other communities that characterizes even the smallest of other minority populations, since most cultural groups spread out in additional interconnected communities often dispersed widely throughout the country.

Although a high percentage of indigenous community members migrate to the urban areas, they maintain a unique connectedness with the home community. In this context, traditional native health care needs of indigenous people suffer because in terms of educational fiscal logistics, addressing those needs simply is not cost-effective. When tribal members leave the reservation to take up residence in metropolitan urban communities, even though they may actually receive a higher quality of health services, they are less likely to have their traditional native health care needs addressed. The European cultural remoteness and the relative isolation of a high number of our Yaqui (Yoeme) members, whether physical isolation in our own communities or in figurative isolation in the urban setting, has meant that a high percentage of our members live a traditional Yaqui lifeway, where the well-being is inseparable and indispensable from our spiritual universe. Among no part of the Yoeme population is this more so than among those of us residing in off-reservation urban settings such as Phoenix (include traditional Yaqui well-being views). It is well known that the majority of indigenous people who live in urban settings maintain strong ties to their respective reservation communities. These ties range from occasional contact with close relations to more involved commitments to extended family, home community, clans, and traditional ceremonial responsibilities. In fact, many of us who migrate to the urban areas seeking educational and economic opportunities consider it a physical move only. Our spiritual, social, and cultural focus remains in our home reservation community. Indeed, many of us who migrate to the urban areas with the intention of returning after accomplishing the specific objectives for which we have left.

It is extremely rare that we Yoeme (Yaqui) think of our migration to the urban area as turning their back on the home community and severing their connection to our cultural roots and homeland. If the Yaqui reservation-based community is the bastion of traditional cultural continuity, then it is the urban-based community that affords them the bridge to the outside world and its

resources that are so critical to maintaining tribal autonomy and cultural continuity in an ever-changing world. The preservation, maintenance, and restoration of native language capability in this context is even more critical due to its implications for our well-being, not only in terms of our cultural continuity, but also in matters regarding how we understand traditional notions of physical and spiritual well-being, and how they relate to health care. The alarmingly high rate of diabetes, particularly among those of us residing in the urban areas, poses a considerable threat to this important continuity that has very real negative consequences for both our urban and the reservation communities alike. Any strategy intended to affect health awareness in the modern context and to improve health outcomes must be comprehensive enough in scope to consider the vitally important link that is the Yoeme language and all that it connotes to the Yaqui people.

Background: Choctaw Nation

Today, diabetes is common among Choctaws—among both the Mississippi Band of Choctaw Indians and the Oklahoma Choctaw Nation. In September 1989, the prevalence of diabetes among the Mississippi Band of Choctaw Indians was 6.5 times the U.S. rate (Johnson & Strauss, 1993). Both the Oklahoma Choctaw Nation and the Mississippi Band of Choctaw Indians now have diabetes prevention and education programs, which emphasize healthy diets and exercise. Both programs also educate members about the risk factors for the disease, and treatment (Choctaw Nation, 2012; Indian Health Service, 2012). Education about the causes of diabetes as well as management of the disease is important. As Dr. Jarratt-Snider learned about the nutritional aspects of diabetes risk as well as the importance of exercise, she has made changes in her own life which she hope will help her avoid the disease that has already impacted members of her own family. With the development of more and more education programs, there is hope of not only reducing the rate of diabetes among Choctaw and other Native American and Indigenous peoples, but also reducing the incidence of severe health problems resulting from the disease, such as renal failure and heart disease.

Storytelling: Traditional Foods and Lifestyles and the Impacts of Colonization and Technology: A Choctaw Perspective, Dr. Karen Jarratt- Snider

Traditional foods and lifestyles of Southeastern American Indians in general may offer important insight on current diabetes risk factors. As with the rest of American society, many Choctaw lives today are more sedentary than in the past. We spend time at desks and computers, watching television, and other activities that result in far less exercise than our ancestors, eat processed food, and consume high fat and high glycemic index foods. In centuries and even decades past, the people worked outdoors gathering, hunting and farming to provide food for our families--gathering, splitting and stacking wood for household heating, hauling clean water, and many more daily activities in which everyone in the community joined. Providing for families and communities, then,--subsistence activities-- involved a good deal of physical activity. A shift from primarily a subsistence, community-based economy to a wage-driven economy, particularly since

the mid twentieth century, has brought a change in the amount of physical activity in the lives of many of the people. In addition to the reduction in physical activity, dietary changes began to occur in the 1800s, due in part to federal Indian policy. Removal forced many to move west to Indian Territory—present day Oklahoma (which is itself a Choctaw term).

Federal policy towards American Indian tribes took many contradictory turns over subsequent decades, but until the 1970's was always predicated on the assumptions that Indians would either assimilate or simply just disappear. Through persistence, resistance, and adaptation, Native American peoples, including the Chahta--like many other Indigenous peoples--, have remained. Yet those many policy changes resulted in loss of land and other natural resources and left many native peoples in a state of poverty and without the ability to continue utilization of traditional foods in their diets. Enter the provision of government surplus foods, or, as many American Indian peoples call them, commodity foods. And why did it matter? High glycemic index foods, combined with foods high in saturated fats and a lack of physical exercise can lead to obesity. Obesity is detrimental to overall health, and is also one of the risk factors for Type II Diabetes. The pattern of changes in lifestyle from subsistence to wage economies resulting in less physical activity and dietary changes from traditional foods rich in fiber and low in high glycemic index foods, to foods high in saturated fats, and processed foods and the rise of the incidence of diabetes in Indigenous communities has been previously noted by several scholars (Joe & Young, et. al., 1993; Lee, 1996; Mihesuah 2005).

Traditional Choctaw foods included a diet comprised of many lower fat foods (compared to those today), such as game (for example, rabbits and deer), and was rich in complex carbohydrates, fiber, fresh fruit and vegetables and nuts. As with so many other American Indian peoples, corn has been an important part of Choctaw foods. Many Choctaw dishes feature corn, such as Banaha (Pvluska Bvnaha), a bread made of a cornmeal mush, which can be combined with peas or beans, wrapped in corn silks and boiled in water or broth. Adding peas or beans to the corn meal makes banaha a complete protein food. Ta-fula, or hominy is a common dish, and still cooked outside over an open fire at many large gatherings. Wild sweet potatoes, peas, pumpkins, beans, hickory nuts and oil, acorns, wild grapes, berries, and greens (turnip, poke, mustard, spinach) wild onions, walnuts, melons, and acorns were among traditional foods found in Chahta diets, as well as crawdads and other fish (Choctaw Nation Cultural Services, 2012).

Corn is a fairly high glycemic index food, but hominy—used in many dishes—has a somewhat lower glycemic index than corn from a can or corn on the cob. Additionally, the pairing of cornmeal with high fiber foods, such as peas, nuts, or beans yields complete protein foods low in saturated fat and rich in fiber. Commodity foods (formerly known as surplus foods), on the other hand, are—for the most part—high glycemic index foods and high in saturated fats. I remember them well—powdered eggs, powdered milk, pinto beans, white rice, flour, white sugar, canned meat (high

in saturated fat and somewhat comparable to Spam), commodity cheese (a processed "cheese food product" similar to Velveeta) and lard. Occasionally, we would also receive a can of grape juice and a can of chicken, but we rarely received those items. I remember the meals my mother would make with those foods. As a child, I thought I just didn't like meat (not caring for the "canned meat"). I can still recall the way that the grease would ooze out of the top of the can as it was opened. My mother would fry it until it was crispy, and then add ketchup, in order to entice me to eat it. I also remembered the traditional foods (cornmeal mush was a staple for many of them) such as mashed sweet potatoes with nuts, banaha, tafula, and I also developed a love of wild greens, fruits and vegetables at a young age. My mother didn't make banaha too often, but many meals included some form of corn meal mush. Today, Indian tacos are a popular dish among many native peoples. But the combination of the high glycemic index (white flour) and saturated fat content (fried bread), make Indian tacos a high calorie food, and one that does not support a healthy lifestyle for those concerned about developing diabetes. Indian tacos are just one example among many of how contemporary diets have shifted from those rich in low glycemic index, low saturated fat diets to high glycemic index, high saturated fat diets.

Discussion

Storytelling provides a cultural context to diabetes and its impact on indigenous people. The perspectives shared yield much needed information from native elders and scholars regarding diabetes. In a collective review of the six stories, four primary themes emerge. One theme embraces the concept that prior to contact with Europeans, diabetes was not known among the indigenous peoples of the western hemisphere. Non-native scholars such as Martin and Goodman (2000) advocate this perspective stating that it was not until the 1940s that certain southwest tribes (Pima and Tohono O'odham) experienced diabetes. Similarly, Roubideaux and Acton (2001) indicate that prior to World War II, diabetes was "not a significant problem for AI/AN communities" (page 206). The relatively recent emergence of diabetes among native people may explain the limited conceptual agreement across the stories suggesting that perhaps insufficient time has lapsed for a collective "cultural understanding" of diabetes to develop.

A second theme identified was the elders and scholars noted that non-native influence on foods and reduction in hunting, gathering and farming have been major factors in the rise of this disease. The narratives explain that the subsistence diet kept the indigenous peoples active and healthy. In contemporary times, indigenous peoples have had to adjust to survive and adopt new foods since traditional staple foods were often not available. These perceptions are echoed in the scientific literature. Wolsey and Cheek (1999) and Teufel (1999) have made strong arguments supporting the impact of non-traditional foods and more sedentary activity patterns on the development of the epidemic proportions of diabetes in indigenous populations.

Another theme is disconnection from cultural roots yielding a state of imbalance or loss of harmony manifest in negative health outcomes, such as diabetes. Cultural detach-

ment is exhibited by a loss of traditional food ways and subsistence activities, loss of traditional language, stories and practices, and even physical separation from land and people. A final theme is hope. All storytellers suggest that the solution lies in the core values and knowledge of the culture. They advocate cultural continuity and revitalization, tribal autonomy and the application of traditional teachings to modern problems. These last two perspectives are common to the various narratives and may apply to all disease processes impacting human health.

The perspectives of these elders and scholars could enhance not only the practice of providers but also tribal diabetes prevention and control programs. In 1997 the US Congress established the Special Diabetes Program for American Indian and Alaska Natives (SDPI) and has awarded health promotion funds directly to tribes. Over the past 15 years, tribal programs have integrated their knowledge of local food and activity behavior patterns and extraordinary creativity to develop locally relevant diabetes prevention and treatment programs. For example, programs have developed and taught healthy ways to prepare favorite foods, e.g. low-fat stew, and promoted physical activity by revitalizing traditional games by hosting community game days and multi-day games (Teufel-Shone et al., 2009). Other creative approaches have involved the use of local health promotion radio programs and public service announcements (often in the indigenous language), youth and community gardens, ropes challenge courses and climbing walls, and even surfing in California and shoeing in Alaska to re-introduce healthy behaviors. Tribal programs have leveraged the strength of community and family cohesion to gain support for behavior change. Programs launched team-weight loss competitions a decade before the method was popularized by the television show *The Biggest Loser* and engaged fathers and grandparents to support breastfeeding before the western medical community advocated the active involvement of family supporters.

Most programmatic strategies are based on the western medical model focusing on changing lifestyle habits and less often on concepts of imbalance and core cultural values. Bullock (2010), a native IHS provider, has said that our model of diabetes has been too small. The western medical approach to diabetes has not considered the health impact of stress created by spiritual imbalance, loss of language and cultural practices and beliefs, and uncertainly of indigenous identities. The perspectives shared by these native elders and scholars could enhance existing tribal programs to yield a more holistic approach to disease prevention and treatment. Diabetes programs might actually support events that address community healing and cultural revitalization as key to halting this condition that directly or indirectly impacts all native families.

Conclusion

These narratives in the form of stories come from a variety of indigenous perspectives. The resulting themes can guide non-native health care providers working with various indigenous people and tribal diabetes prevention and control programs. The concept of imbalance creating by contact with non-indigenous cultures and loss of traditional practices is common but all indigenous people do not all have the same perception of diabetes. Some may hold that changes in food choices and activities patterns can reduce the negative

consequences of the disease; yet, others may feel more strongly that reaffirming traditional beliefs and/or consultation with a traditional healer will be more effective. Health care providers are advised to ask an indigenous patient about perceived causes and even treatments to build a mutual understanding of the condition and treatment strategies. Programs are encouraged to explore and integrate cultural meanings of diabetes and not limit their approach to food and activity change strategies. For an indigenous person, a diagnosis of diabetes has far reaching implications. The diagnosis reaches beyond the individual and impacts the family and reflects the tides of cultural tenacity and loss. Non-native health care providers and even local programs generally know how to treat the person but should partner with traditional healers or elders to treat the spirit.

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Increasing the Knowledge Base: Utilizing the GAIN in Culturally Sensitive Landscapes

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ABSTRACT

Background: *Assessment instruments used in human services settings are often normed for majority populations. The importance of increasing the evidence-based validity of assessment tools in unique populations is essential to providing relevant evaluation, successful treatment, and, ultimately, individual and societal wellness. The Global Appraisal of Individual Needs (GAIN) is a comprehensive biopsychosocial assessment used with both adolescents and adults being admitted to substance abuse treatment in outpatient, intensive outpatient, partial hospitalization, methadone, short-term residential, long-term residential, therapeutic community, and correctional program settings. The GAIN has been used by agencies and systems of care in communities ranging from large urban areas to moderate-sized and small urban communities, rural areas, and Indian reservations. Over the past 10 years, several culturally focused workgroups have convened and given separate presentations about their use of the GAIN and related GAIN findings for their culturally distinct groups. Recently, those groups came together collectively--for the first time--to discuss GAIN administration and interpretation with diverse populations.* ***Methods:*** *Using qualitative methods based in grounded theory, this study identified the commonalities, themes, processes, experiences, and perceptions represented by the multiple diverse workgroups sharing their "in the field" or "practice based" knowledge of the GAIN process from a cultural standpoint.* ***Results:*** *Findings suggest the importance of assessment flexibility, the use of storytelling to improve communication-style differences, the importance of diversity trainings and respectful community relationship-building to increase the acceptance, utilization, and validity of the GAIN among diverse population groups.* ***Conclusions:*** *The findings provide multi-cultural and culturally distinct settings with meaningful information that can be useful for using the GAIN in culturally sensitive landscapes.*

Keywords:
Global Appraisal of Individual Needs (GAIN), diversity, culture, assessment, validity, qualitative methods.

Introduction

Indigenous peoples all over the world tell the story of a monkey, from Australia and New Zealand to Africa. As the story goes, a monkey was swimming across a wide river. The current was strong, and the monkey had a hard time reaching the other side. While crossing, the monkey went under the water several times and nearly drowned. When she finally reached the shore, the monkey passed out from exhaustion. When she awoke, the monkey noticed a number of fish jumping out of the water, so she gathered all of her energy and ran downstream as fast as she could. One by one, the monkey snatched the fish from the water; then, she grabbed a vine from a nearby tree and tied each fish to a vine. Eventually all of the fish died. Why did she do this? The monkey had perceived the fish as trying to escape the river and so she tried to "rescue" them. The fish, however, were not trying to escape at all. Instead, they were feeding on insects just above the water's surface.

This story teaches an important lesson about diversity that can be applied to assessment practices. What we perceive to be correct in assessment practices with one population may be meaningless or even harmful to another population, despite our best intentions. Differences in styles of thinking and cross-cultural communication give rise to potential concerns regarding the use of conventional assessment techniques that are normed on other communities, societies and peoples. Assessment research with ethnic minorities and various cultures has a challenging history (Deardorff, Tschaan, & Flores, 2008; Okazaki & Sue, 1995; Whatley, Allen, & Dana, 2003). Instruments used in human services settings are often either normed for the population most familiar to the developers or are ethnically "glossed" (Trimble, 1991) to provide a sense of working with specific cultures rather than being flexibly designed to accurately assess a multitude of cultures within a larger culture. It is also noted that most psychological instruments do not adequately address the influence of culture on functioning (Hitchcock et al., 2006).

The validity of the data collected with existing biased measures can be enhanced by assessing their degree of cultural appropriateness, interpreting client responses with cultural and environmental norms in mind, recommending changes to administration processes and the instruments themselves, and then implementing those changes. This enhances the fairness of these instruments by allowing people to be assessed in a culturally familiar manner (e.g. language); it also reduces costs and saves development time for new tests (Hambleton & Kanjee, 1995). In addition, many diverse cultures' realities are more meaningfully represented by qualitative techniques of data collection rather than quantitative. Exclusive reliance on quantitative techniques may be too reductionistic to adequately portray realities in a manner meaningful to a diverse range of cultural contexts (Godlaski, Johnson, & Haring, 2006). Hence, increasing the evidence-based support of assessment tools in unique populations is essential for relevant evaluation, successful treatment, and, ultimately, individual and societal wellness.

The purpose of this study is to discover the commonalities, themes, processes, experiences, and perceptions represented by multiple diverse workgroups sharing their "in the field" or "practice based" knowledge of the Global Appraisal of Individual Needs (GAIN) assessment (Dennis, Titus, White, Hodgkins, & Webber, 2003)—a widely-used substance abuse assessment—from a cultural utilization standpoint. This paper gives voice to the experiences of multiple participants, from diverse settings and societies, who are affiliated with the GAIN Coordinating Center (GCC), its ambassadors and administrators. The results of this study will assist GAIN users in effectively implementing the GAIN in a variety of cultural settings. Ultimately, this article aims to inform and provide multi-cultural settings with meaningful information that can be useful for using the GAIN instrument in culturally sensitive landscapes.

The GAIN Assessment

Data collected using the GAIN was not the focus of this project; rather, the focus was on documentation of the experiences described by clinicians, researchers, and other subject-matter experts who use the GAIN as they serve individuals from culturally distinct populations. The GAIN is a comprehensive biopsychosocial assessment used with both

adolescents and adults who are referred for substance abuse treatment in outpatient, intensive outpatient, partial hospitalization, methadone, short-term residential, long-term residential, therapeutic community, and correctional program settings. A copy of the instrument may be found at http://chestnut.org/LI/GAIN/.

The GAIN has been thoroughly validated psychometrically (Dennis, Scott, Godley & Funk, 1999) and is used in thousands of agencies and systems of care in communities ranging from large urban areas to moderate-sized and small urban communities, rural areas, and reservations. The data gathered for this project focused on increasing the knowledge base of those who use the GAIN in culturally diverse settings, but the findings are likely to be applicable to other instruments also.

The GAIN Cultural Sensitivity Summit

Because of the widespread utilization of the GAIN and the desire to build a culturally sensitive workforce, Chestnut Health Systems partnered with the Center for Substance Abuse Treatment (CSAT), a division of the Substance Abuse and Mental Health Services Administration (SAMHSA), to host the GAIN Cultural Sensitivity Summit in San Antonio, Texas in January 2010. The purpose of the summit was to begin a discussion on how to use evidence-based assessments like the GAIN in culturally sensitive ways.

A culturally diverse group of treatment professionals, subject matter experts and certified GAIN trainers from across the country came together to explore ways to encourage cultural sensitivity and adaptability of the GAIN assessments in clinical practice. Seven groups were represented at the summit, including four ethnic groups (African American, Indigenous peoples (American Indian/Alaska Native), Asian American, and Latino/Hispanic) and three non-ethnic groups (Deaf/Hard of Hearing, Gay/Lesbian/Bisexual/Transgender/Questioning (GLBTQ), and Rural/Small Communities).

The 3-day summit included presentations on topics that defined and clarified the meaning of "cultural sensitivity" in clinical assessment and clinical interpretation along with discussions on the implications of those definitions in practice. One of the key objectives of the summit was to develop a consensus and guidelines on reasonable adaptations and accommodations to be used in semi-structured interviewing with instruments like the GAIN in an effort to optimize respect, validity, reliability and efficiency with clients of any cultural background. All summit participants were familiar with the GAIN and many of them used it with clients.

During the course of the summit, each of the seven culturally specific groups worked independently to generate discussion notes in response to specific questions on using the GAIN. These notes included workgroup summary notes, narratives, and comments from summit participant end-of-day surveys.

This article, as a follow-up to the summit, utilizes qualitative analytic methods to distill the workgroups' discussion notes and thus identify the central themes that address the question of how one can use an assessment like the GAIN with cultural sensitivity. This analytically generated advice from the workgroups provides a framework for increasing the knowledge base on how to utilize the GAIN in diverse settings.

METHODS

Foundational research models

Community-Based Participatory Research. The project model was based on the guiding principles set forth in a community-based research protocol, the *Model Tribal Research Code* (American Indian Law Center, 1999) as well as direction from community-based participatory research literature (Wallerstein & Duran, 2006). The Community-Based Participatory Research (CBPR) model is a collaborative approach whereby research is conducted as an equal partnership between academically trained researchers and members of a community. CBPR has emerged as an alternative paradigm that integrates education and social action to improve health and reduce health disparities. CBPR is more than a set of research methods; it is an orientation to research that focuses on relationships between academic and community partners—with principles of co-learning, mutual benefit, and long-term commitment—and incorporates community theories, participation, and practices into research efforts (Wallerstein & Duran, 2006). In this project, each of the seven communities represented in the GAIN Cultural Sensitivity Summit was integrated into some component of the research methodology, as described throughout subsequent text. By doing so, the project incorporated multiple cultures and supported community collaborations.

Grounded Theory. The analytic model used in this project was grounded theory (Strauss & Corbin, 1998). Grounded theory is unique in that data are used to generate theory, rather than the conventional scientific method in which theory drives the interpretation of data. Through the application of grounded theory, qualitative data were used to construct a model comprised of categorical processes that explained the phenomena under study. In this case, the application of grounded theory to qualitative data were used to construct a model that explained how culturally diverse groups organized and interpreted their experiences with GAIN utilization. This study also drew upon grounded theory to develop action-based recommendations for the GCC on using the GAIN in culturally diverse settings. Qualitative methods such as grounded theory have been used in minority populations to develop and test culturally based value measures (Deardorff, Tschann, & Flores, 2008).

Confidentiality and cultural safety

There were no types of deception associated with this project and the Principal Investigator (PI) was an independent consultant and an Indigenous researcher (Seneca Nation of Indians). Furthermore, the GAIN Cultural Advisory Council, an external committee, was part of the analysis review and evaluation process and, because the results are being presented to the community at large, no individual responses were identified. Participants attending the Cultural Sensitivity Summit—including their individual notes, responses, comments, and related verbatim materials—are not identified on an individual level. It is also noted that all GAIN-using sites, including specific minority groups attending and contributing at the summit, had the opportunity to receive a copy of the report upon request. The project did not identify any discomforts related to the physical and psychological well-being of the communities involved; lastly, it did not cause any negative impact on the cultural, social, economic, or political well-being of the cultural communities that were represented.

Data

The raw data documents consisted of written and verbatim data from the workgroups' summary notes, narratives, and comments from the end-of-day surveys. Data were submitted in rough draft form to the Principal Investigator. Two Native American women transcribed the raw data into Microsoft Word documents suitable for upload into the ATLAS.ti qualitative analysis software (http://www.atlasti.com). A male member of the GLBTQ community was recruited to review the materials as a secondary examination to ensure that the initial transcription was completed without error. This was done to improve the rigor of transcription. The total collection of materials included 25 documents, with 16 of the documents transcribed and transformed into RTF files for use with the ATLAS.ti software (nine documents were already in Word format). Data from these documents composed the secondary data set.

Analytic procedures

An independent minority researcher conducted the data analysis using ATLAS.ti software to facilitate the organization of the qualitative data.

Transcript analysis and categorizing. Secondary data were subjected to transcript analysis, a rigorous and labor-intensive process that involved the assignment of codes to text. The substantive codes identify and label participants' main experiences and perceptions of increasing the knowledge base for using the GAIN in culturally diverse settings. Each transcript was open coded (reviewed at a macro level by the PI) several times to identify and label codes, and like-codes were grouped into categories. A *category* is a "theme" or variable which makes sense of what is being communicated in the text. Categories represent concepts that stand for various phenomena, for instance, any problem, issue, event, or happening defined as being significant to respondents (Strauss & Corbin, 1998). In this project, categories were "in the field experiences" or "practice base knowledge" from multiple individuals and agencies that utilized the GAIN in an array of cultural environments. The experiences of these GAIN users represented the processes associated with improved use of the GAIN. They were based on stories of GAIN Summit participants and further represented the building blocks of theory (Strauss & Corbin, 1998). A category that is represented often and appears central to the study and emerging story is called a *core category*.

As coding continued, categories were further delineated through properties, which are characteristics of ascribed categories. They provide definition and meaning and serve as attributes to the categories. An additional sublevel of coding identifies dimensions, which further explain properties. Dimensions provide a range within which the property varies and also provides a location map of the properties along continuums (Strauss & Corbin, 1998). Throughout the analysis, the properties and dimensions of categories were developed. Some categories were eventually absorbed within other categories.

The study also used sub-categorization. Sub-categorization is a method of breaking down higher-level categories. Subcategories were definitive and unique concepts that pertain to the ascribed category and include information about where and how a phenomenon is likely to occur (Strauss & Corbin,

1998). Finally, this study also utilized axial coding. This coding process relates categories to subcategories and codes around the axis of a category.

Memoing. Memoing is an important activity in a grounded theory-driven analysis. As the categories and properties emerge from the coded data, the relationships that link them together also emerge. Memoing refers to the creation of written memos that document the coder's thoughts and ideas about the relationships between emerging categories and the explanatory model. These memos form the framework for explaining the data and also leave an audit trail leading back to the data. The audit trail provides the coder with a means to understand how the data were analyzed and how theoretical models were developed (Strauss & Corbin, 1998).

GAIN Cultural Advisory Council. The GAIN Cultural Advisory Council, a diverse external group of treatment providers and content experts, assisted in the evaluation by providing results verification, input, and insight into the theory building process. This extra step was taken to ensure that results were coded, analyzed, and arranged to show the correct process and final result determination. Lastly, the involvement of the GAIN Cultural Advisory Council strengthened the research design by providing a powerful collaborative effort. Those attending the initial focus group received a raffle ticket for a chance to win an honorarium that was purchased from a remote, rural Ethiopian community in Africa. At the completion of the advisory input-sharing conference call, the raffle was held and the honorarium was awarded.

During the second call, advisory council members assisted with the final review of the results. This process improved qualitative rigor and combated possible investigator, ethnic, or gender bias. Advisory council members attending the second teleconference meeting received a raffle ticket for a chance to win an honorarium, which was purchased from a Native American rural reservation community. At the completion of the second meeting, the raffle was held and the honorarium was awarded.

Research Limitations

One limitation of the study was the lack of full audio- or video-recorded data for observational review or word-by-word line qualitative analysis. To improve validity and rigor, the project used multiple transcribers to validate transcription of hand-written notes, making sure all data were transcribed correctly and all content was used. In addition, the GAIN Cultural Advisory Council held two follow-up sessions with the P.I. in order to discuss and verify the process and outcomes. A second limitation of this study is the generalizability of its findings. Due to the diverse nature of cultural and community environments and assessments, these findings are not to be overgeneralized to every culture or assessment.

RESULTS

The results of the qualitative analysis are outlined in Figure 1. Five categories and one sub-category emerged from the data and represented the main topics of the "in the field experience" or "practice based knowledge" for successful use of the GAIN in culturally diverse landscapes: Adapting the Administration Environment of the GAIN, Understanding and Improving Terminology, Communication Styles, Trainings, Emphasiz-

ing Community Process (core category) and Historical Trauma: Trust and Mistrust (subcategory of emphasizing community process). Most categories had several properties and/or dimensions associated with them.

Adapting the administration environment of the GAIN

Environment can be defined in a number of ways. In relation to this project, environment is primarily described as the overall setting in which the person is situated within the community context. This premise is well described in the social work literature as Person-In-Environment or PIE (Kirt-Ashman & Hull 1999). In a GAIN-using site, the GAIN interviewer (person) who conducts assessments in culturally distinct community settings (environment) is the focal point. Thus, PIE sees people—in this case, the GAIN interviewer—as constantly interacting with the client's various systems, which include family, work, religion, and educational settings. The goal is to adapt the GAIN interview in a way that improves interactions between the person and the various systems or environmental situations in which the GAIN interview is conducted and in which its clinical findings are interpreted.

Flexibility during assessment. Adapting the assessment or adding flexibility to the administration of the GAIN was a topic that many attendees discussed. Attendees stated that GAIN training should reflect ways that individuals administering the assessment could adapt the GAIN for use in their unique setting. The assessment should also continue to be administered in a semi-structured way to maintain validity and fidelity. However, when needed, interviewers should explain items in greater detail so as to fit the client's experi-

Figure 1.
Using the GAIN in Culturally Diverse Landscapes: Recommendations from the Field

1. Adapting the Administration Environment of the GAIN (Category)
   - Flexibility During Assessment (Property)
2. Understanding and Improving Terminology (Category)
   - Identity Questions (Dimension)
   - Taboo Questions (Dimension)
   - Resiliency Questions (Dimension)
3. Communication Styles (Category)
   - Storytelling (Property)
4. Trainings (Category)
5. Emphasizing Community Process (Core Category)

5b. Historical Traumas (Subcategory of Community): Trust & Mistrust
   - Spirituality (Property)
   - Multi-Cultural Advisory Council (Property)
   - "Listening to the Children" (Dimension)
   - Involving Families & Collaterals (Property)
   - Confidentiality (Property): "There Is a Strong Grapevine"

ences within the client's community environmental contexts. This flexibility will increase the client's understanding of the questions being asked and improve the likelihood of an accurate response. A summit participant who stated that it was useful to "hear that I can be flexible" exemplified this. Other summit attendees indicated that it was important to "make it known that the GAIN is meant to be modified/added to, etc." in order to make it more appropriate for each individual. Other responses included: "prep agencies and individuals!" and "accountability to the instrument is important, but emphasize the flexibility during the training." A final recommendation by the advisory council was to "encourage trainees to make notes on the adaptations as they make them" so as to share their adaptations with others who are in need of making similar adaptations.

Understanding and improving terminology

Participants of the summit indicated that terminology of items used in the GAIN is often misinterpreted or misunderstood in differing cultural contexts. An example of this was the meaning of the word "treatment." Its meaning may be unclear in cultures where there are potentially different interpretations, perceptions, or experiences related to treatment. In addition, some summit participants stated that the language in the GAIN is sometimes too technical for clients to understand. Ultimately, how can the GAIN items be adjusted for better community understanding so as to address potential differences in cultural meaning? Summit participants suggested the items should be adapted into layman's terms, meaning that items should be explained more in the contextual language of the area when necessary. Another important recommendation was to reframe items back to clients, or in the words of an advisory council member, "to make the language more general or to re-engage in another way."

Identity questions. A dimension of the greater category, Terminology, is reflected in the diverse nature of cultures. Administration of identity items on the GAIN can be complex. As with many assessment tools, general identifying questions include cultural selections (boxes from which to choose, e.g. race/ethnicity items) that are not diversified enough to successfully include multiple cultures or peoples. For example, within the Asian population there are multiple communities that comprise "Asian." It was suggested that more selections be included on the GAIN to identify cultural community. New efforts cited by the GAIN Coordinating Center address this issue and attempt to balance self-identification in order to support clinical work with individuals, meet reporting requirements, and support a wide range of research on how to improve care (retrieved from http://www.chestnut.org/LI/gain/GCC_Insider/GCC_Insider_issue9.pdf)

Taboo questions. The use of questions that may be taboo within certain cultures is another dimension that emerged in relation to the property of Terminology. For instance, questions regarding school or sexual abuse in some cultures may trigger recollections of past historical traumas, community traumas, or unknown histories that are taboo to speak of. A recent, brief GAIN Q & A (Asking About Menstruation on the GAIN; retrieved from http://www.chestnut.org/LI/gain/GCC_Insider/GCC_Insider_issue9.pdf) is a starting point of discussion for addressing the administration of taboo questions. However, ongoing education about using these items with clients

from different cultures requires ongoing attention. It may also be important to understand differences in interpretation of taboo questions in varying cultural contexts. This can be done by having a dialogue within the community about the reason for and content of these items and how best to administer them in a culturally sensitive manner.

Resiliency questions. Resiliency can be defined as "both an individual's capacity to navigate to health resources and a condition of the individual's family, community, and culture to provide these resources in culturally meaningful ways" (Unger, as cited in McCubbin et al., 2010, p. 262). If differences in cultural adaptation and coping are understood, decision-makers will be better able to design public policies and mental health interventions to meet the needs of different cultural groups (McCubbin et al., 2010). This also applies to assessments within varying cultural environments and communities. With regard to the GAIN instrument, summit participants asked the basic question "How can the GAIN incorporate items to tap resiliency?" Throughout the discussion, the term *resiliency factors* for varying cultural societies became important. This included how to formulate a strength-based relationship with a client within the community context and was best stated by an advisory council member who said, "This is an important issue in community process." Furthermore, having a comprehensive set of resiliency questions in an assessment and administering them in a culturally sensitive manner may address mistrust, build trust, and mitigate historical trauma. Although not specifically a representative of a GAIN issue, participants indicated that resiliency questions are a means of adding a culturally appropriate style for improving acceptance in diverse communities.

Communication styles. Differences in styles of thinking and communication give rise to concerns regarding the use of conventional assessment techniques within diverse cultures (Godlaski et al., 2006). Specifically, the adoption of more flexible communication styles which are consistent with the cultural communication styles of the community that the GAIN is being with used with. Therefore, understanding communication styles, rapport building, and respectful turn-taking-style conversations may be beneficial skills for GAIN-using sites when entering into a community to administer the GAIN. As noted by the cultural advisory council, "Storytelling is important." Storytelling, by nature, allows clients to tell their stories at their own pace to answer questions posed. It allows for more time to explain and does not rush answers from clients. Furthermore, storytelling "allows (the interviewer) the ability to pick out information relevant to the assessment, use reflexive listening, and reframe back to client" (advisory council member). "Storytelling is also a cultural value—it recreates the story rather than telling it in the past tense" (summit participant).

Ultimately, storytelling is the foundation of many cultures. Patience, listening, and observing are a part of cultural oral tradition and are essential skills for understanding the metaphors and relationships inherent during the assessment process (Godlaksi, Johnson, & Haring, 2006). A statement shared by an advisory council member best sums up this process: "Storytelling shares more relevant information. Although it takes more time, it shows respect and gives explanation which helps build trust." When interviewers let clients explain and tell their stories when relevant for them it can help

them to fully describe their thoughts and feelings in response to the questions.

Trainings

Another category that resonated throughout the project was the need for supplemental or additional or ongoing trainings focused on concerns discussed at the summit. This included the need for a more detailed set of diversity-related trainings to engender an increased level of cultural awareness about the multiple communities involved. Topics for consideration included training on communication-style differences, incorporation of culturally relevant vignettes for best practices in assessment administration, retraining modules for past GAIN trainees focusing on cultural sensitivity, using story-telling with a semi-structured assessment, building rapport and community trust, and community information meetings prior to introducing the GAIN assessments at provider sites.

Emphasizing community process (Core Category)

As the data were analyzed, a definition of community collaboration emerged. The core category, Emphasizing Community Process, assumed an overarching role that encompassed the results. This category primarily included discussion of building a cultural advisory board, involving children, family inclusion, and trust versus mistrust issues embedded in historical traumas. These were identified as properties and a sub-category of this core category. In the overall picture, community process involved assessing how to adapt when administering the GAIN to fit the unique community landscape, determining how this adaptation was useful in community engagement, and evaluating the ways in which the use of specialized trainings contributed to community capacity building and GAIN acceptance.

Cultural advisory council. The recommendation and development of a cultural advisory council provided a means through which communities could work with the GAIN Coordinating Center to assist GAIN-using sites in successfully implementing the GAIN within various cultural contexts. One attendee best stated the role of the advisory council: "Let the cultural advisory council serve as implementation mentors."

Woven throughout the discussion of developing a cultural advisory council was the inclusion of the voices of youth (listening to the children). Recommendations included incorporating diverse youth into the cultural advisory council or having some means by which youth could have an opportunity to share their experiences as people who have been assessed with the GAIN. Their input would provide valuable information for the assessment's ongoing development and use in their communities.

Involving families & collaterals. This property of the core category included the potential need to incorporate families into the assessment process. One cultural advisory council member indicated, "Collaterals were key." This approach is similar to collective society thinking (Triandis, 1995). Collectivism is defined as a social pattern consisting of strongly linked individuals who see themselves as parts of a larger system. A second view may be seen in the emphasis placed on family ties and the discouragement of children to achieve psychological separation and independence from their parents (Choi, 2002). Summit attendees

incorporated the ideology of collectivism by emphasizing the need for family involvement during the GAIN assessment.

Confidentiality: "There was a strong grapevine". Confidentiality is crucial during the GAIN assessment process as noted by summit attendees. This is paramount in small communities, and especially true for work within specific cultural contexts. One attendee who noted that there was a "strong grapevine" of which GAIN interviewers must be aware exemplifies the need for confidentiality. Many people in these communities are related, whether by blood, by marriage, or through social networks (e.g., sports teams). Many shop at the same stores, visit the same health clinics, and pet the same dogs walking down the road.

Historical traumas: trust & mistrust. This topic emerged as a sub-category of the core category. Historical trauma is a traumatic or stressful era in history that alters the perceptions or behaviors of a population, culture, or society. The most widely recognized historical trauma in the United States specific to Native Americans comes from the era of the boarding school. In the early 20th century, these schools were established to assimilate Native Americans into mainstream culture. Native American children were removed from their homes, communities, and families and sent to institutions far away. The goal of the boarding schools was to "remove the Indian." Children were not permitted to speak Native languages or practice traditional ways. They were forced to speak English, cut their hair, and wear the clothing of dominating societies. Choosing not to follow the rules often resulted in severe abuse or death (Godlaski et al., 2006).

Because of this and similar historical traumas in diverse communities (e.g., African-American, Deaf) across the United States, communities may be hesitant to accept the GAIN assessment or the GAIN interviewers as they can be seen as part of the dominant society. This hesitation may not be due to the GAIN instrument or to the individual conducting the assessment per se. Rather, the reluctance to participate in the assessment may be due to influences, experiences, and perceptions passed down through generations that emerge in the form of trust versus mistrust. In contemporary assessment practices, the residual effects of boarding schools and related historical traumas in diverse settings may form a barrier that prevents trust between a GAIN interviewer and the individuals or communities with which they aim to work. Communities may view the GAIN Coordinating Center or the GAIN-using site and staff as extensions of a government that they do not trust. For a number of cultural communities, suspicions have run high that the information gathered might be used against them. The GAIN interviewer might be perceived as a person sent to gather secrets, community history or other information for some unknown purpose. Summit participants indicated that in order for the GAIN data collection process to be trusted, to be seen as responsibly used, and given community acceptance, more education related to its intent would be beneficial. The GAIN Coordinating Center and GAIN-using site must be aware of these possible concerns, assess for them, and take them into consideration when conducting assessments within a broad range of cultural settings. One summit attendee emphasized this feeling by stating that communities wonder, "What are they after?" or "Are outsiders trying to get a view of our culture?" which can ultimately lead to a contemplation of trust versus mistrust. It is crucial

for GAIN interviewers to have an understanding of trust versus mistrust issues especially when the interviewer is from a majority culture with majority norms working within minority culture settings.

Spirituality. This property of Historical Trauma was mentioned by a number of attendees and was the topic of a summit presentation. However, it was unclear how the GAIN measured or fully incorporated the assessment of spirituality across diverse cultural contexts. This property was very open and could certainly benefit from ongoing discussion by the GAIN Coordinating Center's Cultural Advisory Council. In fact, during the advisory council's focus group meetings to review results and offer input, it was recommended that the property of spirituality be incorporated as a subcategory of Historical Trauma. This fits well within the trauma context because spirituality often plays a major role in past community historical traumas and in today's diverse societies. For example, spirituality was changed, lost, or abused for generations of Native Americans who were part of the boarding school era.

DISCUSSION

To appreciate the unique contributions of assessment instruments (such as the GAIN), as well as their limitations, one needs a clear schematic map of the multiple layers of a conceptual structure, the functions served at each layer, and how the different layers are interrelated (McFall, 2005). Therefore, the development of a theory for GAIN adoption and culturally sensitivity use is but one part of a complex, multilayered process that the GAIN Coordinating Center can develop, test, refine, and apply.

As part of this project, a theory was built that documented a complex set of interrelated concepts and processes: one that was more than just a listing of themes. The process for developing this theory was dynamic in nature and included action and interaction. The summit participants came together to discuss the application and usefulness of the GAIN in diverse cultures. The data utilized were not collected to answer the question of "How does this naturally work in their specific environment." Rather it assisted to answer the question of "How do we improve the use of the GAIN based on experiences." Thus, the theory that developed drew upon the voices of the summit participants and helped build concrete "next steps" in order to make the GAIN process culturally relevant to the diverse communities it is utilized. Specifically, having the flexibility to adapt the GAIN for implementation in culturally diverse communities, understanding the varying meanings of terminology during the assessment process, utilizing a storytelling process to improve communication styles, promoting trainings focused on culturally diverse circumstances, and collaborating with communities in a respectful and meaningful way are all important elements in moving toward using the GAIN in a culturally responsible manner.

The theory, as grounded in the experiences of GAIN Cultural Sensitivity Summit attendees, can be labeled *Culturally Sensitive Implementation of the GAIN in Community Systems* and is described as "Individuals administering the GAIN instrument in varying cultural climates stressed the importance of assessment flexibility." This essentially reflects a phrase noted during the advisory council discussion - that the goal is "cultural enhancement for a more inclusive assessment." Adapting the GAIN to

fit various cultural communities will support a more appropriate and successful implementation. By doing so in a storytelling fashion, and by reframing questions to improve understanding, communication style is improved. Furthermore, these techniques need to be incorporated through ongoing diversity trainings. These techniques also need to be incorporated into the overall collaborative efforts when promoting the GAIN to communities in order to engender community acceptance, utilization, and benefits to societies that may have past historical traumas that influence trust. Therefore, the community has the ability to shape the meaning, acceptance, and successful implementation of the GAIN assessment.

This developing theory showcases action-orientated outcomes that expands the knowledge base on how the process of implementing the GAIN in culturally diverse environments. Results specify the commonalities, themes, processes, experiences, and perceptions represented by the multiple diverse workgroups sharing their "in the field" or "practice-based" knowledge of the GAIN users' process from a cultural utilization standpoint. The qualitative results can be used to develop a guideline for action and process. Furthermore, the results of the study provide a framework for the GAIN's utility in an array of organizational climates. In response to Antony and Rowa's (2005) question of how to improve assessment tools, the GAIN Coordinating Center is already taking action by involving communities represented at the summit for ongoing discussion. Furthermore, the GAIN Coordinating Center has begun to address sensitive (taboo) questions, ask and identify classifiers (retrieved from http://www.chestnut.org/LI/gain/GCC_Insider/GCC_Insider_issue9.pdf), adapt training materials to reflect various cultures, refine identity items as well as develop a GAIN Coordinating Center Cultural Advisory Council.

Ongoing attention needs to focus on acceptability and dissemination of the GAIN within varying community contexts. Results of this study indicated that this process needs to consider historical traumas and how these influence community trust (versus mistrust) concerns. Furthermore, the GCC should consider how to increase the visibility of benefits to communities by educating and continually developing ways to incorporate best practice examples for working in culturally diverse settings. Ultimately, the GAIN Coordinating Center should work with GAIN-using agencies to continue to focus on a community-based participatory implementation process and stress implementation of the GAIN in a culturally sensitive, respectful, and meaningful manner.

The findings of this study parallel some of the previously written recommendations with regard to diverse communities (Godlaski et al., 2006). These include drawing on qualitative approaches of assessment (storytelling) as well as promoting flexibility in the assessment process. Assessment, and its meaning in diverse cultures, is a never-ending cycle of learning, sharing, and staying open-minded. To be successful in assessment, one must refrain from being like the "uninformed rescuer" swimming in turbulent waters and instead, strive to understand, appreciate, and value the perspective of the fish.

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Community Specific Daily Activity in Northern Plains American Indian Youth

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ABSTRACT

Overweight and obesity affect almost half of all reservation based Native American youth. One causative factor may be low levels of physical activity. The purpose of this study was to compare Native American physical activity in adolescents living on reservations to their urban dwelling counterparts. We examined physical activity using an automated Audience Response System that deployed the validated International Physical Activity Questionnaire (I-PAQ) in 689 children; 377 reservation-based Native American adolescents, 213 (urban) Native American adolescents and in 99 non-Native urban adolescents. Results indicated that overall reservation-based Native American adolescents were NOT less active than their urban counterparts. However, reservation-based Native American adolescents were more active than their urban counterparts for medium intensity outdoor household activity (mean activity minutes per week 243 (SD 297) versus 186 (255), p = 0.02), for heavy intensity outdoor household activity (mean 209 (SD 264) versus 160 (223), p < 0.03), and for medium intensity indoor household activity (mean 210 (SD 246) versus 169 (211), p= 0.05). Compared to the Native urban adolescents, the non-Native urban adolescents were more active by half an hour/day for medium intensity activity (mean minutes per week 1208 (SD1209) versus 949 (909) min/wk, p = 0.05) for any physical activity and were leaner by 2 Body Mass Index (BMI) units (mean BMI 20.8 (SD 4.4) versus 22.4 (SD 5.3) kg/m2, p=0.008). Low levels of physical activity occur similarly in reservation-based Native American and urban Native American 10-14 year old children. Physical activity levels were low in both reservation-based and urban Native American adolescents; improving physical activity in Native American adolescents is an opportunity for community participatory research.

KEY WORDS: *Physical Activity, Non-exercise Activity Thermogenesis, Community Based Participatory Research, Audience Response System, Childhood obesity, Obesity.*

Nationally, two-thirds of all Americans are obese or overweight, and the prevalence of these two conditions is even greater among the American Indian population (U.S. Department of Health and Human Services, 2002). Researchers have examined factors that contribute to obesity and to chronic diseases in American Indians (Nelson, Moon, Holtzman, Smith, & Siegel, 1997; Schweigman, Eichner, Welty, & Zhang, 2006). In fact, some reservation areas served by the Indian Health Service report a 54% increase in type II diabetes among 15 to19 year old American Indians over the past 12 years (Nelson et al., 1997). Although food quality and consumption are factors (Byers, 1996; Curran et al., 2005), diet alone does not explain the increase in obesity. Physical activity, community factors, and environment also play critical roles (Fischer et al., 1999). Obesity is the consequence of sustained positive energy balance whereby food intake consistently exceeds energy expenditure. Furthermore, both food intake and physical activity (the only volitional component of energy expenditure) has both biological and environmental drivers. In this

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work, we tackle physical activity but recognize that it is only one component in a complex adaptive system.

Physical activity is not only important in obesity but also in cancer, diabetes, hypertension, hypercholesterolemia, cardiovascular disease, mental illness and mood . This appears to be equally true regardless of age, race and country of origin (Bauman et al., 2012; Heath et al., 2012; Kohl et al., 2012; Pratt et al., 2012). High levels of daily physical activity are associated with decreased morbidity, increased quality of life and prolongation of life-span whereas low levels of physical activity, or "sedentariness," are associated with greater morbidity and shortening of life . Furthermore, spontaneous physical activity decreases with aging and so may be important in sarcopenia. For the last forty years, expert panels have unanimously called for improved methods and tools for measuring physical activity in order to clarify the role of physical activity in health and disease and to better define the effectiveness of strategies to increase physical activity.

Previously it was thought that measuring the amount of exercise people undertake was the cornerstone to relating human activity to health. However, more recent analyses suggest that sedentariness is harmful and that any type of physical activity beneficial. The majority of physical activity that people undertake, in fact (especially the overweight), is accounted for by many low amplitude movements rather than bouts of high exertion exercise. What is more, most Americans do not undertake regular, purposeful exercise and so for them, non-exercise activity represents the vast majority of total daily activity (Blair & Brodney, 1999; Blair et al., 1995).

Community-based participatory research (CBPR) is a community-needs-based approach to collaboratively investigate health issues in a community. In CBPR community members partner with academic experts in a shared purpose to improve the health of the community. The community representatives partner with the scientists in all aspect of the research mission; from concept planning through execution and delivery. The knowledge gained to given to the community to improve health outcomes and then shared with the scientific community to allow for scalability and shared knowledge. CBPR therefore is an ideal platform to enable Native American communities to address childhood obesity, which implicitly involves the interface between communities and individuals (Fischer et al., 1999).

Approximately 1 in 5 American Indians and Alaska Natives live on reservations or other trust lands. About 60% American Indians and Alaska Natives live in urban/metropolitan areas . To understand the role of habitat on the physical activity levels of Native American youth, we compared levels of physical activity between communities of Native children, aged 10-14 years old, living in reservations and urban communities. To compare the data from the Native children with Non-native children, we included urban non-Native children too. The hypothesis was that there are significant differences in reported daily physical activity between the three residential groups of adolescents.

METHODS and SUBJECTS

We surveyed 689 male and female children aged 10-14 years old, in three reservations (N=377), three urban (N=213) communities, and one (non-Native) urban community.

We adapted the International Physical Activity Questionnaire (IPAQ), a validated questionnaire among cultural specific populations, to gather the community-specific data on physical activity (Craig et al., 2003; Hallal & Victora, 2004; Kolbe-Alexander, Lambert, Harkins, & Ekelund, 2006). The IPAQ is a multiple-choice questionnaire that assesses physical activity across a variety of activities, including: leisure time, domestic (chores, yard), school/work related, and transportation. The IPAQ categorizes these activities based on metabolic-equivalents as high, medium or low intensity.

Age, gender, Native American Status, height, and weight data were gathered first. Then, in order to render the CBPR process scalable and reproducible across multiple communities, we automated the IPAQ survey using the Audience Response System (ARS) (Option Technologies Interactive; Orlando, Florida) (Lee & Dapremont, 2012; Tregonning, Doherty, Hornbuckle, & Dickinson, 2012). The ARS is an electronic system whereby each participant is provided with a hand-held keypad. This enables audience-selected answers to be immediately imported into a database. Confidentiality is assured using unique identifiers. Using ARS we were able to gather IPAQ data in up to 131 participants at one time in either a gymnasium or lunchroom.

Specifically, all subjects were trained on how to use the ARS keypad prior to the assessment. Each question was projected onto an overhead screen one at a time; and participants were asked to submit answers. To overcome variance in reading skills, each question and the multiple choice answers were read aloud. We tested comprehension and the system with sample questions before starting the actual IPAQ survey. When responses from the younger students lagged, the pace of question-presentation was slowed. In general, the IPAQ required approximately 30 minutes to complete. In addition to the IPAQ data, we requested qualitative information from our subjects in order to provide the communities feedback specific to their population needs.

We were mindful of not introducing bias in our research approach and so all processes were standardized. In particular, the researcher team was consistent when setting up and describing the study in each setting. Also, each member of the researcher team was introduced and subsequently identified, their tribal identity, their role at Mayo Clinic, the purpose for being in their school, and the study design.

Relevant tribal councils, individual Tribal Review Boards (where existing) gave their approval for this study, and the Indian Health Service National Review Board served as a "review board" for those communities that did not have an established Review Boards. The school principals and the Mayo Clinical IRB also approved this study.

Statistical Analysis:

The hypothesis was that there are significant differences between the three residential groups of adolescents for reported daily physical activity. Questionnaire data were summarized using means and standard deviations. We examined individual demographic and activity-based questions from the survey as well as a set of composite medium and heavy physical activity variables. These latter variables were created by effectively aggregating responses from individual medium and heavy activity questions, respectively, into four inde-

pendent themes: school, outdoor household, indoor household (medium activity only), and other recreational physical activity. We compared activity-based attributes across levels of residency and race using independent simple t-tests. Two sets of pair-wise comparisons were made: urban vs. reservation-based Native Americans, and urban Native Americans vs. urban non-Native Americans. To account for the possibility of imbalances in groups across levels of gender and age, we re-assessed all comparisons using analyses of covariance, treating gender and age as covariates in each model. All statistical tests were two-sided, and all analyses were carried out using the SAS (SAS Institute, Cary, NC) software system.

RESULTS

Comparisons of physical activity levels across the three groups are reported in Table 1. Results indicated that reservation-based Native American adolescents were not less active than their urban counterparts as a part of any physical activity for medium intensity activity ($p = 0.19$), nor were they less active for heavy intensity activity ($p = 0.50$). However, reservation-based Native American adolescents were more active than their urban counterparts for medium intensity outdoor household activity (mean activity minutes per week 243 (SD 297) versus 186 (255), $p = 0.02$), for heavy intensity outdoor household activity (mean 209 (SD 264) versus 160 (223) minutes per week, $p < 0.03$), and for medium intensity indoor household activity (mean 210 (SD 246) versus 169 (211), $p= 0.05$). Interestingly, compared to the Native urban adolescents, the non-Native urban adolescents were more active by half an hour/day for medium intensity activity (mean minutes per week 1208 (SD1209) versus 949 (909), $p = 0.05$) for any physical activity and were leaner by 2 Body Mass Index (BMI) units (mean BMI 20.8 (SD 4.4) versus 22.4 (SD 5.3), $p=0.008$, Figure 1). Notably, such as the reservation-based Native American adolescents, the non-Native urban adolescents were more active for medium intensity for outdoor household activity ($p = 0.04$) than their urban Native counterparts. The non-Native urban adolescents were also more active for medium intensity activity as a part of school minutes/week than their urban Native counterparts ($p < 0.04$). No statistically significant differences in recreational physical activity were observed across the three groups. Sensitivity analyses adjusting for the potential confounding effects of age and gender yielded similar results to the unadjusted results (data not shown).

DISCUSSION

Obesity is a symptom of imbalance between dietary and physical activity associated factors. It is influenced by biological and environmental factors. Obesity is more common in the American Indian populations than the general U.S. population (U. S. Department of Health and Human Services 2002). Prior studies suggest that increased physical activity may offset and perhaps prevent unhealthy and risky lifestyle choices (Anderson-Lewis et al., 2011; Backman et al., 2011; Davis, Goldmon, & Coker-Appiah, 2011; Eisenmann et al., 2011) that disproportionately afflict American Indians (Hassin, Joe, & Young, 2010; Ritenbaugh et al., 2003; Whitt-Glover, Crespo, & Joe, 2009). Successful promotion of culturally attuned physical activity programs (Hassin et al., 2010; Ritenbaugh et al., 2003; Whitt-Glover et al., 2009) may lead to decreased metabolic disease, decreased cancer, improved mobility, improved mental health and decreased mortality. While the importance of obesity on American

Indian health is agreed and the role of poor quality diet and food proportion has been well studied, little is understood about the interplay between reservation and urban environments with respect to physical activity participation in American Indian youth (U. S. Department of Health and Human Services, 2002). This project was conducted with Native American and non-Native communities to examine physical activity in Native American youth living on reservations and in urban centers. We can conclude that urban and reservation-based environments were associated with similar levels of LOW physical activity in Northern Plains Native American youth. Our findings suggest, that Native American youth in the same environment as their non-Native cohorts expend less physical activity.

Low levels of physical activity are known to be of concern in Native American communities. For example, The Bemidji, Minnesota, area Red Lake Band of Chippewa and the White Earth Band of Chippewa were participants in the "leisure time physical activity study" (Fischer et al., 1999), which revealed that the tribes in Minnesota (as well as, the Menominee tribe in Wisconsin) had statistically significant lower "leisure time physical activity" than that of their non-Native counterparts. While these findings addressed the role of Physical Activity in adults when compared to non-Native adults, this study did not look at Physical Activity among American Indian populations nor did it address the role of Physical Activity in the adolescent population. The purpose of our study was to examine Physical Activity in adolescents because data demonstrate that adolescence is a critical time in a person's life when lifestyle choices are made (Hassin et al., 2010; Ritenbaugh et al., 2003; Whitt-Glover et al., 2009). Adolescents are particularly impressionable and influenced by what's available in their immediate surroundings. A recent study has shown that simply promoting activity while participating in otherwise sedentary activities, such as watching TV or playing video games, adolescents more than doubled energy expenditure (Lanningham-Foster et al., 2009). We decided, therefore, to quantify daily physical activity in Northern Plains American Indian adolescents and compare reservation-based and urban populations.

There were several limitations to the study that we recognize. First, the data were gathered using a questionnaire albeit via a fully automated Audience Response System. However, for the number of children we included (about 700), this was the only feasible approach for us to address our hypothesis. In future studies we hope to use electronic tools such as triaxial accelerometers (Lanningham-Foster et al., 2006). Second, self-reporting limitations occur. One explanation is that retrieving and/or processing the idea of how much time is spent performing an activity may be a novel concept and challenging to comprehend for the younger students. In our studies we found this; especially where younger students would occasionally delay the session and as a result, might have experienced a sense of urgency from older students to hurry. To address this in future, we suggest breaking out the test groups according to age/grade level. Nonetheless, although this phenomenon may have had an effect on some of the responses, age- and gender-adjusted analyses produced similar results to unadjusted analyses, indicating no systematic biases due to these effects. Third, the IPAQ was not specifically adapted for this population and we recognize this as a limitation. However, this would not have added bias to our examination of urban Native and reservation-based Native youth; our principal question. Despite these limitations,

we conclude that urban and reservation-based Native American children in these groups were similar in their levels of physical activity.

While this project was conducted in order to examine environment on Native American youth physical activity, we also sought to demonstrate the feasibility of conducting physical activity research conducted with Native American communities in Native American Communities. Our goal was to devise, test and validate tools that could be used by community-trained research associates. While the scientific community may benefit from data such as ours, we argue that it is communities themselves might most benefit from participation in and designing locally-based, locally -used, locally -interpreted research protocol. The tools we used (Audience Response System) (Lee & Dapremont, 2012; Tregonning et al., 2012) allowed not only for school students to answer the questionnaires in real-time but also for the community to receive analysis and feedback in real time. Linking data gathering to data response; we believe can improve the derivation and delivery of useful data; gathered and used by the community itself – the essence of Community Based Participatory Research (Anderson-Lewis et al., 2011; Backman et al., 2011; Davis et al., 2011; Eisenmann et al., 2011). This is borne out by the work of others; for instance, if the community is invested in the development of the design of the study, it leaves little room for translational gaps when addressing the findings (Burhansstipanov, Christopher, & Schumacher, 2005). Devising and delivering models for locally devised and conducted research may be a powerful tool for community change.

With respect to obesity (and potentially other sensitive health issues), concern might be raised that the issues germane to body weight are too 'sensitive' to be discussed in an intra-community research model. Our experience argued against this. Specifically, when discussing body weight the message, that energy out (physical activity) must exceed energy in (caloric consumption), in order to lose weight or to reach a healthy body weight; was well received and precipitated active and involved discussion. Moreover, it was understood at the community level that, (A) energy in must equal energy out, in order to maintain a healthy body weight and (B) such health interventions are not a cultural challenge, (C) decreased obesity and its contribution to the diseases a population disproportionately suffers from, will result in preserving the culture, (D) addressing the issues affecting the current generation does not have to depend on outside food resources or even science (i.e.; the intra-community research model discussed above), (E) modifying traditionally healthy behaviors such as gathering of food sources, food preparation, cooking, collecting, honoring ceremonies through dance, story telling, and socializing can lead to a decrease in unhealthy, non-traditional sedentary activities and lifestyle choices. These messages, we found, were welcomed and positively received in what became an internal and two-way dialogue.

These studies demonstrate an intra-community model for conducting Community Based Participatory Research (Figure 2), whereby the entire process of research-question-though-outcome is centered on community-perceived need. Here the community not only asks the pertinent question but conducts the research and owns the output. The data in this study underscore a concern that Native American youth may be less active than is healthy. This concern does not, we discovered,

depend upon whether the child lives on a reservation or in an urban environment.

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Prior research experience includes her work as co investigator and research coordinator responsible for the recruitment of all the subjects in the studies performed in Dr. James Levine's Non-Exercise Activity Thermogenesis (NEAT) laboratory.

Ms. Baukol is often invited to present at local and national forums to discuss performing research in Native communities that is culturally appropriate and respectful. She is a proud member of Turtle Mountain Band of Chippewa.

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Facilitating the Success of Native Investigators in Research Careers

Teshia G. Arambula Solomon, PhD
Director of the Native American Research and Training Center

Linking Disparities in Health to a Paucity of Native Investigators

Native people worldwide have long experienced health status worse than that of the non-Native population. Native Americans experience higher rates of disease than other non-Native populations across many areas of health, including diabetes, HIV/AIDS, certain cancers, mental health, and substance use. Factors known to contribute to health status and disparities are complex, and may include multiple social, economic, environmental, and biological factors. Unfamiliarity with our complex health care system may adversely influence health status and also may reduce the acceptability of health research. However, a history of unethical research practices, inaccurate interpretation of findings, and little change in the health status among Native people has created an environment of distrust of research and researchers by Native communities. Building the capacity of Native communities to develop and implement their own research programs and by involving Native researchers as lead investigators could help repair trust relationships in research leading to a reduction in health disparities.

Disparities in Educational Attainment

While data is sparse, the number of Native American scientists and health scientists is significantly lower than any other racial or ethnic group (National Science Foundation [NSF], 2008). We know that this disparity exists along the entire educational pipeline with fewer NA students graduating from high school and college and with fewer applying to graduate programs and health professions programs. Typical barriers to education for any population include poverty and a lack of role models but the historical abuses in the name of education create a barrier that is unique to Native communities.

The Institute of Medicine recommends increasing the number of minority health professionals as a key strategy to eliminate health disparities (Smedley, Butler, & Bristow, 2004). Despite years of efforts however, to increase the number of scientists from underrepresented groups, the number of Native American students in the health sciences is very limited. According to the National Science Foundation in 2006 there were 29,854 doctorate recipients of science and engineering degrees of which 52 were American Indian/Alaska Native (0.17%) (NSF, 2008). Retaining students over the long complex academic career path that can take well over 14 years is key. And graduating with a terminal degree does not immediately translate to an independent research career. The Council of Graduate Schools (2009) reports that of 130,957 graduate students enrolled in health science programs in 2009, there were 892 American Indian/Alaska Natives (AIAN) (0.7%). Strategies found to be successful in working with Native American students include providing research training opportunities, professional skills development, peer networks and role

models (Pewewardy, 1999). Peer relationships can provide considerable influence on student success (Astin, 1993; Nora, 1987; Spady 1973; Terenzini & Pascarella, 1977; Tinto, 1993). Support, guidance, and role modeling is a key function of mentoring soon-to-be scientists (Grossman & Rhodes, 2002; Kram, 1985). *It is critical to surround students and trainees with role models who can facilitate resources and serve as champions.* Mentors must link trainees to those activities prized by both the academic community and the science enterprise, which includes opportunities to publish.

Native American Research Centers for Health (NARCH)

In order to increase the number of Native American scientists, the National Institutes of Health (NIH) in collaboration with Indian Health Service (IHS) developed the NARCH program. NARCH creates collaborations between Federally recognized American Indian and Alaska Native (AI/AN) Tribes or Tribal organizations and institutions that conduct intensive academic-level biomedical, behavioral, and health services research. The purpose of the NARCH initiative is to reduce health disparities, enhance partnerships and reduce distrust of research by AI/AN communities while developing a cadre of AI/AN scientists and health research professionals. The funding also allows Tribes and Tribal Organizations to build research infrastructure.

The Faculty Researcher Development Program at the American Indian Research Center for Health (AIRCH)

The Faculty/Researcher Education and Development program (FRED) at the Native American Research and Training Center (NARTC) at the University of Arizona (UA) provides such opportunities. One such opportunity is the set of articles presented in this issue of the Fourth World Journal.

The Center for World Indigenous Studies in partnership with the NARTC created this special opportunity for the FRED Fellows. This collaboration provided the rare opportunity for the Native investigators to meet the academic requirement of information dissemination through publication, but also to meet the expectation of their communities to provide information to the Native community through this journal. The Fellows were responsible for developing a theme of articles, creating the call for papers, and working with the editors to pull the manuscripts together for review. They received invaluable experience in science writing with feedback from senior investigators and in working to bring a collaborative academic work to fruition.

Summary

Preparing a critical mass of Native investigators in health is an extension of the assertion of sovereignty by setting the research agenda to benefit Native Nations. Highly skilled and trained Native scientists are a critical component for the elimination of health disparities and scientific inquiry. Creating opportunities for Native scientists to succeed, including opportunities to publish in an environment that understands the delicate nature of research in Native communities benefits the young investigator, the publisher, and the community.

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