Pueblo Health: Examining Indigenous Concepts of Well-Being and How Perceptions Have Shifted to Health Today

by

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ABSTRACT

Indigenous Pueblo conceptualization of living well today has shifted mainly due to Federal policies that forced Pueblo people to conform to western way of living moving away from a lifestyle that embraced holistic practices. Native people cannot escape how Western society has shaped the concept of health however, the voices of the Pueblo people and others working in health, acknowledged that Indigenous philosophies, beliefs and practices need to be part of Native health conversations today. My discussion problematizes Native health characterized today as typically represented through the biomedical perspective with the primary focus being the body. Such a limiting perspective dismisses the importance of Indigenous philosophies that embraces broader concepts of well-being to include holistic elements of physical, mental, emotional and spiritual well-being. This study examines the shift in perceptions seeking input from patient and medical providers regarding their interactions, particularly communications in a healthcare setting. Pueblo patients defined what was important in their communications with their health provider. Likewise, health providers referred to their experiences providing healthcare to Native patients to describe what is important to know when treating a Pueblo patient. Patients identified family (without specific medical family histories disclosed), knowledge/beliefs that were or were not associated to the patient's culture, as well as community and family dynamics (that did not delve into traditional medicine or sacred ceremonial activities) as important for their provider to know. The results from the research study highlights the need to examine Native American cultural

diversity education in healthcare including advancing improvements in the training of medical providers.

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When I started my journey to obtain a Ph.D. in Justice Studies, I had no idea what I would encounter. The journey was challenging from the beginning, and at times I felt I could not do this anymore. Now that my dissertation is done, and I reflect on everything I struggled through I remember the words of the Elders, "It's not easy to be a Pueblo Indian, just do your best, that's all we ask." These words reflect my sentiments, but I could not have made it this far if it were not for the people who believe in me, encouraged me, were patient with me, guided me, were firm with me, and cried with me. Askali, Ta aa, to Leadership Institute (LI) at the Santa Fe Indian School, Carnell Chosa for checking on me and taking care of all the expenses that supported my participation in this cohort. Regis Pecos, for your strong support, for being a great mentor, and for being an awesome teacher. Dalene Coriz and Camilla Quam for taking care of the LI shop and taking of everyone else in the entire LI, you both do an awesome job! Askali, Ta aa to my cohort brothers and sisters—I am so proud of every one of you, you have made a huge contribution to Pueblo knowledge. Askali, Ta aa to my committee, Tsianina Lomawaima, Elizabeth (Eli) Sumida-Huaman, and Josée Lavoie. Words alone cannot convey how grateful I am for all that each of my committee members have done to help me accomplish this. I know I was not an easy student to work with but you hung in there with me. Askali, Ta aa, Na tra to my family, my husband Mars, my daughters Leticia and Cynthia, my son Marz Jr., my three granddaughters Stefanie, Maddie and Jocelynn. You all BELIEVED in me and supported me despite not knowing what I was writing about. I hope this will make you proud because it is about our family, the need to heal and create

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PREFACE

This dissertation is the result of a major initiative to expand graduate education opportunities with and for Indigenous people, which was spearheaded by a partnership between Pueblo leadership and institutions, specifically The Leadership Institute at the Santa Fe Indian School (LI) and core faculty at Arizona State University, namely Elizabeth Sumida Huaman and Bryan Brayboy. They co-designed a dissertation format containing a journal article, a book chapter, and a policy paper that together could be utilized by Pueblo Indian institution, communities and other Indigenous communities more broadly. This dissertation follows that vision. I begin with the book chapter concept, which is intended to offer more theoretical insights based on literature reviews and insights gained from my research and where the audience includes scholars, researchers, community members, students and practitioners. The book chapter focuses on theoretical frameworks introduced based on empirical evidence. The journal article follows and is intended to provide a full description of the research study, and in the dissertation format envisioned by the LI and Drs. Sumida Huaman and Brayboy, is intended to serve as the basis from which authors can consider publishing one or more peer-reviewed journal articles in the future. Last in the dissertation format, the policy paper was designed to offer practice/application recommendations based on the research that Pueblo cohort members completed and that could speak to our constituents, which in my case is the Pueblo leadership, community members interested in Native health issues, and institutions like the University of New Mexico and its Sandoval Regional Medical Center.

At its core, my dissertation reconsiders health according to Pueblo Indian conceptualizations of well-being while also offering a critique of dominant western notions of health that contribute to tensions between American Indian populations and western health systems, specifically in Pueblo Indian country in the U.S. state of New Mexico. There are major themes that cut across the dissertation chapters. For example, I acknowledge that U.S. federal policies forced Native people to conform to western ways of living, moving away from a lifestyle that embraced holistic practices. In the U.S. for example, federal government policies were designed to assimilate Native Americans into mainstream lifestyles that disrupted their Indigenous knowledge systems. Today however, Indigenous philosophies, beliefs and practices are increasingly included in Native health conversations, thus expanding the discourse from the focus on physical health to broader concepts of "well-being" that include holistic elements—physical, mental, emotional and spiritual well-being (McCubbin, McCubbin, Zhang, & Kehl, Relational well-being: An Indigenous perspective and measure, 2013).

In this dissertation, I examine major issues, including Native health challenges related to science and industry where I suggest that the health industry, federal and state governments' control the health narrative through the publication of health reports that are strictly based on science-based data limit the information about the people to numbers, and misrepresent the complexity of our reality. Additionally, I analyze individual perspectives of health and perceived challenges in the research and argue that the Native patients in my study view their well-being based on limited bio-physical assessments to gauge health which contradict their own Indigenous philosophies of health

based on values, beliefs and practices. The imperative of bringing forward these stories speaks to the lingering effects of colonization and the impacts on Native perceptions' of health, and in this dissertation, I elaborate on the effects of Western scientific definitions on Native American health noting that it reinforces the values and beliefs of the larger dominant society while minimizing the importance of Native culture, practices, and beliefs or in some instances, are ignored. This is significant for the final section of my dissertation that offers policy recommendations based on study findings—meaning, how can Pueblo community, local, and genuine patient-provider partnerships regain control over narratives that influence how resources are applied and strategies for health care reconsidered?

Aligned with the dissertation format expectations for the Pueblo/Indigenous cohort program, the framework of the book chapter further deepens exploration of Pueblo philosophies conceptualizing well-being that reflect what is referred to in New Mexico as "the Pueblo way of life." I examine shifts from Indigenous philosophies of well-being to Western focus on human physiology. As Native health is of concern in health research and practice, work is being done to incorporate Indigenous knowledge and practices in health interventions, recoveries and revitalizations, and my research is an opportunity to consider Indigenous ways of knowing and doing to address the health issues Pueblo people are dealing with today. I thus draw from models that incorporate Indigenous knowledge and practices to illustrate how life changes that align with Indigenous cultures and contexts might support improvements in health conditions.

My research introduces Pueblo values and beliefs as the foundation for research and relationship-building with Indigenous peoples and toward a more refined focus on patient-provider interactions, especially communications between the Pueblo patient and health provider. My research examines what Pueblo patients consider is important in their communications with their health provider, and likewise, health providers refer to their experiences providing healthcare to Native patients to describe what they believe is important to know when treating a Pueblo patient. As communication and relationship-building are process-oriented changes, it is my hope that read as a whole—from in-depth research description to theoretical frameworks to policy recommendations—can serve a collaborative process where Pueblo communities, patients, and providers can reflect upon what has been shared in this work.

CHAPTER I

PERCEPTION OF HEALTH CHALLENGES: A PUEBLO PERSPECTIVE

Introduction

This section of the dissertation first acknowledges settler colonialism as impacting Indigenous societies in a multitude of ways—physically, mentally, emotionally—which impact health as we understand it today. I review some of the major challenges for contemporary Indigenous and Pueblo health in the U.S. and attempt to pay attention to the diversity with and among Indigenous communities, as well as the relationships and distinctions between individual beliefs and practices and community beliefs and practices. I provide a brief overview of my research with Pueblo patients and Pueblo and non-Pueblo providers with one healthcare system in New Mexico in order to highlight what is distinct in these interactions with special attention to ideas of culture—where culture is unpacked in my research according to its role in the health of Pueblo people and medical interactions and recommendations for particularly non-Pueblo provider interventions.

Major Indigenous health challenges

Indigenous concepts and practices of health and well-being are increasingly being used to address current health challenges among Indigenous populations, but the work is slow because many, including Native people themselves, are readily convinced that Western medical approaches provide the best solutions to the health issues that Natives face today. Native perceptions of health are influenced by what is happening in the larger society. For instance, health reports describe Native Americans as experiencing poor

health status when compared to other populations. As new reports are issued, Native people are led to believe Native American health is not improving (NM Dept. of Health, 2014; U.S. Dept. of Health & Human Services, 2015). Western science directs the implementation of the modalities used for cures and therapies, so society is convinced that improvements in health are only those implemented by those trained in Western science approaches. Fearing being diagnosed with a disease and being convinced that only Western medicine cures all illnesses, Native peoples disregard some of the fundamental principles for "living well" that are central to their own Indigenous philosophies: daily prayers, hard work, compassion for others, good thoughts (Naseyowma, 2016).

As health statistics indicate that Native American health status continues to decline, Native people seeking to restore health concepts grounded in Indigenous knowledge and practices, are attempting to identify meaningful methods and treatments to improve Native health and to re-instill confidence that Indigenous livelihood is the prescription for well-being. Native health is based on "ideals rooted in cultural norms and values that extend beyond the state of physical body" (Adelson, 1998, p. 6) and is not only the absence of disease or mental illnesses as Western interpretations would lead us to believe. Today, however, Native health is typically dominantly represented through the biomedical perspective with the primary focus being the body. This perspective limits the interpretation of what makes a healthy person to be a body that is free of disease (Adelson, 1998). Furthermore, definitions of health change over time as society changes. In the past, many Native American concepts of health and well-being were closely

interwoven with the lifeways of Indigenous people. For example, Pueblo political advocate and co-Director of the think-tank Leadership Institute (LI) in New Mexico, Regis Pecos, has argued that Indigenous health/well-being is "living well" or as people understanding the intimate relationship with their natural environment and being involved in traditional practices and ceremonies. He states that *engagement in ceremonies* positively affects physical health, spiritual beliefs, self-worth, and fosters the development of compassion for others (Pecos, 2007). Native conceptualizations of health such as this are not readily known today or accepted as legitimate due to disruptions caused by colonization and other oppressive acts (Hodge, Gordon, & & Cross, 2009; Linda Bane Frizzell & Donald Warne, 2014). Instead, definitions of health and well-being reflect the ideals of middle-class Americans and are perpetuated by modern Western biomedicine and physical science (Crawford, 1994).

Today, Native peoples' understanding of their health echo ideals and perceptions found in the greater society; the Indian Health Service (IHS), the federal agency responsible for the healthcare of American Indians (Native Americans) reinforces these perceptions through the publication of health reports. These IHS health reports use statistics such as mortality, morbidity, and hospital or outpatient utilization data to describe the state of Native American health. Information such as the leading causes of death (mortality), the top ten health conditions (morbidity), as well as the information detailing the reasons Native individuals sought healthcare (utilization), are used to define the health of Native Americans today (Indian Health Service, 2015). The reason this is

problematic is because reports like this focus only on the deficits contributing to the existing narrow one-sided descriptions of Native American health.

What is known about Native American health today is predominately illness and disease, so it is then unsurprising that Native peoples consider understandings of health as primarily related to health conditions (categorizing illness) and medicine (to treat disease). However, multiple authors (Gone, 2011; King, Smith, & Gracey, 2009; Suina, 2016; Walter, 2017) have argued that Native health statistics need to be considered within a historical as well as sociocultural context, because definitions of Native health and well-being were not always limited to illnesses or physical conditions. It would appear that understandings of Native American health are recently shifting from those in the twentieth century that focused on Western medicine including medical care and treatments to Indigenous concepts of well-being and types of healing (Tlatilpa, 2015). Adding to this shift, many experts in Native health have also argued that the underlying causes of the current health crises are a result of specific factors related to colonization, globalization, migration, loss of language and culture, and disconnection from the land (Adelson, 2000; Chino & DeBruyn, 2006; Gone, 2011; Suina, 2016; Warne, 2005). The argument is that Native peoples experienced drastic and quick changes in their Indigenous way of life resulting from these factors; however, researchers and Native peoples today are still learning how these factors directly or indirectly influenced their own and others' perceptions of Native health today. In this section, I have generalized some of the broad concerns regarding challenges to both perceptions and realities in Indigenous health. In the following sections, I further delineate these challenges into

three main themes—*challenges related to science and industry*, *factors that contribute to perceptions of Native health today*, and *individual perspectives of health and perceived challenges*—before focusing more closely on Pueblo Indian conceptualizations of health and what is being done more recently (in the past two decades) to rethink health in ways linked with cultural practices and values.

Challenge #1: Native Health Challenges Related to Science and Industry

One of the challenges in Native health is understanding how Indigenous and non-Indigenous patients and service providers arrive at their conceptualizations of Native American health and how their definitions of health in relation to Native people influence perceptions of personal, family, and community health that may have policy implications. Research methods linked with interventions and treatments intending to address Native American health depend on ideas and initiatives developed at the national and state levels. At the national level, the Indian Health Services (IHS) in the U.S. is responsible for healthcare services for Native American tribal members with resources provided by the federal government (Tlatilpa, 2015; U.S. Dept. of Health & Human Services, 2015). At the state level in New Mexico, where my research was conducted, the state addresses Native American health in the same way it approaches other populations—specifically, tribes and Native American entities compete for health resources so a few tribes are awarded funds. Therefore, in the health industry, federal and state governments ostensibly determine how Native American health is addressed. For instance, both federal and state government entities produce information that define Native American health needs, and these same entities control the funding towards those needs. Based on

identified health needs, the expectation would be to provide financial resources to those populations needing the most assistance in those areas. However, Native projects and services that receive funds are expected to apply methods and strategies proven to be effective in *general populations*. This is a complex dynamic that impacts research, treatment, and popular perceptions among those invested in Native health issues; at the very least, Native projects and services must conform to health goals and measures fit to those suited for middle-class White Americans (Crawford, 1994).

One example of this tension that may be readily relatable is in the area of weight loss. For the sake of conversation, in Pueblo Indian communities, let us assume that losing weight or being physically 'prepared' for the rigor required to participate in certain community functions is firmly connected to Pueblo values, beliefs and practices; meaning, in order to "take part" in ceremony, one's physical health is viewed as important. The notion of "taking part" is filled with expectations that are geared towards a person's completing the ceremony from beginning to the very end, where ceremonies are not just day-long stand-alone activities. Today, however, perhaps only a few Pueblo people may exercise regularly, and "getting ready" for ceremony starts weeks before we are called together. In my own observations, I have seen people usually start jogging, cutting back on sodas, drinking more water, as well as mental preparation that involves clearing the mind of bad thoughts. Many community members I have spoken with worry that they may not finish the ceremony and fear people noticing and saying that they "did not do things the right way." These are critical implications for one's physical health because from a Pueblo traditional perspective, the health of the individual is directly tied

to the health of the community, and the health of the community relies on the individual to participate in ceremony. At the same time, actions associated with preparing oneself to be physically able to participate in ceremony also requires more than exercise and is a mindset because “taking part” is associated with spirituality, obligation and the commitment to upholding cultural practices and beliefs. We can see then that physical health and actions like weight loss are linked with something deeper, not only with one’s physical appearance in looking and being thinner, which has become an industry in and of itself linking media with popular health.

I have witnessed Pueblo people, like others, drawn to current health trends like thinness. Although losing weight is not a new phenomenon, what is new are the methods used to lose weight. I have been intrigued by personal conversations where Pueblo women describe their methods for weight loss. They talk about why they want to lose weight, strategies, and how to gauge success. One lady wanted to lose weight because she did not want to buy bigger clothes. Another said she wanted to lose weight so she would be ready to dance for the feast. Then there was the woman who just wanted to be slimmer. Plans for weight loss included quitting drinking sodas, stopping eating carbohydrates, and even creating elixirs like apple cider vinegar made with herbal tea and lemon. During the times we interacted, each reported some success losing weight along with clothes fitting loose, feeling energized, and ridding the body of toxins. An interesting comment came from the apple-cider-vinegar drinker, who said that the drink tasted terrible, but the benefits outweighed the awful taste; it cleansed her body and burned body fat. The young woman had learned about the apple cider vinegar drink from

Facebook postings and got the recipe from YouTube. I do not recall any references to concerns about their physical health or how losing weight would improve their multiple forms of health. This example illustrates that Pueblo women, like most other women in mainstream society, consider a slender body to be an important aspect of their physical image and the primary fuel motivating their weight-loss goals. The desire to attain a slender body is important for many women and they use quick and easy methods to achieve this goal (Adelson, 2000). We see women enticed by weight-loss methods that do not require changes in diets or becoming physically active. Instead, women are turning to appetite suppressants, special concoctions, expensive weight loss programs, or medical procedures to reduce stomach size or get rid of fatty tissue. These quick fixes stem from what is marketed in mainstream society as methods that produce quick results.

Complicating our understanding of health, powerful federal and state governments, pharmaceutical, and medical groups are known to manipulate health information to serve their interest and needs (Adelson, 2000; Bane, Frizzell & Warne, 2014; Crawford, 1994). In these cases, science is implicated. For example, Robert Crawford (1994) argued that the Western scientific model of medicine is based on disease or illness and "negates the conventional self - understood as 'healthy,' with illness implying blame and irresponsibility" (p. 1355). If we look at the example of obesity, which is filled with stigmatizations, Rebecca Puhl and Chelsea Heuer (2010) point out the harmful weight-based stereotype that "overweight and obese individuals are lazy, weak-willed, unsuccessful, unintelligent, lack self-discipline, have poor will power and are noncompliant with weight loss treatment" (Puhl & Heuer, 2010, p. 1019).

Relatedly, health statistics categorize Native Americans as having the highest incidences of Type II diabetes (NM Dept. of Health, 2014; U.S. Dept. of Health & Human Services, 2013; Indian Health Service, 2015), and the recommended strategies that focus on blaming the individual pay little consideration to the lifestyle changes Natives endured due to federal policies that led to loss of Native lands and severe almost overnight changes to traditional land-based lifestyles. The problem then is that the stigma of obesity and a number of other ways of characterizing Native peoples will often be described in health statistics and reports as preventable but without the contextualization regarding historical issues but also current assets (e.g. the Pueblo example of physical fitness in relation to ceremonies). These characterizations can impress on readers and policymakers that Native Americans are irresponsible and, in some instances, even hinder their own care (Puhl & Heuer, 2010).

Important to recognize is from where conceptualizations emerge: Crawford (1994) argued that "health and healthy" are concepts rooted in classism, and at the core are practices that promote capitalism. For instance, the overprescribing of opioid pain medications by medical practitioners began with the powerful pharmaceutical industry incentivizing health care providers for prescribing pain medications in an attempt to increase pharmaceutical sales and capital worth. In popular media today, we can see that the opioid epidemic is rampant in our society causing havoc in all aspects of living today and across race and gender demographics. I have personally experienced this with a family member, who became addicted to medication prescribed to cope with the pain resulting from an accident. Eventually, his dependency on pain medications opened the

door to heroin. Today, our family deals with the emotions, frustrations, fears, and anxiousness of an opioid-dependent person. Increasingly, practitioners are exercising more caution when prescribing pain medications. Unfortunately, pharmaceutical industries continue to provide considerable incentives to health care organizations that purchase these medications, while releasing often biased or incomplete information on possible side-effects (Naseyowma-Chalan, 2015).

It is also important to note that conceptualizations of health, self-identity—including who we are, what we know and where we come from—influences our viewpoints of health and well-being. Crawford (1994) described health and the pursuit of health as "a ritual of personal regeneration in which middle-class identity is secured and conspicuously displayed" (Crawford, 1994, p. 1347). He argued that health today is central to modern identity; health implies what it means to be a good, respectable, and responsible person (p. 1348). In his study of health, Crawford discussed the ties between self-identity and health and concluded that the massive social, economic, and cultural changes of the modern world influence our perceptions of health. His statement, "individuals re-create themselves by way of projects that represented the new order and their desired place within it" (p. 1348) explains the phenomenon associated with the notion of the "healthy self," which remains a popular construct today. As middle-class populations of the commercial and industrial societies of Europe and America expanded, the commodification of health became an essential component of what it meant to be modern, progressive, rational, and distinctive (p. 1349). These characteristics are thus viewed as normative. Crawford's arguments help us to rationalize the health movement

today whereby achieving a "healthy self" aligns all of us with normative standards of living.

Health Disparities and Influences on Native American Health

Like Crawford (1994), I argue that normative standards of living form the basis for broader definitions of health, and health statistics are instrumental in this process. Health statistics provide visual and other interpretations to describe the data, but rather than being straightforward, data can be understood and interpreted differently depending on the audience. When focused on Native peoples, the words used to elaborate on their health conditions that are drawn from statistics overwhelmingly imply deficits and hint that individuals are to blame for their persistent health challenges. Health data and related narratives constructed by non-Native scientists are dominant examples of how Native Americans endure the effects of colonialism today through the propagation of data that lends itself to further oppression and discrimination (Adelson, 2000; Cajete, 2005; Dozier Enos, 2015; Gone, 2011; King, Smith, & Gracey, 2009; Pecos, 2007; Suina, 2016). Additionally, despite any negative constructions of Native health, support for interventions or programming is often unstable. For instance, IHS is not a federal entitlement program as its funds are obtained through a special supplemental appropriation. Consequently, access to health care for Native people may be inhibited due to resource limitations, which Tlatilpa argues is a deliberate act aimed at disenfranchising Native Americans thus, impeding their access to healthcare and adequate resources to address their unique needs (2015).

What I am attempting to argue then is that Native health disparity and health inequity are concepts that need to be at the forefront in order to bring awareness to just how extensive and complex Native health is. We know that differences in health are noted between social populations based on race, income, gender, disabilities, and geographical location (Whitehead, 1991), and these differences highlight biases that exist and point out injustices that not only is not everyone is afforded the same opportunities and access to healthcare in the U.S., but also that the very construction of their health is defined by others for them. Whitehead defined health equity as the "moral and ethical dimensions of differences that are avoidable, unnecessary, unfair and unjust" (p. 219). Health inequities are regarded as biased against specific social groups and can result in a poor survival rate due to a heavier burden of illness and the onset of illness and disability often at a younger age (Whitehead, 1991). Health disparities are considered inequities if "unnecessary and avoidable." They adversely affect populations who have systematically experienced greater obstacles to health services and other determinants of health (employment, access to educational opportunities, etc.) because of race, ethnicity, religion, socioeconomic status, gender, age, mental health, cognitive, sensory, or physical disability, sexual orientation or gender identity, and geographic location (U.S. Dept. of Health & Human Services, 2013). Health inequities are associated with poverty, illiteracy, and lack of education, to name a few (Whitehead, 1991). Whether the circumstances are related to health inequity or health disparity, both bring attention to the injustices that continue to plague our society.

Three decades later, Whitehead's message is still relevant that disadvantaged populations in the U.S. continue to die at younger ages, experience more illnesses, and are least likely to receive high standard healthcare (1991). In Native cases, her arguments validate that discriminatory practices, unjust laws and economic and political disadvantages are the result of colonialist and paternalistic wardship that continues to impact the lives of Native American people. However, conversations regarding health can be expanded with health experts and researchers who are interested in learning how health policies and systems do not align with the needs of all populations in the U.S., and it is this moment to which my research seeks to contribute.

Western Science Data and its Influence on Native American Health

I would be neglectful if I did not touch more closely on the role of science in Native health. Native American health is understood through health reports, and these reports largely contain a reoccurring theme that Native Americans in the U.S. experience the worst health outcomes compared to other races. This is not a racial or ethnic competition for who has the "worst" health situation as there are needs for more nuanced research questions and approaches that consider the health of all populations across context and time. However, as my interest is in impacting ideas of Native health that empower Native communities, my work has been to focus on details within these reports that imply self-culpability. As stated earlier, research concludes that most of the health conditions that contribute to Native Americans' poor health status are preventable, directly and indirectly implying that this diverse population of over 570 tribal nations in the U.S. lags in behaviors such as eating healthier, being more physically active, and

engages in unhealthy activities such as smoking too much commercial tobacco and consuming excessive amounts of alcohol (for examples, see NM Dept. of Health, 2014; U.S. Dept. of Health & Human Services, 2013).

With regards to health data focusing on Native physiological health, reports have also convinced Native people and health practitioners that numbers—blood pressure, weight, body mass index, to name a few—define the individual state of health. I have often wondered if this information has adversely affected the confidence of my own Pueblo people and caused them to question the benefits of using Indigenous knowledge and practices to address health conditions. In other words, Pueblo people, like most of society, tend to place their trust and confidence in Western medicine, so it is not surprising that Western treatments and interventions are considered before traditional curing and healing practices.

Numbers and the science behind them matter, and as Maggie Walter, an Indigenous sociologist whose research focuses on race relations, inequality, research methods and methodologies explained, "as we invest ourselves and our communities in the defined categories, we increasingly use statistics to help us tell ourselves who we therefore define our relationship as though they constituted as real things" (personal communication, 2017). In other words, health statistics extract problems and if this information becomes the only source used to understand Native American health, the opportunities to address Native health are limited (Adelson, 2000; Suina, 2016).

At a Tribal Data Sovereignty Institute held in Pueblo lands in New Mexico in 2017, I had the opportunity to listen to Dr. Walter and to meet her. She presented her

research on Western science-based data and explained that Western data narratives are designed and executed to maintain the status quo and cautioned anyone using science-based data to "be aware of who is presenting the data, what is the data being used for, and who the data is for" (personal communication, 2017). Data interpretation is not always clearly understood by those reviewing the data. The cultural and social realities reflected in statistics but not identified as such are loaded with viewpoints of those controlling the information. I see data as a powerful tool used to hold government accountable to their citizens; in the case of Native Americans, data can be useful to hold the IHS accountable: Health statistics remind us that Native American health is not improving even with resources being put towards systems improvements to address those critical health issues. At the local level, I have seen many Pueblo people accept the label of being called unhealthy, which leads to validating efforts to address health directed toward the physical aspects, mainly body weight, once again conforming us to the Western middle-class standards to which Adelson (2000) referred.

Challenge #2: Factors that Contribute to Perceptions of Native Health Today

Native Americans may not necessarily be aware of the factors that form the perceptions of health we have come to accept, nor perhaps do those working in health fields have the opportunities to learn and reflect on what influences the health perceptions and realities of Native Americans. For example, many Natives are now learning how the vast changes in Indigenous lifestyles began with the implementation of federal policies created to terminate their populations, followed by policies to assimilate them into Western European society. I have observed in my own Pueblo communities that people

are realizing how closely colonization impacts our lives today, and in our own learning settings, we are asked if what we are doing [programs and services] today moves us further from our Pueblo values, replicating government policies, or closer to those values that we wish to reclaim, encouraging us to be mindful of what we believe and how we work and holding us accountable to ourselves and to our people (The Leadership Institute at Santa Fe Indian School & Sumida-Huaman, 2018). As a Native health researcher and advocate for reclaiming Pueblo understandings and practices of wellness, I understand that the federally and scientifically-informed strategies used in current services and programs, in fact, may continue to dismantle Indigenous belief systems and ways of life, causing me to question whether the lack of progress in Native American health outcomes is due to implementation of inappropriate strategies. Most importantly, if more Indigenous people developed their own processes for exploring how dominant policies have changed their lives over time, they might be inspired to reflect on how their Indigenous knowledge could improve their well-being.

Lingering Effects of Colonization and the Impacts on Native Perceptions' of Health

As I have discussed in previous sections, concepts like self-identity lend themselves to definitions of health. If oppression continues to reign in our daily lives, we struggle to escape the pressures found in the domineering and oppressive relationships reinforced by the Western structures and modalities (Freire, 1994), including institutionalized education, which is related to self-identity development. Brazilian scholar Paulo Freire stressed that education serves the interest of the oppressors who seek to "preserve a profitable situation" (p. 54). The methods used to educate today are

intended to “change the consciousness of the oppressed, not the situation which oppresses them” (p. 55). Freire’s pedagogical theory combined with Crawford’s notion of self-identity (1994)—who we are and how we think of ourselves— reinforce the perception of self as influenced by the powerful pairing of capitalist values and domineering forces. If we accept that we live in an oppressive society, and that our perceptions of our health are not ours alone but representations of how others perceive us, we can be more critical of Western scientific definitions of Native health as reinforcing values and beliefs of the dominant society while Native culture, practices, and beliefs are minimized or completely ignored. Furthermore, as Native people continue to face threats, whether from Native language loss or the prevalence of health disparities, those who work in health must not only seek methods to positively impact Native health but also simultaneously strategize to maintain and protect Indigenous knowledge, beliefs, and practices that can form the basis for alternative understandings of what health can be.

In Pueblo communities, Western capitalism’s impact on the wage economy is evident by the ever increasing extravagant (by traditional Pueblo standards) display of material goods and wealth. In my Pueblo doctoral cohort, we students joked amongst ourselves about “keeping up with the Joneses,” which is a comparison to one’s neighbor as a benchmark for social class or the accumulation of material goods (Martin, 2019). We used this American saying to describe what was happening with Pueblo people wanting to impress upon others that they are monetarily rich and therefore able to purchase copious amounts of material goods. This thinking contrasts with what we are taught by Pueblo community members about being humble and only using necessary resources.

Inevitably, shifts in thinking and in ways of doing will occur; however, the degree to which groups are involved in making these changes predicts how groups will adjust to changes. In my own experience, I see the effects of this shift as spilling over into Indigenous philosophies of holism (heart, body mind and spirit) and resulting in a narrowing of Native thinking about what constitutes a good life, including physical health and disease.

Challenge # 3: Individual Perspectives of Health and Perceived Challenges

The concept of being healthy today does not necessarily reflect concepts that define Native Americans' health and well-being (Adelson, 2000; Suina, 2016; Warne, 2005). Crawford (1994) defined "healthy self" as aligned with standards of health and living of the American middle class. Like other Pueblo health researchers (Suina, 2016; Tenorio, 2018), I see Pueblo living as determined according Pueblo epistemology, ontology, and axiology. Health is defined by purpose and intent of life and underscored by the unique relations between humans and the natural environment. Our values, beliefs and traditional cultural practices reflect these understandings. As a whole, these elements are upheld in Indigenous life that extends into family, community, cultural practice, psychological and spiritual well-being, interpersonal relations, and environmental influences (McCubbin, McCubbin, Zhang, Kehl, & Strom, 2013). However, due to the other challenges I have outlined above and shifts in self-perception, Native people today may view their well-being based on limited biophysical assessments to gauge health. Body weight, blood pressure, body mass index, and other physical health indicators, are used by individuals to measure their 'healthy self.' Critical aspects of Native lives such as

family commitment, community involvement, spiritual well-being, and interpersonal relations, are often not mentioned as things important to one's health and well-being (McCubbin, McCubbin, Zhang, Kehl, & Strom, 2013).

Adelson (2000) drawing from John L. McKnight (1986) pointed out that fitness and longevity may or may not have anything to do with physiological wellness, but that people are "obsessed with health – particular ideals of bodily fitness and longevity" (p. 4). Regardless of the result—whether trim or not, whether thirty or ninety—the prevailing image of our obsession is that of a disease-free, slender, fit, and youthful body.

Perceptions about Health: What Native people are saying about health

Forty years ago, as a young adult living in a Native community, it seemed that the only times I was aware that people went to the doctor was when they did not feel well or when they had a checkup because of an illness. Moreover, I did not learn a person was ill until after his or her death. As Western health care continues to expand in our communities, the manner in which people respond to this vary. Peoples' reactions to a death linked to an illness, personal evaluations of how health care is provided, and discussions of how they manage their personal health, speak to how a small sample of Native people respond to health issues and also constitute areas for us to address through research.

A most notable change in Pueblo communities is that family members have assumed the role of home health aide, a role that many are not trained to perform but do so because we are taught to take care of family members when they are ill. I have listened to individuals in my own community share the stress they have experienced not knowing

ways to provide the best care or support for their loved ones. Others have expressed dissatisfaction with the care their family member received in hospitals and have accused the doctors at local IHS clinics of providing inadequate care. A common complaint I have heard is, “They don’t do anything for you when you go there, they just prescribe Tylenol.” Some blame the medical provider for a family member’s death claiming that the provider did not diagnose the illness properly, so treatment was delayed or subpar when it was delivered.

I learned from my formal research and informal interactions with many Native people that their greatest health fear is being diagnosed with an illness, believing that death will soon follow. Several Native women I know are thus reluctant to get an annual exam fearing they will be reminded of their impending doom or that point out illnesses that will further stigmatize them—lose weight, you have diabetes or high blood pressure, etc. The women I speak with regularly say that they would rather not know their health risks because that would just be another thing they would have to worry about and rather than have an annual health checkup, they might focus on self-help measures like losing weight as reassurance they are keeping healthy (Naseyowma-Chalan, 2015).

Individual Perceptions of Health: What influences the Perceptions?

As I have discussed, Western ideologies of health and Indigenous traditional practices, including participation in ceremonies and the preparation prior, often present conflicting viewpoints of what health is and what it can be. A person wanting to lose weight to achieve a body image that society has identified as being healthy, may experience conflict because of the close association between food and cultural practices.

Food is vital to human life and central to many cultural practices, but ironically (due to its industrialization) it is identified as the culprit responsible for health issues such as diabetes, obesity, heart disease, and other health conditions (Axelson, 1986). To complicate this further, I recall an example from a Pueblo cohort classmate and fellow Indigenous health researcher Rachell Tenorio (2016) who shared her views of conflicts when an individual's dietary restrictions disallow them from eating food that is commonly consumed in their culture. She pointed out that conflict may occur when a person is unwilling to eat certain foods causing others to perceive them as unappreciative or wasteful (Tenorio, 2016).

Food is vital in Pueblo culture, and the work of Marta L. Axelson (1986), explained how food and its use is interrelated with cultures widely. She found that differences in food practices depend on how people use food within their culture. The methods to acquire, select, prepare and consume food reflects the complex interrelationships, interactions, culture, and the society in which we live (Axelson, 1986). Most cultures engage in practices involving food however, those practices have changed over time, causing conflicts because ideals and practices do not align with the culture. Based on a written example provided by Rachell Tenorio (2016), making a person feel ashamed because of the types of food they eat is a tactic used in Western society to discourage people from eating unhealthy food. She explained that to use food to degrade a person conflicts with the original intentions of reciprocity and personal gain. For instance, today excessive quantities of food have become the standard in the Pueblo practice of reciprocal 'payback' and contradicts the ancestral community-based practice

of providing just enough food so that everyone will have something to eat (Tenorio, 2016). Tenorio pointed out that Native people struggle to maintain the practice of sharing food and not be persuaded that more is better. Most importantly, inexpensive processed foods and soft drinks have replaced fresh foods of Pueblo community production prior to colonization, such as corn, chili, beans, melons, squash, and wild game meat. This is due in part to the inexpensive cost of processed food and its availability and the decline in farming and hunting in Pueblo communities.

These examples, together along with the conflicts that I cited between cultural practices and food, and the conversations of the Pueblo women regarding weight loss, are perhaps indicative of a broader shift in Pueblo life from communities focused on helping each other to ones more becoming increasingly oriented towards individual needs. Rather than displaying support, compassion and concern for others, we must ask if our people have become more apt to disregard someone when they are ill, or shame or blame that person for their illness leaving them to cope by themselves.

In this vein, a health challenge rarely discussed is then how individuals fit not only into our own communities, but also in the greater mainstream. Are there generational differences of perception, and what might those imply? For example, what do young women in their mid-twenties and younger think about with regards to their health? What do older generations understand with regards to their health? For young Pueblo women, being physically prepared to finish an entire ceremonial dance is important and so is being told by community members— “You danced nice.” As a woman in the grandmother generation, I remember that hearing this was a great

compliment because community members paid attention to the details of a woman's dancing, which again lend themselves not just to physical fitness but as previously outlined, the person's dedication to community through their participation, and this extends to all community members. For example, Cochiti Pueblo community members (which is the community in which I am married) speak about the importance for everyone to take part to enhance strength to restore balance and well-being for all (Cochiti Pueblo Health Council, 2008).

A Community Perspective of Health Challenges

Now that I have outlined a thematically organized health challenges, I turn to community perspectives regarding health challenges, which narrow my focus in preparation for what I will discuss on Pueblo health, which is the focus of my research study described in the next section (Chapter II) of this dissertation.

In 2008, I participated in a Cochiti Pueblo community health forum where community members discussed their perceptions of health. Cochiti Pueblo is one of the Southern Keres-speaking Pueblos along the Rio Grande in New Mexico. There are approximately 1000 community members in total off and on-reservation, and there were approximately 57 people of different ages in attendance at this forum. The questions asked of community members included, "What does being healthy mean?" "What ways do Pueblo people stay healthy?" (Cochiti Pueblo Health Forum, 2008). Rather than follow an approach of starting the conversation using statistical health data that represents a deficit-based narrative (e.g. how sick we are), the questions were deliberately created to elicit positive and strengths-based perceptions, and more importantly, the process

encouraged participants to respond based on their lived experiences. For instance, responses to "what does being healthy mean?" included "being able to participate in activities in the Pueblo, both physically and emotionally;" "being healthy also means being healthy spiritually, mentally, emotionally;" "healthy means living to a ripe age of 90+," "being there to see your grandchildren and children grow into adults;"; and "being able to participate physically and emotionally in Pueblo activities and being there for your children and grandchildren" The responses revealed the importance of knowing and practicing cultural traditions and spoke to conceptualizations of *being healthy* for Pueblo people of different generations.

The responses to "what ways do Pueblo people stay healthy?" demonstrated an awareness of the importance of being physically active and healthy, and most notably acknowledged the integral role of spirituality in staying healthy. For example, responses included, "taking part in traditional ceremonies and dances;" "following our way for healing;" "helping out in good times (weddings, baptisms) and in bad times (funerals);" "chopping wood; kneading dough." I recall some of the participants remarking that they did not expect to share their experiences, and they found other participants' comments uplifting and relatable, so they too contributed their stories. This conversation provided vital information according to what Pueblo members identified as essential to the health and well-being of their people and community. The repeated references to culture, tradition, ceremony, and beliefs confirmed that these core elements are vital to this Pueblo community's existence. Therefore, Pueblo knowledge and traditional practices

must be maintained, and being healthy and living a balanced life will help achieve this goal.

That forum, over a decade ago now, opened the door to hearing firsthand from Pueblo people what matters to them; it conveyed a perspective of health that stood for what each participant believed and wanted for his or her future. Participants delved into the importance of cultural practices and the meaning these practices have on their daily living. This forum created an opportunity to realize the shift toward what we might think of as self-determination, or the ability to determine how we wish to live as Indigenous people, and many expressed some enthusiasm that they could regain control of their heath through reclaiming what we know and have lived. By allowing people to voice what they perceived is needed for the health and well-being of them and the community people gain confidence and exercise their power and become more involved in critical issues such as health (Chino & DeBruyn, 2006). To me, the important take away from this kind of community discussion is knowing we can influence young Pueblo children, that we have the cultural knowledge resources to do so, and that Pueblo teachings inspire hope that 'living well' is possible.

A Pueblo Perspective of Well-being

I would be remiss in this dissertation to not offer alternatives to Western constructions of illness that dominate ideas of health for Native people. Picking up on what I have discussed in the section prior and casual mention of 'living well,' I now deepen the conversation on what well-being might mean.

In the thirty years I have worked in health, I have noticed a movement away from depending solely on Western science approaches in areas such as medical care, treatments, prevention and intervention strategies to identifying Indigenous practices and beliefs to address health issues. In Native American health, Indigenous knowledge and practices are being applied to health interventions and treatments; however, being that health is dominated by Western health science, it is vital that Native peoples are confident that their cultural knowledge and practices offer answers to health issues. This is an important nuance—the challenges of Native health today do not only relate to health conditions, the challenges are to fundamentally reclaim Native peoples' confidence in being in control of their health. A primary issue is communications—are Native people able to articulate their concerns, their health priorities, or their fears and when is it safe to do so (e.g. the Cochiti health forum). Across the U.S. and Canada, among Natives, I have seen interest in incorporating Indigenous practices and beliefs with mainstream interventions or treatments, illustrating an increased awareness of factors contributing to Native health. The movement is taking hold, but dominant Western methods and strategies still challenge applying cultural practices to improve well-being. Native peoples' perception of self and degree of confidence are predicated on how general society views Native groups, yet Indigenous identity and Indigenous knowledge are the key to dismantling the negative perceptions we have of our population.

Restoration of knowledge and reclaiming of identity is a step toward protecting the Pueblo way of life, which involves reaffirming the value of Indigenous knowledge, histories, and practices that outline our definitions of well-being or whatever we wish to

call it. Native people can remember the teachings and apply them to their understanding of health. In a conversation with my own father, a Hopi Elder, he shared his understanding of "living well" in this way,

> Hopi says when you are born, you have one line to follow. If you get off the line you are not living your own life, you are living other people's lives, not thinking for yourself and that is when you get sick or start doing wrong things" (Naseyowma, 2016).

Working in health and my personal experience drive my motivation to challenge the existing health narratives produced by powerful entities such as governments and health industries. Although many have accepted these narratives without question, more Native peoples today are calling for a resurgence or reclamation and restoration of Indigenous knowledge to define health and well-being based on principals, practices, and beliefs that have meaning to them. In 2012, several individuals contributed to a Pueblo health framework using the core elements of heart, body, mind and spirit in Pueblo beliefs and practices. The Pueblo health framework, which I participated in developing, was presented at a 2012 Pueblo Convocation, which gathered together 400 Pueblo people from across the 19 Pueblos of New Mexico, to illustrate a concept of Pueblo well-being. The framework demonstrated how for instance creation stories underscored the importance of why Pueblo people exist and how specific roles and responsibilities guide the actions of the people and lead them to living what we understand as a good Pueblo life. We are taught from oral tradition that key cultural elements, such as the ceremonial

calendar, describe how the natural environment such as the seasons, solar and lunar systems, and landscapes contributed to living well or living in balance.

There are numerous examples of how Pueblo life has changed, including what I have alluded to previously as a most impactful shift from agricultural livelihoods to wage earners, as well as the re-education of Pueblo people through forced Western schooling, the subsequent decrease of Native language speakers over each successive generation; and the reliance on Western practices to guide our systems of political representation and tribal management. These changes are the result of forced federal policies and have contributed to shifts in belief (in ourselves). As a result, methods Pueblo people once used to care for themselves and their community are increasingly replaced by Western treatments. Those of us working in health constantly hear about the negative health situations Native peoples face; this thinking has become so engrained in us that we also find ourselves using the same negative jargon. All the while, Pueblo peoples' health and well-being continue to decline despite advances in Western medicine and methods for treatment and prevention (NM Dept. of Health, 2014; U.S. Dept. of Health & Human Services, 2013). Pueblo people can exert their involvement in health conversations starting with culturally-based definitions of health to shift the thinking of health from a Western biomedical science and capitalistic perspective to a viewpoint based on Pueblo ways of life which bring out the practices, beliefs and values that exemplify strengths.

Reclaim Indigenous Pueblo Health

The knowledge and practices rooted in Pueblo philosophies constitute the force that protects "who we are"—the practice of religion, language, access to resources, and

maintenance of body, mind, heart, and spirit, or wellness (Dozier Enos, 2015; Pecos, 2007; Suina, 2016). Religion, language, and natural resources are inherent qualities of wellness that anchor Pueblo teachings and practices. Furthermore, Pueblo teachings remind us that human existence is not independent but interwoven with the environment and the universe (Suina, 2016).

Cochiti Pueblo health educator and scholar and Indigenous data sovereignty advocate Michelle Suina (2016) suggested that even casual conversations constitute data that provide insight into how people are thinking about how current situations with regards to health. In her own work, she was curious about Pueblo perceptions of health, particularly thoughts and experiences that connect health with Pueblo practices. She discovered that most Pueblos understood health according to the Western definition of health–being free of disease and illness, being physically fit, and eating well (but according to more trendy standards). She probed them to share their thoughts about Pueblo philosophies and practices, and developed three questions to start this conversation: What do Pueblo people know and believe to be true? How do Pueblo people know and believe to be true? What values guide Pueblo people? (Suina, 2016; p. 74). She learned that instead of dwelling on the negative aspects of illness and disease, Pueblo people were eager to share personal stories which added to existing narratives describing health and well-being fitting for our communities. This kind of research gives us hope for the future of Pueblo health through the lens of our own understandings of well-being.

Reframing the Pueblo Health Narrative

Pueblo people have maintained their Indigenous values, beliefs, and practices but as actions of colonialism disrupted Pueblo ways of life, grandfathers and grandmothers had to find ways to save practices (Cochiti Pueblo Health Council, 2008; Dozier-Enos, 2016; Cajete, 2005; Suina, 2016; The Leadership Institute at Santa Fe Indian School & Sumida-Huaman, 2018). Based on recent research, we understand that Pueblo health today encompasses spirituality - ceremony, kiva, prayer, religion; community - being together, sharing, pursuing common interests; family – multigenerational ties; physical health – strong, disease-free; farming – corn, chili, beans, squash; hard work – farming, chopping wood, cleaning home and community (Cochiti Pueblo Health Council, 2008; Suina, 2016). Although our people adapted to Western-style daily living—working outside the community, attending school, grocery shopping versus growing vegetables and hunting small game— and Indigenous practices and beliefs declined, the memories of what we understand to be true remain. However, there is much healing that needs to happen. For example, Don Warne (2005) pointed out that the adversity our communities face is rooted in the loss of land, traditional culture and lifestyle and has weakened our identity as Native people eventually resulting in the loss of Indigenous living practices and a decline of knowledge that once guided our daily lives.

However, there is empowerment in our awareness of these processes of loss. By creating space for Pueblo people to come to this awareness and also voice what is important to well-being today, knowledge and practices dating back to time immemorial

can be recognized for their value and serve as an important reference point when redefining health. As stated by an Elder from Acoma Pueblo,

> We need to help each other through spirituality, through these kinds of gatherings and dealing with the difficulties we are all facing together—trying to live in some manner of peaceful coexistence when we know we are so different. Moreover, yet it is up to each of us to do something in one small way to ensure that all of us are going to contribute something. (Native Health Leadership Institute, 2008)

In addition to healing amongst ourselves, we also continue to challenge dominant narratives and state and federal policies through their reporting procedures and representation of Native peoples. The status quo in Pueblo health should question the narrative: Who is writing our existence? Whose voice is being presented? Creating our health narrative is inherently tied to our right to self-determination, and any time Native health is the topic of discussion, we should be present and demand clarity. Those controlling current narratives can be made aware that lumping Native populations aggregately diminishes our inherent sovereignty, among other damages.

Conclusion: Non-conformity and Self-Determination

So how do we move forward into a new era of defining Pueblo health and in a way that can be shared with other Indigenous populations where useful? A growing body of work identifies factors that contribute to healthy development and well-being in situations where people have encountered extreme hardships, trauma, and deprivation (Adelson, 2000; Chino & DeBruyn, 2006; Crawford, 1994; Gone, 2011; Pecos, 2007;

Suina, 2016). Many of these studies are attempting to dismantle the Western ideologies that have caused our people to stop believing that we possess the knowledge, strength, and ability to create our notions of well-being. As Walter cautioned us, cultural, social realities reflected in statistics/data reflect the colonizers, not our cultural, social and political realities; we do not have to accept any data as the entire truth (personal communication, 2017). As I have emphasized consistently, Native people easily fall into thinking about health and well-being only through the lens of physiology and medical science leaving out Indigenous beliefs and practices for well-being, which include well-being as multidimensional and involving that which is beyond the individual (King, Smith, & Gracey, 2009, p. 79).

Reframing the Native health narrative can firmly establish that Indigenous-specific health factors are interrelated with colonization, globalization, migration, loss of language and culture, and disconnection from the land, which have contributed to health challenges of Indigenous peoples. We can move towards self-determination through renewed Native health narratives that help restore Indigenous peoples control over their lives and destinies, and perhaps this begins with listening and sharing teachings and knowledge that are directly aimed at restoring positive self-image and identities that reflect living well.

CHAPTER II

INDIGENOUS AND PUEBLO PHILOSOPHIES AND PRACTICES OF WELL-BEING

Introduction

This chapter offers a comprehensive explanation of my study. As mentioned in the Prologue, it is a full description of my research from which I hope to draw one or more journal articles that can reach wider Indigenous audiences and as envisioned by the designers of the Pueblo cohort program.

Prioritizing the discussion in this chapter, I begin with an overview of Indigenous and more specifically, Pueblo Indian philosophies and practices in relation to my overarching dissertation concern regarding patient-provider interactions. More specifically, this chapter introduces historical construction of health that are dominated by western/European constructions of health and illness. In addition, I discuss Pueblo Indian and Indigenous constructions of health and well-being that draw from cultural conceptualizations of our existence as Indigenous peoples in a particular place. The landscape of Indigenous health describes the dominant constructions of health that impact the Pueblo peoples in the state of New Mexico provided in my research working with Pueblo patient and Pueblo and non-Pueblo providers.

Prior to describing my study, I open with a discussion on researcher positionality, which is a critical starting point for Indigenous researchers describing how we have arrived at the work we are doing and that shares with readers the many influences that shape who we are as researchers. Here, I also introduce my research design as comprehensively as possible, including my research site, data collection and analysis

methods. Prior to sharing the findings of my study on Native patient-Native/non-Native health care provider relationships, I discuss two considerations that were discussed in detail with all participants—defining notions of well-being and ideas of trust in patient-provider relationships. I then move into describing my findings, which highlight a) observations and testimonies of patient apprehension and confidence, b) experiences of medical treatment decision-making, and c) the centrality of knowledge according to providers, which provides insight regarding what appear to be persistent tensions but also opportunities underlying western and Indigenous conceptualizations of health.

Dominant and Pueblo/Indigenous Discourses of Health

In most health reports today, Native populations in the United States rank highest for health disparities and, when compared to other races, Native populations experience the worst health status (US Dept. of Health & Human Services, 2015; Indian Health Service, 2015). A report issued by the U.S. Commission on Civil Rights (2003), *A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country,* described an alarming situation with Native American health with the following statistics: "Native Americans are 670 percent more likely to die from alcoholism, 318 percent more likely to die from diabetes, 204 percent more likely to suffer accidental death when compared to other groups" (U.S. Commission on Civil Rights, 2003, p. 34). Although this report dates back fifteen years, the health status of Native American groups has not improved, an unfortunate reminder that Native populations cannot depend on the federal government to address the issue. Native values, beliefs and practices exist despite numerous efforts to annihilate the populations and, attempts to force them to abandon their way of life. The

will to overcome hardships is in the spirit of Indigenous ancestors and the Native people today. I assert that the answers to sustain Native knowledge and way of life will not be found in Western methods. We must examine how to incorporate Indigenous ways of living as well as Indigenous ways to heal and treat illness after all, Native existence today is our identities defined by who we are and what we know.

Native people cannot escape how modern society has shaped the concept of health. Indigenous peoples are particularly vulnerable to dominant definitions of health and mainstream trends in health practice due to major lifestyle shifts and restrictive policies resulting from Euro American colonialism. For example, U.S. federal policies forced Native people to conform to western way of living moving away from a lifestyle that embraced holistic health practices. The Snyder Act of 1921(25 USC 13) is the first federal policy that established the government's involvement in the health and social well-being of Native people. The Snyder Act was enacted "for relief of distress and conservation of health" (Sixty-Eighth Congress, 1924). There were positive outcomes from this legislation such as curbing infectious diseases and preventing deaths of Indigenous people. Much later, the permanent reauthorization of the Indian Health Care Improvement Act [enacted in 2010 as part of the Patient Protection and Affordable Care Act (P.L. 111-148)] provided specific legislative authority for Congress to appropriate funds specifically for the health care of Indian people. However, as Tlatilpa (2015) noted, federal government's involvement in the health of Indigenous people was not because they cared about the health issues affecting Indigenous populations. She argued the real reason was that "so their [colonizers] own health could remain maintained" (p. 14).

According to Tlatilpa, federal health policy infringed on Native American sovereignty by "allowing the federal government to exert more regulation over Native American affairs thus undermining the sovereign status of tribes and their rights to self-determination" (p. 14). Early interventions were based on settler methods and practices and Indigenous healing practices and cures were not allowed (p. 14). This action began the movement of health and healing away from Indigenous concepts and practices to methods heavily reliant on science-based medical models.

In 1948 the World Health Organization (WHO) defined health as a state of complete physical, mental and social well-being and *not merely the absence of disease or infirmity* (Medical News Today, 2017, my emphasis). More recently, researchers have defined health as the ability of a body to *adapt to new threats and infirmities*, and the role of modern science is to dramatically increase *awareness of diseases and how they work* (Medical News Today, 2017, my emphasis). While these definitions of health dominate broad conceptualizations, Native languages, on the other hand, may not have a single word for health; instead, Native people understand health as maintaining well-being stemming from teachings that depict human living as a relationship to the environment and the universe (Adelson, 2000; Cajete, 1999; Enos, 2015; Gone, 2011; Leadership Institute at Santa Fe Indian School & Sumida-Huaman, 2018; Prilleltensky, 2005; Suina, 2016).

Pueblo teachings describe human existence as linked to the natural universe. Our ancestors lived each day knowing that an intimate relationship with their environment meant human existence and their environment co-existed (Cajete, 2005; Pecos, 2007;

Suina, 2016). My people - Hopi and Taos Pueblo - traditionally were farmers and living the life of a farmer meant daily routines of prayer, hard work, visioning and strategizing, patience, and thankfulness that resulted in the balance of heart, body, mind, and spirit. I asked my Hopi father if the Hopi people have a word for health and he said, "loma qatsi," which translated into English means "good living" (Naseyowma G. , personal conversation, 2018). My father added these words are often used with the saying "namitunutyal di – take care of your life" (Naseyowma G. , personal conversation, 2018). The words do not refer to illness, disease, or even the mechanics of the body, instead the words express encouragement to live life well and to offer wishes to take care of yourself. The same may hold true for other Native populations.

In 2010, the Pueblo of Cochiti, a southern Keres-speaking community, held a community forum for its 714 on-reservation tribal members. The Healthy Ko'tyit[1] Community Health forum was held to reflect on Ko'tyit past and present to guide the path for future generations. Community members were asked, "What does it mean to be healthy?" Respondents referred to cultural practices and beliefs such as participating in traditional dances and ceremonies, engaging spiritually through prayer, farming, and being with family (Cochiti Pueblo Health Improvement Council, 2010, p. 14). I have wondered if perhaps the question, "Are you living well?" is more culturally and linguistically appropriate to ask a Native person when asking about their health. The forum participants took part in a large group brainstorm to define health from a Ko'tyit perspective using past, present, and future photographs to have participants show how

[1] Ko'tyit is the traditional name of the Cochiti Pueblo people.

Ko'tyit people stayed healthy in the past and present, and how future generations will stay healthy. Farming figured prominently in conversations regarding "healthy people" and "healthy communities'" there was general agreement that farming—planting seeds, tending to gardens, preparing the harvested food, and participating in spiritual celebrations praying for a good life meant "living healthy in the Pueblo way" (Cochiti Pueblo Health Council, 2010).

Community members also acknowledged, however, that subsistence farming has been replaced with modern conveniences such as fast foods, grocery stores, and other modern amenities. Pueblo Elders were disheartened because many people do not farm anymore; they associated the decrease in farming to the decline of peoples' health and well-being. The Elders believed that western thinking and practices have replaced Pueblo living, resulting in a disconnection in Pueblo philosophies, practices, and beliefs and how we live today, which according to one community member, "may be why people are ill so much and why more people are being diagnosed with a disease" (Cochiti Pueblo Health Council, 2010).

At the same time, Indigenous philosophies, beliefs, and practices are now being included in Native health conversations, thus expanding the dominant discourse from exclusive focus on physical health to the broader concept of "well-being" that includes holistic concepts of physical, mental, emotional, and spiritual well-being (McCubbin, McCubbin, Zhang, & Kehl, 2013). McCubbin et al. characterized well-being as:

> the sense of satisfaction and happiness derived from confidence and perceived competence to overcome adversity, respect and be in harmony

> with nature and ancestors through cultural practices, the management of financial resources, family commitment, access to quality health care, and involvement in and contributing to one's community. (2013, p. 362)

Well-being in the public health domain is defined as a "positive state of affairs in which the personal, relational, and collective needs and aspirations of individuals and communities are fulfilled" (Prilleltensky, 2005, p. 54). Within this context, Prilleltensky clarified well-being as the "satisfactory state of affairs for individuals and communities that encompasses more than the absence of disease," thus bringing attention to the notion that there are many aspects of well-being that reach far beyond health and encroach into the realm of values, thriving, meaning and spirituality (p. 54). The work of McCubbin et.al and Prilleltensky challenge the dominant definition of health and well-being and call attention to all the critical facets of human existence beyond physical health.

Pueblo teachings are also expansive and inclusive. They define well-being as the human connection to spirituality, which some believe to be our Creator and Mother Earth (Cajete, 2005; Naseyowma, 2016; Pecos, 2012). Stories shared by Pueblo Elders remind the people that traditional ceremony and practices as well as our values and beliefs move us in the direction of achieving wellness. Thus, it is critical to examine Indigenous philosophies in order to define well-being in a way that fits with Indigenous living today. My research reviews the shifts from Indigenous philosophies of well-being to more mainstream concepts that focus on human physiology. As Native peoples' health is of grave concern to health research, practice, and those of us in health services, work is being done to incorporate Indigenous knowledge and practices in health interventions,

recoveries, and revitalizations. To illustrate how Indigenous ways of knowing and doing are applied in methods to address health issues today, I review models developed by Pueblo people to illustrate how Pueblo knowledge is being used to support changes in peoples' lives that improve health conditions.

Positioning Self: My Place, My Knowledge, My Relations

Positioning self by identifying place, describing the foundation of personal knowledge, and acknowledging relations have become integral research requirements for Indigenous researchers. In doing so, we assure readers that the cultural knowledge used is accurate, appropriate, and that the writer is presenting concepts and ideas based on a lived Indigenous experience where the researcher is accountable to Indigenous peoples and community/ies. Indigenous scholars scrutinizing other Indigenous scholars' work is a necessary process because we seek to protect our work as it represents our people; thus, identifying self and verifying Indigenous knowledge legitimizes the connection between the Indigenous scholar and the Native community (Kovach, 2012). My research builds on Indigenous epistemologies and my personal experiences and those shared with me by others to demonstrate how the facts, information, and skills gained from Indigenous education create a deeper understanding of Indigenous health and the concept of well-being.

My Indigenous knowledge connects to my Hopi family from Moenkopi Village, my family from Taos Pueblo, and my family in Cochiti Pueblo, Ko'tyit. My home is in Cochiti Pueblo where I have lived for twenty-five years. I have three children, Leticia, Marcelino Jr., and Cynthia, and I have three beautiful granddaughters, Stefanie,

Madeline, and Jocelynn. My career in health started over thirty years ago in an Indian-owned organization working in alcohol and substance abuse prevention. Events in my personal life also prompted my interest in health. I lived with a family member one who struggled with alcohol addiction so my experience combined with the knowledge I gained working in alcohol and substance abuse programs directed my work. I began my health career assisting tribal programs in developing community-based strategies to combat the effects of addictions. My personal experience spurred me to be sensitive to others who experienced similar situations and I found that by sharing my personal story others were inspired to believe loved ones can recover from addictions.

My work as a health educator led me to health planning, contributing to the development of tribal health policies at the national, local, and tribal levels. I had the wonderful opportunity to work for my tribe, Taos Pueblo and for two years managed the Tribe's programs for diabetes prevention, public health nursing, early childhood home visiting, and the Elder meal and supportive care. My work in health has journeyed full circle, beginning with community health education that wove in health planning and health policy development, managing my Tribe's health programs and now to my current work in healthcare. Today, I share my knowledge as well as learn from others by participating in forums that pertain to Pueblo health and contribute to discussions on tribal health policies and decision-making.

The experience and knowledge I acquired inspired me to pursue the examination of Pueblo health and well-being. I am inspired by the stories people share of their successes in their recoveries from addictions or illnesses. I discovered the stories help

individuals heal emotionally and spiritually giving hope that recovery from disease and illness can happen.

Indigenous and Pueblo Constructs of Well-Being

Well-being is a concept that many Indigenous Non-Western cultures use to capture the essence of a holistic approach to health and illness. A generalized Indigenous concept of holistic is often considered to be the interconnections between the mind, body, spirit and heart. Well-being in the public health domain is defined as a "positive state of affairs in which the personal, relational, and collective needs and aspirations of individuals and communities are fulfilled" (Prilleltensky, 2005, p. 54). Prilleltensky (2005) expounded on 'well-being' bringing attention to the paradigm shift in health and human services from a singular focus on strength, prevention, empowerment, or community conditions to the integration of these four approaches. Prilleltensky conceptualized the state of health promotion as,

> reactive, individual, alienating, and deficit-based approaches that foster patient hood instead of health, citizenship and democracy, to a strength-based, preventive, empowering and community-oriented approaches to promote personal, relational and collective well-being. (Prilleltensky, 2005, p. 11)

Prilleltensky examined health promotion based on a framework built on personal, relational and collective well-being. He argued that a singular focus on strength, prevention, empowerment or community conditions is insufficient, and advocates for the conceptual integration of the four components (p. 11).

Prilleltensky's argument is based on the premise that well-being encompasses three primary sites – "personal, relational and collective with each [having] has specific signs or manifestations, sources or determinants that define well-being" (p. 11). He proposed that each aspect of well-being - personal, relational and collective - are situated in sites, signs, sources, and strategies that establish well-being (p. 54). *Sites* refer to the location of well-being and may include person, relationship, or community; a situation that relies on interdependence (p. 55). *Signs* refer to the manifestations or expressions of well-being. People respond to what they "feel and think when they are happy, satisfied, or experience a high quality of life" (p. 55). *Sources* of well-being are the sources or groups of determinants such as the ability to exercise control, voice and choice (p. 55). Prilleltensky's well-being framework proposed an expanded view of health with elements that align with Indigenous way of life philosophies., and his work builds on the argument that well-being is multi-dimensional with intertwining delicate layers that if one layer of our well-being is not in sync, well-being is not achieved. On the other hand, if an individual is experiencing an illness but has accepted that fate and expresses contentment, well-being is achieved.

McCubbin et al. (2013) examined the concept of "relational well-being" from the perspective that it correlates with Indigenous worldview because it is a relational construct situated in ancestral roots integrating values, beliefs, and practices that validates interdependent and relational association of the individual, family system, neighborhood, community and society therefore deemed a culturally appropriate measure of well-being. They argue this reasoning supports the use of "relational well-being to determine

appropriate interventions for Indigenous peoples" (McCubbin, McCubbin, Zhang, & Kehl, 2013, p. 356). Indigenous relational well-being is characterized as the sense of satisfaction and happiness (well-being) derived from confidence and perceived competence to overcome adversity, respect and be in harmony with nature and ancestors through cultural practices, the management of financial resources, family commitment, access to quality health care, and involvement in and contributing to one's community (p. 356).

The dominant Western concept of health does not reflect on how one's personal realities and values have been formed, and a Western term that captures the essence of the Indigenous life goal - 'well-being' seems to be the best word. Adjustment and adaptation involve both the retention of one's primary ancestral roots as having an independent and lasting impact on one's functioning and the integration of values, beliefs, and practices of the dominant culture. This definition grounds my position advocating for the use of well-being to define the desired outcome to live an Indigenous Pueblo way of life that at times may include having to deal with a disease or illness.

Concepts of well-being derived from Indigenous knowledge

A growing number of interdisciplinary studies explore the causes of the disparities in Native health, and the studies often cite the lack of or the need for a better understanding of the cultural and historical factors associated with the health and well-being of Native people. Naomi Adelson (2000) asserted the experiences associated with a person's culture and history are vital in understanding health and well-being and can never be separated from cultural norms and values (p. 3). In *Being Alive Well: Health and*

the Politics of Cree Well-Being, she applied this concept to examine the health and well-being of Whapmagoostui Cree people of Quebec, Canada, and she critiqued dominant Western views of health:

> [The] dominant model of health is both biased and incomplete and constrains individuals to a proscribed biological and social morality, and this casts those who do not conform at odds with the regime of disciplinary power controlled by various institutional, corporate and bureaucratic agendas. (p. 8)

Adelson asked the Whapmagoostui Cree people to define health and well-being and learned there was not a single word for "health" in the Whapmagoostui Cree language. She learned that "being alive, well" were the English words that best described the Whapmagoostui Cree philosophy and way of life and its physical and spiritual connections (p. 62). A Cree Elder correlated being healthy with land: "If the land is not healthy then how can we be" (p. 3)? The Elder's statement linked the impacts of taking of land to the state of the health and well-being of the Whapmagoostui Cree people.

The relationship between health and well-being as tied to land is not uncommon among other Indigenous philosophies of well-being. In the work Michele Suina and I (2010) performed with the Cochiti Pueblo people, they were asked to define a healthy community and the participants agreed that "being healthy is not just about maintaining the physical health, such as through exercise and medication, nor is it just about individual health; rather, the concept is sophisticated and complex in that it is connected to a total Pueblo way of life, and the land; it is communally focused" (Suina, 2016, p. 76).

Donald Warne (2005), an Oglala Lakota physician, presented his investigation of Indigenous health and well-being as a person trained in Western medicine and treating Native people dealing with disease and illness. His experiences helped him to realize that Western concepts of health did not uphold Indigenous philosophies of well-being nor were the multifaceted dimensions of Native lives considered for medical treatment (p. 542). In *Traditional Perspectives on Child and Family Health,* he suggested that health disparities exist in Indigenous communities because of imbalances in family and community (p. 542). According to Dr. Warne, the health phenomenon Indigenous peoples experienced relate to loss: "loss of ancestral homelands, culture, language and other components of traditional life which led to loss of identity as Native people" (p. 543). He argued that allopathic medicine or Western medicine "is not adequate in terms of addressing the holistic nature of how disease processes are experienced by individuals" (p. 542). From a traditional perspective, the health of the community and the family determines the health of the individual. He also noted that the adversities in Native communities are associated to loss, such as loss of culture, loss of language, and loss of land, which led him to name a health condition symptom as "spiritual illness" (p. 543). This, according to Warne, justified the need for treatment and interventions that incorporate Indigenous ways of knowing, practices and cultural beliefs (pg. 543).

Indigenous scholarship challenges existing conceptual frameworks and argues that human existence is not confined to singular aspects, such as health, education, or economic status. In fact, much of Indigenous discourse defines human life as relational with Indigenous knowledge connected to human existence and all that exists in our

environment and universe (Adelson, 2000; Cajete, 2005; Suina, 2003; Sumida-Huaman, 2017; Warne, 2005). As Adelson (2014) wrote, health encompasses physiological conditions as well as "broader cultural and political realities so when speaking about health, the first step to understanding its various meanings is not to confuse disease with the study of health" (pg. 14). In my view, this statement speaks to a time when Native people understood the intimate relationship between themselves and their environment and knew it was the essence of their survival and identity as a people (Cajete, 1999, p. 4).

Indigenous practices of well-being

In the literature referencing Indigenous philosophies and knowledge, colonialism is often cited as a contributing factor to the negative dilemmas Indigenous people face today. Several Native scholars have identified historical trauma as a core risk factor associated with the illnesses and diseases suffered by population subjected to the henious acts of the colonizers – white settlers (Brave Heart, 1998; Gone, 2011; Hill, 2006; McCubbin, McCubbin, Zhang, & Kehl, 2013; Suina, 2016; Warne, 2005). Maria Yellow Horse Brave Heart (1998) studied a pyschoeducational intervention designed to initiate a grief resolution process that Lakota providers could apply as a behavioral health intervention and treatment method for their clients. Yellow Horse Brave Heart hypothesized that historical trauma and the devastating effects of colonialism – including the loss of life, land, language, culture, and identity -- have been significant factors in the health and well-being of Native people (p. 300). Therefore, Native health research considers acts associated with colonialism as factors that contribute to negative health conditions such as substance abuse, diabetes, cirrhosis of the liver, heart disease, and

suicide, to name a few (Indian Health Service, 2016; New Mexico Department of Health, 2013; U.S. Commission of Civil Rights, 2003).

Beginning in the late 1990s, The Leadership Insitute at the Santa Fe Indian School (LI)[2] developed a state-wide conversation process involving Pueblo peoples, policymakers, and other stakeholders about the most critical issues impacting Pueblo communities. I both participated in and facilitated LI discussions on Pueblo and New Mexico tribal health. Three elements were central to our process, which could be viewed as akin to think-tank sessions but utilizing Pueblo protocols of discussion and dialogue, which emphasize caring for participants, listening, and recommendations for action based on consensus. The elements we adhered to were (1) Centering Indigenous/Pueblo core values: sharing values and remembering mentors and role models; (2) Examining federal policies and their impacts: gaining in-depth knowledge of policy intentions and learning how policies changed the lives of Pueblo people; (3) Producing solutions that support the maintenance of Pueblo ways of life (Leadership Institute at Santa Fe Indian School & Sumida-Huaman, Indigenous core values and education: Community beliefs toward sustaining local knowledge., 2018, p. 16). We constructed an empowerment-based discourse, whereby the topic of colonization signifies Indigenous peoples' courage and strength needed to survive the atrocious treatment by the colonizers. The fact of Indigenous peoples' survival and the survival or revitalization of our values, practices, and beliefs demonstrate that Indigenous knowledge systems are sophisticated, brilliant, and creative ways of knowing. Lessons learned from colonizing experiences hold

[2] The Leadership Institute established in 1997 by Pueblo Leaders and intellects is Pueblo "think tank" convener that uses Pueblo facilitation process to engagement stakeholders.

answers for Indigenous peoples to restore Indigenous ways of life and to strengthen our Indigenous identities.

Linda Tuhuwai Smith (2012) wrote that advancing Indigenous scholarship legitimizes the constructs of Indigenous knowledge to create alternate systems of meaning and signification. She asserted that Indigenous knowledge actively identifies, discloses, and unmasks the legacy and persistence of colonial power structures (p. xii). Today, Native people face greater risks for being diagnosed with a disease, dealing with episodes of being ill, or the unthinkable – premature death, and the situation is prompting a call for action to revamp health conversations. Indigenous-led conversations, such as those facilitated by the LI, draw attention to how and why Indigenous way of life has changed. Recognition of enduring core values, however, inspires Native people today to embrace Indigenous knowledge and to use this knowledge -- philosophies and practices -- to reclaim Indigenous identity.

Indigenous scholarship argues that epistemologies, ontologies, and axiologies provide meaningful knowledge; they are reliable sources for examining the dilemmas Indigenous people face today and are useful for finding solutions to the dilemmas. Anthony Dorame (2017), a Tesuque Pueblo member, has presented an Indigenous knowledge paradigm that Tesuque Pueblo people have used since time immemorial. The paradigm includes methods and practices that teach values, traditions, and practices guiding members how “to live a Tewa life” (p. 187). He demonstrated how the knowledge system is structured and the actions – teachings, advice, practices—are applicable in any situation ranging from disciplining a Pueblo member or advising a

member on a role or task. The example he offered focused on his own learning of community, nature, and land resources centered on Tesuque, which were gained from his uncle and involved pedagogy of experiential learning by hunting or gathering natural resources. The very idea of teachings, advice, and practices are meaningful tools that can examine circumstances as well as identify solutions to the challenges Tesuque people face (p. 193). The framework defines the Tewa values, beliefs, practices, and traditions that encourage meaningful and supportive engagement when needed to restore balance and harmony (p. 193).

In health conversations today, social boundaries, Native traditions, and narratives linked to Native health are rarely considered when examining health conditions or in diagnosing and treating health conditions (Garroutte, Sarkisian, Goldberg, Buchwald, & Beals, 2008). However, linked with Indigenous research, more formalized notions of Indigenous health increasingly recognize and reaffirm Indigenous teachings as meaningful constructs that can establish appropriate strategies to improve the quality of life for Indigenous people.

For instance in 1999, the Substance Abuse and Mental Health Services Administration (SAMHSA) promoted Gathering of Native Americans (GONA), as an evidence-based intervention curriculum that acknowledged Indigenous practices as a valid form of healing. The curriculum became known as culture-based planning with engagement strategies that Native participants were familiar and comfortable with (SAMHSA, 2016). The technical approach is based on an Indigenous theoretical framework incorporating vision, circles of relationships, and sense of hope (p. 2). The

GONA curriculum engaged participants in understanding the impact of historical trauma and began healing. The program was known for the cultural interventions used to promote healing from personal traumas and host communities would create safe environments so participants would support when each other dealing with personal trauma and hurt. GONA participants expressed the hope they felt "we used our culture and cultural ways to work on community building and healing" (SAMHSA, 2016). GONA was implemented across the country and is recognized as the catalyst for inspiring painful conversations about the Indigenous histories which led to devising culturally-based strategies to address health and social issues affecting Native people (Tlatilpa, 2015, p. 26).

A second example of the incorporation of Indigenous perspectives in health teachings is the work of Cochiti Pueblo community member Michele Suina (2016) who conducted a small research project where she examined Cochiti Pueblo members' perception of being healthy. The responses included relationships – "getting along well with others; keeping the environment safe and clean; tradition – taking part in ceremonies and speaking the language; spirituality – knowing values, practices and beliefs; respecting self – staying free of drugs and alcohol and, taking care of your body" (p. 76). The Elders added that being healthy meant living the life of a farmer. In their minds the life of a farmer encompassed key elements for a healthy living: working in the fields several hours a day kept the body physically active; working together helped build and maintain relationships; sharing harvest with family and community members instill the value of caring for each other. This experience moved Suina to reframe the health

discourse through "incorporating the Pueblo ways of knowing and learning into health education while critically analyzing the challenges inherent within typical Western health education approaches" (p. 76). She realized the importance of agriculture as a Pueblo way of life, as a lifestyle that demanded hard work, interaction with others, learning traditional teachings, and participation in ceremony – all aligned with Pueblo living (p. 73).

Farming and what the action symbolizes in terms of Pueblo cultural beliefs continue to guide the lives of Pueblo people despite more Pueblo people transitioning to jobs in the urban areas or in community programs eight hours a day, Monday through Friday. This means that not everyone farms all the time or for subsistence as they did ancestrally, but the act of farming even small plots of land remain culturally meaningful in the community. For example, the traditional ceremonial calendar has functioned as a planning tool, a reminder of important seasonal events, scheduled ceremonies, and significant times in history. The traditional calendar guided farmers with planting the seeds, cultivating plants, harvesting and food preparation. Today, we continue to rely on the traditional calendar to organize our lives but instead of helping us to plan and act to farm, the calendar is a planning tool for ceremonial, religious or life. The traditional ceremonial calendar reminds us what Pueblo life was in the past and what it is now in the 21st century. The traditional calendar keeps us connected to culture and practices; it represents the ingenuity of our ancestors who created it.

At a Pueblo-wide gathering in 2012, Regis Pecos shared an Indigenous learning paradigm based on Pueblo epistemologies that describes Pueblo way of life along with

the philosophies, beliefs, and practices that guide Pueblo living (Pecos, Pueblo Convocation, 2012). Social boundaries, traditions, and narratives that reinforce identity and place in this world collectively define health and well-being for Pueblo people, and Pueblo peoples' work contributes to greater understanding of health and well-being in the context of a Pueblo way of life.

Broadly speaking, Indigenous teachings define human life as relational; meaning, Indigenous knowledge connects human existence to all that exists in our environment and universe (Adelson, 2000; Cajete, 2005; Suina, 2003; Leadership Institute at Santa Fe Indian School & Sumida-Huaman, 2018; Warne 2005). As a health researcher and service provider, I have encountered individuals experiencing illness who returned to Indigenous teachings and experiences and improved their health condition. The story of one such individual inspired my interest in Pueblo epistemology, including using stories from Pueblo people to motivate others to believe their Pueblo knowledge and practices can bring about positive changes to our health and overall well-being. I retell the story here and argue that storytelling is a critical aspect of the journey toward healing. Stories have been passed down through tribal communities for generations, giving listeners the opportunity to reconnect and identify with past tribal realities. The story emphasizes the value placed on believing in oneself, looking inside oneself for insight, and finding the strength there to cure illness (Hodges F. S., Pasqua, Marquez, & Geishirt-Cantrell, 2002).

A Story of Indigenous Healing

The story takes place in a pueblo community located in northern New Mexico. This pueblo community continues to engage in ceremonies which reinforce language as

well as the traditions defining roles and responsibilities for all community members. The teaching method is similar what is known in western society as mentoring. In this story the ceremony is for the boys who are selected to be mentored by older men and Elders. The story tells about a father who mentored his son in this Indigenous Pueblo education ritual and how the father's experience created an unexpected recovery from diabetes.

I will call the father Jose, a pseudonym to protect his identity. Jose is a 37-year-old Pueblo man who was diagnosed with Type II diabetes. At the time of this story, he required insulin medication to manage the disease. Jose said he had given up on making any improvements with his diabetes. He dreaded his medical checkups because he was told the same thing, "If you don't change your lifestyle; lose weight, eat healthier, get more exercise and stop drinking alcohol, you are going end up dying at a young age." Jose said when he was first told he had diabetes he tried to do everything the doctor recommended, including eating better and exercising more. He joined a weight management program at the Pueblo. He received free vouchers for a spa where he would swim, use the exercise machines, and sit in the sauna. He admits his greatest battle was eating healthy and not drinking alcohol. He felt he failed when he was told he needed to start the insulin medication. It was difficult for Jose to get used to giving himself the insulin shots. There were times he just did not want to give himself the insulin shot, so he did not take the medication. He attributed his condition getting worse to not taking his medication. Each time he went for his medical checkups he knew he was going to be told the same thing: "If you don't change your lifestyle you are going to die."

Jose understood his health was not good, that he was facing kidney damage that might require dialysis treatments for the remainder of his life. He was very emotional about his condition; he expressed guilt that he might not be able to take part in the Pueblo education ritual with his son because the leaders might not allow him to use "white man medicines" while in ceremony. He worried about how he would take his medication. Jose expressed how important it was for him to be with his son in the ceremony; he did not want his health to prevent him from participating. He was excited about the opportunity to relearn traditional practices he learned ten years prior.

A few days before Jose and his son entered into the ceremony, Jose had his blood glucose tested. The test indicated his blood glucose numbers (13%) exceeded recommended levels for a person with diabetes. The recommended blood glucose number for a person with diabetes is less than 7%. Jose knew he needed to take the insulin medication but had to get permission from the head man because the rules did not allow individuals to use "white man medicines." Jose said he was afraid to ask because everyone would find out he was a "diabetic," he hated being labeled as that. He got permission to use the insulin, and in the beginning, administered his shots regularly. At times he was so busy he forgot to take the medication. When the time came to refill the prescription, he decided not to refill it and completely stopped using the insulin. In his words, "If the creator decides to take me then I will die doing what I love doing, learning and practicing our cultural ways."

Being involved in the ceremony changed Jose's diet, his daily activity, and his thinking. His diet consisted of natural foods – Indigenous plants and vegetables, meat

from game animals. He and his son could only get from place to place by walking. He estimated that he and his son walked at least ten miles most days. He says he began to think better; he worried less and his thoughts were now focused on the lessons of the day.

Jose lived this life for about six months. When Jose was able to return to the clinic for his check up and for his medications, he had an unexpected conversation with his doctor. This is Jose's rendition of that conversation:

> Dr. Summers[3] walked into the room and I was sitting on the exam table, and she looked at me said, Hello, I am Dr. Summers and I said I know you, don't you remember me, you were always getting mad at me cause I won't stop drinking and I ate too much McDs. She looked at me real good and yelled out my name, Jose, is that really you, wow, you lost a lot of weight, where have you been? I told her I bet you thought I died huh. She said I'm not going to lie I thought something bad had happened to you, but I know by now that someone would have told me if you had died. Then I said you probably thought I was in jail, huh? She laughed.

Jose was weighed, and his blood glucose was tested. Dr. Summers was surprised with the results; he had lost 30 pounds, and his blood glucose level was less than 7%. Based on the test Jose did not have to take the insulin medication anymore and he was happy about that. The doctor asked Jose what he did to improve his health. Jose told her, "I lived the Indian way - no white man food, no riding in cars and no beer. Man, I didn't even miss the beer after a while."

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3 Name changed to protect anonymity of individuals.

I met Jose when I worked in his tribal community, and when he shared his story I was struck how his story demonstrated how Pueblo traditions and practices can positively impact health and well-being. Jose added that during the time he spent with his son, he developed a closer bond with him motivating him to be a better dad. Interestingly, Jose claimed he did not realize the extent to which the drinking [alcohol], eating bad food, and being lazy affected his health. At the same time, Jose's experience illustrates the Pueblo epistemology of well-being describes the connection with heart, body, mind, and spirit.

American Indian epistemologies frame learning and doing through self-knowledge; and this knowledge is acquired through the connection to the natural environment. Jose's story fits Cajete's (2005) description of an Indigenous learning experience: "a subjective experience tied to place: environmentally, socially and spiritually" (p. 71). Cajete's definition makes sense to explain Jose's success in overcoming diabetes: Jose's reconnection to traditional Pueblo living was *intentional*, he was *responsible* for his son's traditional education, and he had to be *prepared* mentally and physically to take his son out into the wilderness for his daily lessons.

Today, we are seeking methods with positive effects outweighing the level of negative affects to enhance Native peoples' focus on opportunities to converge cultural concepts of well-being with the Western concepts of health (Suina, 2016; Cochiti Pueblo Health forum, 2010; Pueblo Convocation, 2012; Leadership Institute, 2008; Warne, 2005). The underlying message is that cultural concepts explain human existence; meaning, humans do not exist in this world alone, and therefore our well-being is linked to the natural universe and our teachings explain that an intimate relationship exists

between the people and their environment. Our ancestors' survival and identity depended on the knowledge of this relationship. As argued, for Pueblos, farming was our way of life, epitomizing the relationship between the people and natural universe and our very identity as Pueblo people (Cajete, 2005; Pecos, 2007; Suina, 2016). For me, *Indigenous well-being* captures the significance of these relationships, and as Indigenous communities become more aware of the root causes of the large-scale social problems they face, they are realizing the value in implementing culturally and contextually anchored solutions in the problems they face (Gone, 2011, p. 197)**.**

Change Over Time

For the past century Native American lives have shifted from Indigenous lifestyles (e.g. agricultural and communal) to Western lifestyles (e.g. sedentary and individualistic). Pueblo people share a concern that our Pueblo way of life is declining. We witness that with the diminishing of Pueblo languages, for example, community members are expressing confusion in their Pueblo identity, which relates to loss of lives due to disease or feelings of despair. We are witnessing an overall weakening of the "structure" of Pueblo living. Pueblo people working in health are turning to practices rooted in Pueblo teachings and practices to shift the conversations from "health as a disease" to the Pueblo concept of heart, body, mind, and spirit that captures a state of well-being reflecting Pueblo living (Suina, Naseyowma-Chalan, Lucero, Albert , & Lucero, 2012). Over time, changes have occurred in our ways of doing, ways of thinking, and ways of existing. For example, when I attend community gatherings, among the ladies will often be discussions on ways to lose weight. One person might say she

stopped drinking sodas and lost ten pounds. Another person might have quit eating carbohydrates and feel her pants loosen around her waist and more energetic. Others might take on the latest fad, like apple cider vinegar and herbal tea concoctions that purportedly cleanse the body and get rid of bloating. I see this conversation as an example of how western ways of thinking and doing significantly affect Native people's thinking and doing; these Native women have bought into the obsession with health "linked to particular ideals of bodily fitness and longevity" (Adelson, 2000, p. 4). How does this thinking fit with the future Pueblo life? The Pueblo people are concerned about the future of their children, families, and communities; many have expressed the need to reclaim a way of life that is fitting with traditional Pueblo life. The expressed hope is for all members to speak their Pueblo language, to re-establish traditional food systems connected to farming, and to work side by side young and old (Cochiti Pueblo Health Improvement Council, 2010; Romero, 2018; Suina, Naseyowma-Chalan, Lucero, Albert & Lucero, 2012).

Cultural resurgence aims to reclaim our place in greater society as Pueblo people. In the 1960s Cochiti Pueblo experienced the traumatic construction of Cochiti Dam Lake, one of the largest man-made lake and the 10 largest earth-filled dams in the U.S. (Pinel, 1988; Pecos, 2007). The dam was constructed despite an outpouring of opposition by Cochiti Pueblo; it severely impacted Cochiti Pueblo ways of life by destroying sacred cultural sites, the Cochiti Pueblo farming valley, and relationships with the environment. The destructive impacts continue into the present (Pecos, 2007). Prior to the dam every family farmed a plot of land by the river. Everyone helped to farm, harvest the crops, and

shared what they worked hard to produce. By the time the dam was completed in 1975, the farms, orchards, and summer homes by the river were bulldozed, leaving only memories. The devastation was exacerbated by dam seepage that damaged remaining farmlands. As a consequence, farming was lost for a quarter of a century, keeping a whole generation from learning and practicing a way of life that defines Cochiti Pueblo people (Pinel, 1988).

The devastation caused by the dam expanded when the idea of building the Town of Cochiti Lake was thrown into the mix with building the dam. Although the town was proposed to be built on Cochiti Pueblo tribal lands, the Pueblo authority of the tribe would not be recognized. Regis Pecos was twenty-two years old, fresh out of Princeton at the time of the dam was being constructed and the plans for the town were moving forward quickly; he participated in the "fight to protect the people, those who had gone before us and those yet to be born" (2007, p. 646).

Although I was not living in Cochiti at the time of dam construction, I witnessed the destruction of farmlands caused by the dam seepage. My husband was an adolescent when the construction of the dam started. His family had returned from Reno, Nevada where his father worked at Stewart Indian School. With the dam under construction most of the farming had come to a standstill. It took almost ten years to complete the dam and soon after farmlands began flooding. After a long arduous legal battle with the Army Corp of Engineers, a system was developed to ease the seepage. By this time my husband and other young men his age had accepted that they would never have crop fields by the river; they would not work alongside their fathers and grandfathers in the fields hoeing

weeds, irrigating, or harvesting corn, squash, and other crops. They had resolved that farming was gone and along with it the foundation of their role as Pueblo men. My husband described how he felt about this period in his life, “it was like cutting a piece of my manhood out of my life” (Chalan, 2018). His greatest disappointment was that the people blamed one another, leading to disputes among the members of the Pueblo. The animosity and contention continue today to play out among the young people not even born at the time.

The construction of the dam and town propelled a movement to resist the destruction and institute our knowledge, our values, and our practices (Pecos, 2012). The logical place to start is with ourselves; then move on to programs and services, at each juncture asking ourselves: “Is what we are doing moving us further from our core values or is it helping to sustain our way of life?” (Pecos, 2012). Recognizing and understanding change, knowing what is driving change, and reclaiming our Pueblo knowledge and practices ignited the movement to intervene, recover, and revitalize. In the following discussion I address Pueblo practices as possible methods for examination and interventions.

Pueblo practices as health interventions

For centuries, Native people successfully depended on their cultural practices to achieve and maintain good health (Adelson, 2000; Warne, 2005). Regaining appreciation for Pueblo health practices entails understanding the philosophies that define Indigenous knowledge and cultural practices, and these philosophies span the body, mind, and spirit.

Re-affirming and explicitly claiming values

For example, the Pueblo core values framework is a tool with its origin validated with historical narratives known to the non-Natives as creation or origin stories. In the numerous testimonies provided in various LI forums, Pueblo people confirmed that the framework's structure and categorical elements assisted them gain a clearer understanding of the messages conveyed in creation stories (Leadership Institute at Santa Fe Indian School, 2012). The core values tool explains what Pueblo life entails and guides us in our roles fulfilling our responsibilities for maintaining Pueblo ways of life. The framework can be used to design methods that include Pueblo strategies to address the physical health and social issues Pueblo people are facing.

In the Indigenous worldview; relationship or connectedness provides the foundation for an Indigenous person's sense of belonging (Hill, 2006, p. 210). In her work examining factors associated with Native mental health, Hill (2006) cited a study conducted by Acton and Malathum (2000) which identified sense of belonging as a factor that contributed to increased health-promoting behavior. A similar analysis of Pueblo core values, critical issues, and community-based solutions was developed by Pueblo community members and leaders through the Leadership Institute at the Santa Fe Indian School. Pueblo Core Values theory is an ideological framework based on axiology and epistemology expressed through Pueblo creation stories, related Pueblo cultural practices, and community-enacted beliefs. The framework is a blueprint for community life that depicts Pueblo living that has existed since time immemorial. Pueblo epistemologies survived the devastation of colonialism, and although the methods for passing the

knowledge from generation to generation have changed, the message remains the same: "cultural identity is rooted in place, beliefs, and cultural practices" (Leadership Institute at Santa Fe Indian School & Sumida-Huaman, Indigenous core values and education: Community beliefs toward sustaining local knowledge., 2018, p. 18).

The Pueblo living framework consists of three dimensions: core elements, traditional calendar, and core values. According to Pueblo teachings, the creator gifted Pueblo people with land and natural resources, language, laws and customs, governance structures, families and communities described as core elements (Leadership Institute at Santa Fe Indian School & Sumida-Huaman, 2018). Core elements represent the purpose for Pueblo living and the resources available to Pueblo people. The core elements thrive on how the people live their lives daily as well as traditional practices. They describe the foundation of Pueblo life with stories passed from generation to generation and explain the intention of each element and the significance to Pueblo life. The message shared in the stories reminds Pueblo people that their survival will continue as long as the core elements exist; Pueblo people are expected to sustain and maintain the core elements.

The core elements represent Pueblo life. For instance, land and natural resources represent the physical space where human live. The core values framework defines the roles of the people -- male, female, infant, adolescent, adult, and Elders. The framework considers that lives shift, and the high likelihood that the people might stray from living by the principles identified in the core values. However, recognition of the core elements of laws and observations of custom through practicing the traditional calendar aim to restore balance and harmony. One common method used by Pueblo peoples to restore

balance and harmony is to seek guidance from ancestors; this creates the bond that is part of spirituality. Family and community are responsible for these practices and include the people and everything that exists within the physical space where the customs, practices, and daily activity are carried out. Our Pueblo languages create the communication paths to share values, beliefs, and teachings and to share what is learned and is seen as necessary for interaction (Pecos, 2007).

Pueblo knowledge is the connection between land and the universe organized by the seasons, the natural environment – land, water, sun, and rain -- and the traditional calendar. The traditional calendar recognizes that our lives shift with the seasons and peoples' daily living and traditional practices shift with the seasons. Core values are the guiding principles that dictate behavior and help people understand the difference between right and wrong with the instructions that:

> People follow clear protocols and cultural practices through a traditional calendar (spring, summer, fall, and winter) of seasonal activities and daily work through which core values, instructions for how to live in this world as human beings, are exercised and affirmed. (The LI & Sumida Huaman, 2018, p. 5)

Pueblo peoples' lives follow a set of guiding principles, or core values, which define behaviors, expectations, relations, and responsibilities. Core values also relate how Pueblo people came to exist in this world and our moral responsibilities; values define a way of life taught through traditional stories, lived experiences, and rituals. Values include love, respect, compassion, faith, understanding, spirituality, peace, and empathy.

The teachers of our Pueblo values and moral responsibilities include a cadre of parents, grandparents, Christian and traditional godparents, aunts, uncles, and the community family. The Pueblo core values "offer insight into the ideals that connect Pueblo people to their cultural practices and traditional stories for purposes of harmony" so learning is constant and teachers can be anyone (Leadership Institute at Santa Fe Indian School & Sumida-Huaman, Indigenous core values and education: Community beliefs toward sustaining local knowledge., 2018).

In her work Sumida-Huaman discussed the disruption of Pueblo knowledge systems through assimilative federal policies and contemporary social problems creating opportunities for children and young people to "reject" Pueblo values and be influenced by other examples that may conflict with Pueblo teachings (Leadership Institute at Santa Fe Indian School & Sumida-Huaman, Indigenous core values and education: Community beliefs toward sustaining local knowledge., 2018). This situation has spawned an urgent appeal to counter the disruption and restore the teaching of Pueblo values. The LI acted by adding a dialogue process that became a standard conversation tool for any LI forum. In the forums, the participants responded to questions that asked what "core values sustain who they are" and who are person(s) responsible for teaching them their core values (Leadership Institute at Santa Fe Indian School & Sumida-Huaman, Indigenous core values and education: Community beliefs toward sustaining local knowledge., 2018). In her work, Sumida-Huaman referred to this exercise as "values retrieval" and noted this engagement process was acknowledged as a unique method of exchange that demonstrated the importance of recognizing personal core values as well as affirming the

purpose core values have in our lives. The exercise reinforced practices of building relations, teaching and sharing with others, and acknowledged that everyone has a part in teaching and learning be it "communal, familial, interpersonal and personal" (The Leadership Institute & Sumida Huaman, 2018).

The core values framework is designed to motivate people to make practical decisions about what they can do to reclaim their Pueblo way of life. The framework inspires hope encouraging everyone that they possess the Pueblo knowledge and skill to contributions towards re-instituting Pueblo knowledge in the methods used for programs and services meant for our people. The assimilative actions intended to dismantle Pueblo knowledge systems and there was an assumption that the core values were not practiced anymore. This was not the case displayed by what took place in LI forums. Participants opened up; they elaborated on their core values, reflected on the special learning moments and at times cried because for many it was the first time they shared openly the things that were important for them.

Rethinking sovereignty

Anya Dozier-Enos (2015) elaborated on a notion of *deep sovereignty* as a Pueblo theoretical framework to better understand how Pueblo knowledge and Western education intersect, impacting Pueblo children. Deep sovereignty is based on Pueblo philosophies that define specific aspects of Pueblo sovereignty. She argued, "Sovereignty as a foundation for cultural survival reaches more in-depth than politics and government and [reaches] into the very way of life a people" (p. 25). A fundamental principle of the framework acknowledges that Pueblo people live in a "pluralistic society" with Pueblo

people constantly interacting with the western world (p. 27). As an educational tool, deep sovereignty outlines the Pueblo way of life defined by religion, language, (natural) resources, and wellness (p. 33). According to Dozier-Enos these core elements "contribute to Indigenous sustainability" and are interrelated categories that define the well-being of the community. Living life grounded in the four elements reaffirms Pueblo identity articulated by Dozier-Enos as the "foundation for each person having value and being valued" (p. 34).

However, the concept of Pueblo deep sovereignty must necessarily include ways of thinking about our food systems beyond just metaphor. Pueblo sovereignty as historically farming people whose cultural practices are linked with land and food in more than subsistence ways but spiritual ways must also include considerations of how Pueblo people interface with modern food systems, including the commodity foods that our people receive. For example, Michelle Chino et al. (2009) conducted a study on patterns of commodity food use among American Indians and concluded that American Indians made up a significant percentage of the populations that rely on food subsidy programs sponsored by the federal government (p. 286). A significant finding related to the pattern of community food - if a person ate commodity food growing up more than likely the parents and grandparents were also raised on commodity (p. 286). Chino et al. findings indicated that regular and continued use of commodity food items over the life course may influence food preference (p. 287). They cited the findings of Dillinger et al. (1999) that noted parental preferences and practices can strongly influence children's behaviors, including diet/food choices (p. 287). This study provided an excellent example

of how Indigenous knowledge pertaining to food was replaced with a western knowledge of food - federal food subsidy and now is linked to chronic diseases such as obesity and diabetes (p. 287).

These examples offer us the challenge that Pueblo lives may not change for the better if we continue to rely on western-based approaches, whether education or food systems, because those approaches carry the colonialist spirit (Pecos, 2012). We also need to understand the active role of policy impact on all facets of Native life, historically and in contemporary society. For example, the first time I heard the LIs federal policy presentation (which outlines 100 years of destructive policies towards Pueblo lands, languages, and spirituality), some painful memories came back to me. I recalled episodes during the times my father struggled with alcohol addiction, and instead of feeling the shame and wanting to blame, I understood that it was not my father's choice to leave his home and family but he agreed to leave home because he was concerned what would happen to his family if he refused. The federal government threatened to send the heads of households to jail if their children did not go to school. For a long time, he harbored an intense anger and resentment, and his way to cope was by using alcohol. He was away at school for two and when he returned home, he was married, had a new-born son and already drinking excessively (Naseyowma G. , personal conversation, 2018).

The efforts to use our Pueblo knowledge and practices to address local challenges and to celebrate milestones are quickly developing at the grassroots level. In 2007 a group of Cochiti Pueblo women came together to form the Cochiti Youth Experience (CYE) a non-profit organization to expand opportunities for young Cochiti Pueblo

members to make healthy life choices through the traditional practice of farming, to educate youth about their tribal history and to encourage youth to keep healthy by participating in the traditional lifestyle of a farmer. CYE was precipitated by a community health forum where a group of community members framed a vision of a "healthy community/healthy people" describing the community as the place where people were engaged in some type of farming and the people re-learn the connection between being agriculturists and the Cochiti Pueblo traditions and ceremonies (Cochiti Pueblo Health Council, 2008).

The farmer mentor program pairs youth ranging from five years old to early teens with farmers, often times one of their relatives in the fundamental practices of Pueblo farming. In addition to learning how to grow vegetable gardens and harvest the crops, young farmers provided fresh fruit and vegetables for their families. For many young people eating fruits and vegetables grown by them was a new experience and when they shared their harvests with others, the youth were rewarded with praised and recognized for their thoughtfulness and hard work. Experiencing the physical activity involved in farming such as hoeing, irrigating, pulling weeds by hand and so forth, enabled the young farmers to appreciate the importance of getting up early to complete most of the hard work while the air is still cool. The project offered the Elders the chance to re-establish intergenerational learning. Elders imparted their knowledge regarding relationships such as knowing kinships, learning the proper ways to greet people, and explaining cultural teachings while enhancing language skills (Romero, 2019). The Cochiti Pueblo Youth

Experience project became known as a project closest to capturing a Cochiti Pueblo definition of well-being that most of the members found relatable.

Adae Romero, CYE founder described the intent of the organization as "agriculture and traditional Pueblo farming is the ancestral gift, the framework offers present day Pueblo people a guide to even our most complicated modern day social problems" (Romero, 2018). From 2012 through 2014, the program received funding from First Nations Development, McCune Foundation as well as funding from Cochiti Pueblo to implement an intergenerational farming program with thirteen youth, male and female paired with an Elder tribal member and together they planted a small vegetable garden of corn, squash, melons, and chili. Although the goals of the program were to increase opportunities for youth to make healthy choices, those involved in the project did not consider their participation as improving their health instead, they embraced the teachings from the Elders. The youth were proud of their hard labor and the harvest produced which they shared with family and others. The Elders and youth formed relationships which led to the Elders providing guidance in cultural practices. Everyone who participated in the program experienced the rich benefits on all levels – individual, family and communal. This is but one example of how the rethinking of Pueblo values, practices, and ideas of sovereignty can be translated into practices that offer us pathways for Pueblo practice that respond to colonial impacts.

Research Study: Examining Pueblo Patient-Provider Interactions

The alarming reality of American Indian and Alaskan Native (AI/AN) health today is that the population experiences some of the most significant health disparities of

any population in the United States (Indian Health Service, 2015; Frizzell & Warne, 2014; Nelson, Stith & Smedley, 2002; Tlatilpa, 2015). Unfortunately, this translates into AI/AN having short life expectancies compared to other populations in the United States (Indian Health Service, 2015). Native American (AI/AN) populations in New Mexico experience similar situations noted by health reports that indicate Native Americans have the greatest health disparities in seven of ten categories: chlamydia infections, obesity among adults, diabetes deaths, HIV infections, motor vehicle deaths, alcohol related deaths, and pneumonia/influenza deaths (NM Dept. of Health, 2014). With disease and illnesses increasing (Indian Health Service, 2015; NM Dept. of Health, 2014; U.S. Dept. of Health & Human Services, 2013), more Native health research is examining culturally specific influences within medical encounters for Native Americans (Roter & Hall, 2006; Saha, Arbelaez, & Cooper, 2003; Shelly, et al., 2009). Note that disease and illness are distinct but related categories—for example, disease is exemplified by the diagnosis, which can be long-term; illness is what characterizes the disease.

Health research examining the effects of race and ethnicity on provision of healthcare found that social factors impact health outcomes; communication between provider and patients is vital and linked to improving patient satisfaction, treatment compliance, and health outcomes (Roter & Hall, 2006). Effective communication and establishing trust are recommended strategies to reduce barriers and encourage meaningful patient-provider interactions (Nelson, Adrienne, & Brian, D.S., 2002). According to Debra Roter and Judith Hill (2006), patient-provider communication is “one of the fundamental ingredients of medical care, and meaningful communication between

the patient and provider has proven to legitimize feelings of fear and physical pain and is a means for patient and provider to define who they are, what they expect of each other, and what kind of relationship they will have" (pg. 4).

In 2014, the American College of Obstetricians and Gynecologists issued a committee opinion citing an Institute of Medicine report (2003) that identified communication differences between physicians and patients as reasons for biases in physician and patient communication. Researchers examined culturally specific influences within medical encounters for Native Americans and found that health care providers working with Native patients benefitted from understanding communication differences (Simonds, Christopher, Sequist, Colditz, & Rudd, 2011). According to the study, providers who understood Native history and culture as well as variations among tribes reported having good relationships with Native patients. However, research that further examines Native American patient-provider communication is limited; no research exists that examines the types of information that Pueblo patients define as relevant to their health and well-being, which they believe should be conveyed to providers.

My dissertation research focused on Pueblo patient and provider interactions to better understand perceptions of what is important in the communications between the Pueblo patient and health provider. Such information included facts about family (without specific medical family histories disclosed), knowledge/beliefs that were or were not be associated to the patient's culture, as well as community and family dynamics (that do not delve into traditional medicine or sacred ceremonial activities). My

research sought to include viewpoints from providers and patients that could improve communication in addressing AI/AN health issues. I hoped to identify factors that matter to a specifically Pueblo patient. I expected that whatever I learned from participants would bring attention to some of the gaps in health care services. The research that I share here speaks to the need to build and repair trust between Pueblo patients and providers. The results of my study will contribute to guidelines for training and education of health care staff, specifically providers at the University of New Mexico, Sandoval Regional Medical Center (SRMC).

Significance of the Study

Indigenous practices that once guided people in daily living are not a dominant force in Pueblo lives today. Today, Pueblo people concepts of daily living revolve around being healthy i.e. free of disease and physically mobile, having the means to provide for self and family, and taking part in ceremonies (Dozier-Enos, 2015; Pecos, 2007; Suina, 2016). Being healthy, living a healthy life are Western concepts many Pueblo people have adopted and often refer to when discussing their lives.

While I did not research "Pueblo culture," my work sought to highlight how elements of our culture—practices, teachings, and beliefs—guide the ways in which our people think and act in order to uphold traditions and ceremonies. Approaches such as reflecting on history, storytelling, and personal reflections have served to guide and inspire my research and validate Pueblo epistemology as a viable framework to examine Pueblo health and well-being today. However, the stories shared are also collections of

generations of Pueblo people surviving horrific experiences, reflecting the efforts our people made to remain resilient despite attempts to destroy our culture, even today.

What we know about dominant healthcare practices today is that healthcare providers who tailor their approaches to the social, cultural, and linguistic needs of patients have improved health outcomes and increased respect for and mutual understanding with their patients (Murray-Garcia, 1998). I embarked on this research because I believed that healthcare for Pueblo people may call for different methods and approaches, and this research may reveal new knowledge that is presented directly from Pueblo people as well as providers with experience delivering care to Native American people. My research illustrates how Pueblo people perceive health today and how each person incorporates their beliefs and practices in their health and well-being. Approaches applied in health care health today are often standard practices used with all populations that do not consider the unique or distinctive situations of different populations (King, Smith, & Gracey, 2009; Marrone, 2007; Simonds, Goins, Krantz, & Garroutte, 2013). Standard medical practices are expected to improve the health of all populations (Institute of Medicine & Board on Health Science Policy, 2003), however, health statistics demonstrate that Native American health in fact continues to decline (Indian Health Service, 2015; Institute of Medicine & Board on Health Science Policy, 2003; NM Dept. of Health, 2014).

Discourse examining colonization of Indigenous Pueblo populations identified that programs linked to the federal government may actually reinforce intentions to continue the assimilation of Native people into mainstream U.S. society (Pecos, 2007).

Pueblo people desire to maintain Indigenous Pueblo beliefs and practices, so finding solutions that support healthy living embedded in Pueblo philosophies will contribute to maintaining Pueblo ways of life.

Research Design

Pueblo epistemology and methodology frame my analysis to maintain the integrity of what I understand as Pueblo knowledge, which is conveyed through storytelling in various settings, at certain times, by certain community members. Note that I do not delve deeply into these elements as this dissertation is not a study of culture per se, and Pueblo communities are protective of cultural practices. Of Indigenous methodologies generally speaking, Margaret Kovach (2012) described Indigenous methodology as being "holistic [in] nature, focusing on the metaphysical and pragmatic, on language and place, and values and relationships" (p. 57). Indigenous epistemologies can never be standardized, for they are in relation to place and person (Kovach, 2012). In this case, the research methodology reflects my participants' location in Pueblo homelands in New Mexico. Like other Pueblo researchers, I recognize the ways in which knowledge is transmitted among Pueblo people (Dozier Enos, 2017; Pecos, 2007; Suina, 2018). Storytelling is integral to my research methodology, as a recognized "Indigenous pedagogical method practiced by many American Indian tribes to transmit educational messages" (Hodges, Pasqua, Marquez, & Geishirt-Cantrell, 2002, p. 6). In my research, stories from both patients and providers offered critical context for the findings that describe individual experiences of interactions between health care providers and Pueblo individuals.

My own understanding and practice of Pueblo knowledge, our traditional practices, and cultural beliefs combined with concepts of health that embrace Indigenous viewpoints also guide this qualitative research. I could not separate who I am from the work that I do and why I do it. Earlier I argued that imperialistic concepts of Western biomedicine have limited Pueblo people's participation in healthcare. On the other hand, Pueblo epistemology defines concepts of "living well" also known by many as holistic health—heart, body, mind, and spirit. Understanding how these concepts fit with who Pueblo people are today can aid in the development of appropriate intercultural communication strategies that will enhance positive interactions when seeking health care. This study used qualitative methods to gather information to identify categories of knowledge that patient participants believed are necessary to convey to providers. The study did not explore patients' medical histories or current health conditions but rather aimed to understand patient-provider interactions and cross-cultural communications. The primary research questions included:

> *Research Question: What are the current conditions of communication between health care providers and Pueblo patients?*
>
> *Research Sub-questions: What might be existing gaps in communication? For instance, how comfortable is the patient in sharing sensitive matters such family problems, or financial challenges? What are patient-provider visions for appropriate communication that they believe will lead to positive outcomes for Pueblo patient health?*

Context and setting of the study

The research was conducted in Sandoval County, New Mexico. Sandoval County has a total area of 3,716 square miles that includes the incorporated municipalities of Bernalillo, Cuba, Corrales, Jemez Springs, Rio Rancho, and San Ysidro, as well as all or portions of seven Indian pueblos and all or portions of six tribal entities/lands (Simply Design Inc., 2019). The Pueblos/tribes include Cochiti Pueblo, Jemez Pueblo, Jicarilla Apache Nation, Laguna Pueblo, Navajo Nation, San Felipe Pueblo, San Ildefonso Pueblo, Sandia Pueblo, Santa Ana Pueblo, Santa Clara Pueblo, Santo Domingo Pueblo, and Zia Pueblo. Among these communities, five distinct languages are spoken, including Zuni, Tiwa, Keres, Towa, and Tewa.

Native Americans residing in Sandoval county receive their health care through a complex health system consisting of community tribal health clinics that are either managed by the Indian Health Service (IHS) or a federal health care program operated by the tribal government. Tribal clinics operate full-time while smaller community health stations may operate only part-time. Services are available Monday through Friday (a typical work week) and mainly consist of primary care and pharmacy prescription dispensing. Other local health programs include diabetes prevention and disease management services, plus other health-related services, including nutrition, aging, substance abuse, community health representatives (CHRs), and emergency medical services (e.g., ambulance).

Services in each community vary and some types of medical care are limited. If an individual requires specialty care such as orthopedic surgery, the community health

care provider refers the individual to a local medical facility. Local medical facilities include: the University of New Mexico Sandoval Regional Medical Center located in the city of Rio Rancho; the University of New Mexico Hospital in Albuquerque; the Crista St. Vincent's Hospital located in Santa Fe; Presbyterian Hospital in Rio Rancho or in Albuquerque. For many Native Americans, the diverse health system places them in unfamiliar environments. People from different cultures are cautious due to negative experiences in their interactions with services and people outside their communities. Navigating the different medical systems and adjusting to each facility's work culture increases patient vulnerability, making it difficult to communicate their health issues each time they encounter different health care staff (Kelly & Brown, 2002).

Sampling

My data collection period ran from August 2018 through January 2019. Medical providers were recruited from the University of New Mexico, Sandoval Regional Medical Center, Inc., and other medical facilities using the researcher's email network. Arizona State University Institutional Review Board approved the Social Behavior application including the materials used in the study on January 18, 2018. In addition, Jamie Silva-Steele, President/Chief Executive Officer at UNM SRMC, provided a letter authorizing the researcher to use the hospital email system to recruit providers for this study.

Recruitment was conducted by word of mouth, flyers posted in public locations in the Medical Center facility (on the five floors and main public areas), and my own professional email network with a flyer attached to the email announced the study.

Minimal response using these methods led the researcher to apply a snowball sampling technique. Individuals who first volunteered to be a participant recruited other participants from among their acquaintances.

The research was not conducted on reservation land, but in places chosen by the participants such as the coffee shop, restaurants, library, and by phone. A total of fifteen individuals agreed to participate in the study. Each interview took approximately forty-five minutes to one and half hours to complete. Eight participants identified as patients. The participants represented a cross-section of different Pueblos. I have deliberately chosen not to identify participants as belonging to specific Pueblo communities, for confidentiality purposes given the small sample size. The small number of participants—while indicative of important issues— means that individuals do not speak as representatives for their Pueblos. Patient participants included (a) two Elders eighty years or older, one male and one female; (b) two young adults, from twenty-three to thirty years old, one female and one male; and (c) four adults from forty to fifty years old, all female. In this study, seven participants were health care providers, and I identify them here according to professional title and gender: (a) two physicians (b) two female registered nurses; (c) two female clinical social workers; and (d) one female community health representative (community health worker); four of the health professionals were Pueblo.

My research applied five criteria to determine if an individual met the qualifications to be a patient participant: (1) a member or affiliated with one of New Mexico's 19 Pueblo tribes; (2) a current New Mexico resident; (3) over the age of 18; (4)

able to speak and read English; and (5) had a medical encounter in the past two years. Two criteria were used to screen health care providers for the study: (1) a person who delivers health services or whose work influences the health of a person; and (2) has delivered health care service to Native American patients.

The Interview Questions

The study consisted of one-on-one interviews with separate sets of questions designed for each participant group. Questions were developed to better understand the barriers that Pueblo patients encountered when obtaining health care. I work at a medical facility and I have conversations with Native patients about their experiences where misunderstandings occurred between them (patient) and the provider, and where patients report feeling uncomfortable causing them to think they were being treated differently because they were Native American. The interactions I had provided background for some of the interview questions and also encouraged not only the patients but the providers to address misunderstandings.

The patient interview questions were designed to elicit information that patients believed are necessary to convey to providers. The research was not focused on information that pertained to personal or family medical history, instead, the stories patients and providers shared about medical encounters defined certain encounters as "critical incidents." Critical incidents are the significant events individuals recall through stories that describe the impressions the event had on the person. The event is critical because it is accepted as having some type of impact on the participant—whether viewed as positive or negative. Medical experiences were narratives of family or community

history, cultural knowledge/beliefs, community and family dynamics. Adhering to strict Pueblo rules, the interview questions did not delve into traditional medicine or sacred ceremonial activities. Participants were cognizant of the restrictions, so any mention of cultural healing practices were in subtle references. The essence of patient input was their experience or the experiences of a family member in obtaining medical care. Questions for each group are similar in content but worded slightly differently.

Each group responded to five open-ended interview questions:

1. *Tell about your experience(s) when you had to seek health care.*
2. *What is important for providers to know about or be aware of when treating Native American patients?*
3. *What are the ways a hospital, clinic, emergency room, urgent care, or any other health care service can best take care of the health needs of the Native patients?*
4. *How were the health care providers knowledgeable and respectful of Native culture, values, and beliefs?*
5. *What kind of education and training would you recommend to better prepare physicians and other health care staff to be better able to provide culturally appropriate health services for Native American people?*

Just as observations and work experience guided the development of the patient interview questions, similar logic was applied in the development of the health care provider questions. Health care provider input was based on their experiences in providing health care to Native patients and was focused on five open-ended questions:

1. *Describe an experience you had with providing health care for Native Americans.*
2. *How can health care providers deliver health care that is respectful of the culture, values, and beliefs of Native patients?*
3. *What is essential for providers to know when treating Native American patients?*
4. *How can health care systems best respond to the health care needs of Native patients?*
5. *What education and training can prepare physicians and other health care staff to be better able to provide culturally appropriate health services?*

When scheduling interviews, participants were given options for locations to conduct the interview, including my office at the UNM SRMC or a site selected by the participant. Protecting the participants was addressed in the informed consent. Each participant received a hard copy of the assurances which I reviewed with each participant. In the review, I explained the purpose of the study, how long each interview was expected to last, and assured there were minimal risks other than the normal risks inherent to daily life. In terms of benefits and risks, I made it clear there were not any direct benefits in participating in the study, however, their input may be used to improve communication practices between Native patients and healthcare providers. I assured the participant any information provided during the interview would be held in confidence. I explained their participation in the study was voluntary and advised them they did not have to answer any questions they do not want to and they could withdraw from the study

at any time and would not be penalized. Once consent was secured, interviews were digitally recorded and subsequently transcribed verbatim, then stored on a password-protected computer accessible only to the research team. Participants were made aware that all the recordings and transcriptions would be destroyed after three years.

In addition, following Pueblo protocol I showed my appreciation for those who volunteered for this research. I provided them with snacks, water, juice, and a small gift bag filled with UNM SRMC coffee mug, computer screen cleaner, hand sanitizer, first-aid kit, and a writing pen.

Conceptualizing a Data Analysis Framework

Research that examines Native patient-provider communications/interactions is limited. My data analysis was guided by two similar studies targeting similar populations. Len Kelly and Judith Brown (2002) conducted research with Canada First Nations patients and healthcare providers to understand the interactions between physicians and their patients and to identify strategies to improve relations for better health conditions (Kelly & Brown, 2002). Another study performed by Vanessa W. Simonds, Suzanne Christopher, Thomas D. Sequist, Graham A. Colditz, and Rima E. Rudd (2011) studied "barriers and facilitators to good patient-provider interactions to enhance participation in health-promoting behaviors" (Simonds, Christopher, Sequist, Colditz, & Rudd, 2011, p. 836). Both studies examined the attitudes and experiences of physicians and Native patients that affected patient-provider interactions. Similarities in both studies led me to consider their methodologies and apply portions from each to this research.

Kelly and Brown (2002) argued that communication issues make cultural differences apparent, noting that patient care and community context are inextricably linked; "physicians need to understand the social structure and value system of the communities they serve" (Kelly & Brown, 2002, p. 1650). The researchers recognized that gaining the participants' trust was vital in acquiring accurate depictions of negative and positive perceptions of patient and provider communication. They used member checking where participants read and critiqued their interview transcripts to check for accuracy and mitigate biases (Kelly & Brown, 2002).

Research conducted by Simonds et al. applied several methodologies including the seminal work of John C. Flanagan who developed the critical incident technique (CIT). CIT is a data analysis methodology that assesses "human behavior in such a way as to facilitate their potential usefulness in solving practical programs" (Flanagan, 1954, p. 327)—where "their" refers to characteristics of human behavior. Simonds et al. applied CIT to identify the detailed descriptions of positive and negative patient-provider interactions from both the patients and providers in a rural Native American community (Simonds et al., 2011). CIT is an established method utilized generally in storytelling where the respondent describes a critical incident that is memorable to them and had some type of impact on the participant (Flanagan, 1954). Objectivity in CIT is then viewed in relation to the number of events or incidents that are made across different participants, or as Flanagan described, the "tendency for a number of independent observers to make the same report; two things have the same effect or, one has more or less effect than other with respect to some defined proposed or goal" (1954, p. 335). Data

for this study was extracted from personal experiences/stories (behaviors), and through methods found in CIT I discovered the complex factors that influence how Native people experienced healthcare.

Applying CIT techniques, the findings from Simonds et al. expanded the existing patient-provider communication conceptual framework developed by Roter and Hall (Roter & Hall, 1987, cited by Simonds, Christopher, Sequist, Colditz, & Rudd, 2011). The framework categorized patient-provider communication as either task behaviors or socioemotional behaviors. Task behaviors are "technically based skills used in problem solving that comprise the base for expertness for which the physician is consulted" (Simonds et al., 2011, p. 837). Socioemotional behaviors as "intrinsic behaviors, including small talk, joking and non-verbal behaviors" (Simonds et al., 2011, p. 837). Interview responses were then categorized as provider action or feelings/interpretations and patient action or feelings/interpretations. Methods and the findings from the two aforementioned studies provided helpful direction in developing the data analysis for this study, and methods borrowed from them—used during the translation of interview data and the categorization of the facts—were helpful in defining the findings.

Coding – Steps to Organize Data

While I utilized methods, frameworks, questions, and considerations from other research with AI/AN populations (e.g. CIT), I identified key words to organize and make sense of my interview transcripts (Leech & Onwuegbuzie, 2007). Reviewing the responses line by line, the key words were selected based on whether it reflected a response to interview questions. For example, I considered how the responses from

participants referred to an experience; perceptions of values held (e.g. respect); knowledge desired, held, or lacking (e.g. what providers/patients should know, how health systems should provide healthcare, and education/training). I was able to derive terms emerging from healthcare experiences of patients such as "scared," "fearful," "angry," "understanding," "caring," "nice," and so forth.

Next in my analysis, I identified areas where the analytical frame of CIT helped me better understand the data. For example, by first utilizing the key words in context approach, I was able to identify the ways in which the words were used—meaning, what words, ideas, and participant thoughts surrounded the key words that were emerging. I began to see how participants held in common their reflections of certain incidents/events. The notion of trust began to emerge from both patients and providers. Trust was described as referring to personal confidence, feelings, or emotions and as related to past negative experience. As a researcher, I also observed that participant behaviors often linked their recollections of negative experiences with issues of trust—for example, crying when describing an incident or feeling, or change in voice tone or volume when expressing anger regarding an incident or feeling. For instance, one female patient participant recalled a physician interacting with her in a way that the patient interpreted as derogatory, "talking down to her" so much that the patient sought another provider; and at that point in telling her story, when explaining the incident, the participant began to cry.

When analyzing my data at this stage, I began to see further connections with research on patient-provider communication through AI/AN patient-provider interviews

and CIT. Simonds et al. found that communications are "influenced feelings/interpretations related to action" (Simonds et al., p. 840). In their work, the categories of analysis were labeled as patient actions, patient feelings/perceptions, provider actions, and provider feelings/perceptions (Simonds et al., 2011). This categorization scheme was helpful, and I used the same general categories to organize responses from participants: patient actions, patient feelings, provider actions, and provider feelings, as shown in Figure 1, p. 50.

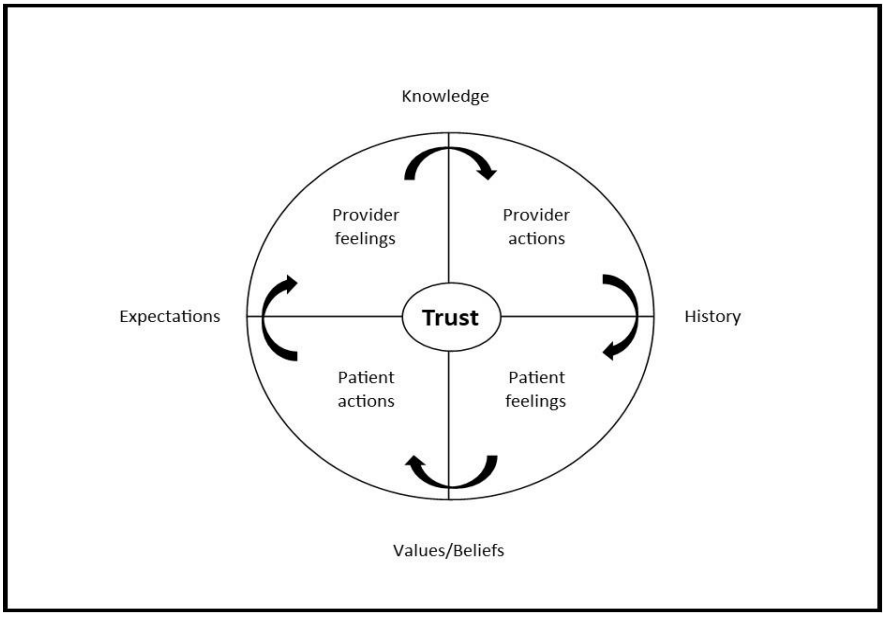


Figure 1: Patient-Provider Interaction Conceptual Framework (from Simonds et al. 2011).

Figure 1 reveals that relationships are key in the patient-provider interaction framework. Reciprocal relationships exist between actions and feelings of provider and patient. For instance, provider actions are perceived and interpreted by the patient who then responds with actions; patient actions are then interpreted by the provider, who responds again

with action. Actions and responses are cyclical and can begin at any of the four points—patient action, patient feelings/interpretations, provider action, and provider feelings/interpretations. Moreover, responses, whether from a patient or the provider, are influenced by outside forces. The influences were identified as repeated responses impacting patient or provider actions, feelings, or interpretations. Simonds et al. identified influences in their study as: medical encounters (medical related), individual knowledge, past experiences in seeking health care, participant expectations, family, and community. Like the categories, the influences are themselves interrelated.

At the time Simonds et al. completed their study, minimal research existed on AI/AN communication in health care. They wrote that there is an "incomplete understanding of patient-provider interactions in clinics serving Native Americans" (Simonds et al., 2011 p. 837). Applying their conceptual framework in my study expands their work and knowledge of the characteristics of Native patient and health care provider interactions, but more importantly builds on my intention to add to discourse specific to Pueblo health.

Study Results

Defining health and well-being

In this section, I discuss what I refer to as "precursors." Precursors are concepts that we might assume we share definitions for but that perhaps need to be more clearly defined. For example, Western terms such as "health" and "well-being" are often assumed to be related strictly to bio-physical health. As part of the interview, warm up questions were asked of both groups of participants asking them to define the terms

health and well-being. The participants' perspectives merit specific attention as they tell us about differences and similarities in definitions, and why those might be. I found that how individuals defined these terms varied depending on age, gender, current personal situation, and experiences in seeking healthcare. The definitions provide context regarding patient-provider interactions that I present as findings.

A 30-year-old Pueblo male whose recent health encounter when he sought mental and behavioral health services defined his physical health and the notion of well-being based on what he was "feeling" at the time, as well as in general being "ok": "Right now, my health is I would say is in decent shape. Well-being is, 'I'm ok, I'm all right.' I'm in average condition, I guess" (Pueblo male patient, 10/8/18). A female participant age 24 years old with a young child, in college pursuing a degree in early childhood education, defined health and well-being as associated with her physical health and what she did not do:

> I would say when it comes to my health, I guess I would call myself healthy. I don't do drugs, I don't drink alcohol, I don't get sick often. I do eat fast foods, but I really try to avoid them" (Pueblo female patient, 10/9/18).

While these two adults in the 20-30 age range viewed health and well-being mainly in terms of physical health, individuals in the age range of 35 to 50 years old presented a broader perspective that included both bio-physical health and other factors they associated with well-being, including mental, emotional, spiritual, and physical states, as well as community and family. Most individuals in the 35-50 age range based

their perceptions of health and well-being on personal experiences in seeking healthcare. For example, a 48-year-old Pueblo woman reflected on her recent experience dealing with her mother's medical condition as well as her own medical experiences. She described health and well-being:

> health is my physical self while well-being is my body, my spirit, my emotions, and my mental health. Well-being is not the same as health, I can say I'm well but be dealing with an illness – it's my perception of how things are in my life" (Pueblo female patient, 9/10/18).

Older patient participants defined health and well-being in distinctively different ways. For instance, two Pueblo Elders in their 80s defined health and well-being in terms of the balance between physical strength and physical freedom from disease or illness:

> I have experienced some health issues, which I never did have in the earlier part of my growing up. My health is very important to me. Being not ill, and not sick, that is what my health is all about" (Pueblo female patient, 9/10/19).

An 85-year-old Pueblo man had similar views about health and well-being based on his concern with physical mobility: "Not have difficulty in getting around. My health is getting medical care; workers are open to me and treat me good" (Pueblo male patient, 9/11/18). This participant also credited the kindness and caring of the healthcare providers to his successful recovery after a fall—alluding to the notion that the caring attention from providers linked with teaching were important processes for his own

healing: “They [physical therapist] showed me how to keep my muscles strong” (Pueblo male patient, 9/11/18).

Based on these examples, we can see that Pueblo people of different ages will consider health and well-being in relation to a number of factors, including bio-physical strength and mobility, freedom from disease and illness, as well as other factors that include mental and emotional considerations. I argue that Pueblo patients’ responses need to be evaluated relative to our relationships to and the influence of the general population; this is an important area for future research.

Health care providers were also asked to provide their definitions of health and well-being. Providers’ definitions of health and well-being stemmed from their knowledge as trained medical or health services professionals along with their experience of providing health services to AI/AN populations. Responses were not vastly different among this particular group, with the notable differences reflecting their professional experience as well as the services each provides. For example, a white male family practice physician who completed medical school and his medical residency in Israel learned first-hand the challenges a population encounters in seeking medical care in a country where there is political tension. He returned to the United States and worked at the Gallup Indian Medical Center. Three years later he came to work at UNM hospital as a family practice doctor in a community clinic in northeast Albuquerque. Today he works at the UNM Sandoval Regional Medical Center in the family practice clinic.

As a medical provider with an array of experiences, he explained that his definition of health and well-being is based on what he has learned is important to the people for whom he provides services. He said,

> Health is knowing that your body is functioning well; you are not struggling with disease and illnesses. If you have a disease, you are managing well so it is not inferring with your daily activities. Well-being is having stability in your life" (white male provider, 9/17/18).

This physician emphasized "functioning well" whether a person has an illness or not, a sentiment also expressed by the other physician who participated in this study. Similar to the other medical provider, the medical surgeon defined health and well-being as a condition of living life without pain and illness, "[health and well-being is] having the ability to do and pursue the things that are important to you in your life; to be free from pain and illness with as little medication as possible" (non-white male provider, 9/8/18).

While both these definitions of health focused on illness and being free from pain, other providers such as the community health worker (known in Pueblo health systems as community health representative or CHR) included community. The CHR who participated in this study referred to what she learned from interacting with her people about what is important in their lives: "The community is safe. People are eating healthy, people are physically active, and people know how to live a healthy life" (Pueblo female provider, 9/13/18). CHRs usually are from the communities they serve so their greatest asset is their firsthand knowledge of the community's culture and health needs. Most

CHR's health career is built on work in their communities and their perceptions of health relate to that experience.

Additional medical providers included two nurses who work and live in their communities. They both asserted that health is holistic and includes considering the whole body, but not just bio-physical health; rather, wellness exists in relationships with others, such as family members, with one's culture and belief systems.

My interpretation of how Pueblo and non-Pueblo providers defined health and well-being is that professional training requires considering those terms according to dominant bio-physical and medical training. Like the Pueblo patients, the Pueblo providers heavily emphasized health and well-being as also related to relationships that patients have with their family members, communities, their cultural activities, and their spiritual beliefs. Ultimately, the range of considerations when thinking about terms like health and wellness require the ability to broadly conceive of these terms in ways that also regard the local context, in this case is the Pueblo community.

'Trust' is the Core of Patient-Provider Communication

"Trust" was a salient theme in many of the interviews with both patients and providers. Trust as conceptualized based on the interview responses refers to the key or the goal to good patient-provider communication: it must be developed. Responses from both Pueblo patients and healthcare providers noted that trust is central to effective patient-provider relations, which determines the degree of success in the health care process. Patients described situations where trust was a factor in how they communicated with a health care provider. On the other hand, providers noted that having trust with the

patients enabled them to determine the best treatments for the medical conditions. An Elder Pueblo woman shared that she had several episodes of dealing with a serious illness, and each time she was worried about the outcome; however, based on interactions with health care staff she began to trust they would take care of her. The Pueblo elder woman stated,

> I got really ill. I was informed by the doctor that took care of me that I needed to go have a colonoscopy done. I was scared, my gallbladder was not the way it should be. I had surgery, 4-5 doctors would come and see me and they would tell me what was going on with me. I felt like I could trust them. This made me have confidence in them, they were going to take care of me (Pueblo female elder, 9/10/18).

Other examples highlighting trust included the story of a Pueblo female patient in her 50s who shared that she had successfully managed her diabetes condition for twenty-five plus years partly due to having the same provider from the time of the initial diagnosis. Her trust was uncertain when she faced getting a new provider:

> I'm a diabetic and previously Dr. Dee[4] was my doctor for 24 years. I trusted her and she trusted that I knew how to take care of myself. Recently she retired and I have a new doctor which was different because I didn't know her. When she left I was unsure how my new doctor would treat me; if she understood that I have a good grasp on taking care of my diabetes and my medication. When I explained to her what I did and what

[4] Name changed to protect anonymity of the person.

> changes I made she was OK with it; she didn't say I had to change it to whatever she wanted. After this I felt I could trust my new doctor (Pueblo female patient, 9/17/18).

At the same time, as described by participants, trust is not a given but can be tenuous, lost, built, gained, or broken. Trust, according to the story told by an 18 year-old Pueblo mother, trust was broken when she took her infant daughter to the pediatrician and he made negative remarks about her being a young mother. She felt that she was not treated well, attributing the negative treatment to the doctors who stereotype young Native mothers as not prepared to have children:

> When doctors talk down to us (Native Americans) like we don't know what they are saying or we don't understand. That's how I felt when I was getting my daughter's health care. I didn't like the way I was treated. I didn't trust him so I found my daughter another doctor (Pueblo female patient, 10/9/18).

Another negative encounter was relayed by a 30 year-old Pueblo male patient participant who sought health care to get medications as a part of his substance abuse treatment. He described feeling reluctant to go to the clinic because he felt that he was going to be judged. Whether he returned or not would depend on the how he was treated. He stated:

> When staff are nice and treat me good, and doctors treat me no different from anybody else they treat I feel okay. When I feel like they are treating

> me differently because of my illness I lose trust in them. I don't go back to him (Pueblo male patient, 10/9/18).

Providers, like the patients, also identified trust as integral in treating a patient's medical condition, and they were aware that this was a factor for patients in determining whether or not they would continue with their treatment. A Pueblo family therapist attributed her patients' trust in her to her knowledge of her patients' different tribes and Pueblos. She noted that establishing a relationship by identifying something that both patient and provider have in common can enhance opportunities for the patient to follow their treatment recommendations:

> Conversation [with Native American clients] is different because I'm familiar with the culture. [It] makes a difference that they know I am a Native. They seem to be more comfortable answering my questions and when it comes to a treatment plan they are willing to participate (Pueblo female therapist, 9/20/18).

Pueblo providers added more examples of how gaining trust from the patient is vital. The community health nurse whose patients are Pueblo members from her community added her perspective that a provider must be respectful and accepting of the different Pueblo beliefs and ways of doings things, and she attributed this approach to how she gained the trust of the people to whom she provides health services. She said, "We need to be respectful of what they believe in. Not everyone is fully traditional or fully part of the church—everyone doesn't share the same beliefs. This is how I gain the trust of my patients" (Pueblo female provider, 9/13/18).

Working in her community twenty plus years, a Pueblo community health worker added another dimension to the conversation regarding building trust and cultural familiarity. She shared that establishing trust also varies among individuals, community, and Pueblo or tribe. She explained that within her community, people speak about culture and refer to language, ceremonial practices, and beliefs as things that are important not to share with others who are outside of the community and culture. Using her experience as a health care provider in her community, she noted that being aware of what people valued created a degree of trust between the provider and patient:

> Trust is established by understanding the traditional and cultural values of each pueblo. Providers that are mindful of differences in practices and beliefs have better relations with patients. Our people mostly trust those doctors, nurses and pharmacist that have been around for a long time, like [names a physician]. Those that have been here a long time know what is important for the people (Pueblo female provider, 9/13/18).

Being a provider delivering medical treatment for various populations including Native Americans, a Pueblo nurse shared what she learned from interacting with patients and examples of what can build or destroy trust. She noted that some patients, mainly the Elders, told her they feel uncomfortable when the provider is on the computer and typing on the keyboard, without looking at the patient, while he/she is asking the patient questions.

> Most providers conduct patient examinations with touch; they want to feel that the patient trusts them or are comfortable with them, but some

> providers are afraid to touch the patient. Elders told me they do not know "how a doctor can diagnosis me without ever touching me." I think providers interacting—either physical contact or speaking to the patient—is a factor in how the patient will trust a provider (Pueblo female provider, 9/13/18).

A social work therapist whose clients include Native American families that have children under the age of 5, some living in Pueblo communities, and the majority residing in the cities of Albuquerque or Rio Rancho, New Mexico, discussed the importance of the provider displaying compassion because she learned patients interpret this action as the provider caring about them. She stated,

> When you [provider] show you are concerned about the patient [family], listening carefully to what they are saying, take notice of things in the home that are important to the family such as pictures, artwork, pets, anything in the home, patient feels the provider cares about them and is going to take care of them (Pueblo therapist, 9/20/18).

What I heard from my interviews is not an anomaly. Establishing patient trust is accomplished by positive interactions with the health professionals, patients in my study revealed that while trust is a vital component of patient-provider interactions, establishing trust with Pueblo patients requires time and explicit consideration of a number of factors, including cultural sensitivities surrounding what is even appropriate to know about Pueblo communities.

Pueblo Patient-Provider Interaction

Building on the precursors that I have introduced—individual definitions of health and well-being and the role of trust—which were extensively discussed with participants, this section outlines major themes that speak to the Pueblo patient-provider interaction. The themes inevitably address how trust is influenced in these interactions. Both patient and provider data are provided under major themes that speak to actions and feelings, which are interrelated. I first offer an explication of major themes that emerged from patient participant conversations.

Labeled as a Native American: Negative Stereotyping

A 23 year-old Pueblo mother shared her story of the first time she took her newborn daughter for her first medical check-up and described a "bad experience" related to the way the doctor spoke to her. As a teen mother at the time of her daughter's birth, she expressed being conscious of the stigmatization of Native teen parents by mainstream society. She had stated, "I felt labeled because I am a young Native American mother…We [Native people] are known for bad health—alcoholic, being overweight." She went on:

> My daughter's doctor, her pediatrician, was in Albuquerque and at first, we had a bad experience with him because he seemed to talk down to us only because I was a teen parent. I felt like I was being labeled out because I was Native American. I didn't like to deal with him on those checkups so ended up switching the doctor to a woman, which was better. She didn't talk down to us like the other provider did. Now we go to Kewa

> clinic. That's where she [daughter] gets all her checkups. They treat us fairly over there, they treat us good… (female patient, 10/9/18).

Due to the rampant negative images of AI/AN peoples that I outlined earlier, patient experiences regarding negative stereotyping by providers should not come as a surprise. At the same time, hearing the testimonies of Pueblo patients should raise alarm as the stereotyping relates to decisions they make regarding their healthcare services.

Patient Apprehension and Provider Respect

Pueblo patients described feeling apprehensive and self-conscious due to conditions that resulted from what they construed as their fault or due to their own neglect. A 42 year-old Pueblo female patient shared that her most recent experience seeking medical care was for her physical exam. Prior to the exam she was anxious and fearful because she had not maintained her medical exams regularly. What drove her to seek medical attention was experiencing recurring symptoms that she feared may have been signs of a more serious health condition.

> I neglected my health by not having my annual exams. I knew I had to have my pap smear done because I had symptoms that was making me worried. I started to worry that I may have cancer. I was scared as it came closer to my appointment. I turned to my higher power. When the medical test results were sent to me, I read them and it noted "unremarkable." I didn't know what that meant so my worry continued. This kind of stress can make you sick too. I couldn't sleep and eat (Pueblo female patient, 9/13/18).

Although she was afraid to discuss her concerns with her provider, due to concern regarding the seriousness of her symptoms, she had to overcome the fears in order to ensure that the appropriate tests would be conducted. Awareness of these kinds of issues—that patients may feel guilty or at fault for their own conditions and suffering are important feelings for providers to acknowledge in order to build rapport and trust with patients.

At the same time, it is important not to take for granted that trust exists when working with seemingly confident patients. Apprehension and distrust may exist in situations even if individuals are confident about their health. A 53 year-old Pueblo woman received medical treatment at least twice a year for diabetes disease over a 24 year period. However, she described apprehension during her most recent medical visit because her doctor had retired.

> I'm a diabetic, and I got the diabetes when I was pregnant so I've had it for over 25 years. Previously my doctor was [states doctor's name]; she was my doctor for twenty-four years but she recently retired so I have a new doctor who my last visit was with which was different because I didn't know her. So I wasn't interactive as I was with the doctor that I'd seen forever but turned out that she understood I have a good grasp on my disease and medication. So when I explained to her what I did and what changes I made she was okay with it and she didn't say that I had to change it to whatever she wanted. My new doctor respected that I knew

how to manage my disease. I thought, “She’s going to be okay” (Pueblo female patient, 9/17/18).

In this case, the patient perceived trust on the part of her provider that she knew how to manage her own disease. For the patient, this helped to alleviate her apprehension and to create a positive image of a new relationship.

Interestingly, one Pueblo provider noted that distrust of the healthcare system is connected to historical legacies. For example, a Pueblo participant stated, “A lot of them [providers] don’t know our history [Pueblo history] and how things have changed. They just tell us, ‘don’t do this, don’t do that.’ They don’t realize it’s their government that changed our lives” (Pueblo provider, 9/13/18).

Medical Treatment Decision-Making

Another factor that influences trust is the dynamic among patients, their family members, and providers; in medical care, patients and/or family members are expected to make decisions regarding medical treatments or end of life matters. Several patients shared their stories having to make these decisions; they illustrate how vital clear provider communication and compassion are while making medical decisions. A 50 year-old Pueblo woman described the experience she and her family had when their mother was ill. Her mother was brought to the emergency room because she did not feel well, and seven days later she passed away. The daughter described this time as terrifying because she witnessed her mother’s condition deteriorate quickly, and she had the responsibility of deciding her mother’s treatment and care. Being responsible for her mother’s life was “the hardest thing I ever had to do,” particularly when one of the

doctors insisted on a medical procedure, and the daughter was uncertain how this would help her mother. She recalled feeling frustrated, confused, and scared. She said:

> So they started telling me, pushing—"We can do dialysis, we can do this to get her back." And I'm like, "She's not breathing." I was really thinking that it could happen [help her] until the respiratory therapist came, and I asked him if she even initiated any of her breathe, and he said no. So I said, "Well there's my answer, I can't keep her like that." Before this I was confused by what the doctor was telling me, like giving me hope… (Pueblo patient, 9/10/18).

Other patient participants also discussed the dilemma of making decisions about medical procedures, and the importance of providers giving clear communication, but most importantly, being in agreement with the other members of their provider team rather than providing what patients might perceive as mixed messages. Uncertainty or different messages relayed by different providers created doubt and distrust and exacerbated an already tense time for patients.

Overall, Pueblo patients considered their medical interaction as positive or negative depending on the feelings and action dynamic—their own feelings and the provider's actions. Patient sensitivities played a critical role in their resulting actions, such as seeking alternative healthcare if they perceived a negative interaction with their provider. Not all encounters were considered problematic or triggered difficult feelings on the part of the patient participants. Take for example the 30 year-old Pueblo man who needed a medical exam to participate in a substance abuse treatment program. Prior to

this medical encounter, he has few experiences of seeking health care, and those were often negative. He described expecting to encounter unfriendly staff, having a long wait time, and being judged for his health issue. However, he was pleasantly surprised: "It was okay. It was not what I expected. I expected a long wait but wait time didn't seem long at all. It was reasonable. Care was excellent—nurses, everybody was nice and helpful" (Pueblo male patient, 10/9/18). Based on past experiences seeking health care, he expected the same type of encounter but, not having to wait long and being treated kindly by staff he described his most recent medical encounter as a positive experience. Likewise, an 80 year-old Pueblo woman described several medical encounters, and she chose to elaborate on the time when she was "very sick" and she attributed her recovery to having good medical care and being treated well. She said,

> I got really ill, very ill. I was scared. I was told I needed to have a colonoscopy done. I didn't know what that was. I had a good lady doctor. I could understand her real good, she took good care of me (Pueblo female patient, 9/10/18).

The Centrality of Knowledge: Provider Responses

Consistently in the interviews, providers described how their professional knowledge had/was/could adapt(ed) to delivering health care in a manner that is respectful of Native cultures. Providers explained how the knowledge and experience they gained delivering health care to Native people has evolved into perceptions of what a provider should know in treating Native patients, specifically lessons learned (e.g. being familiar with cultures living in the service area; knowing about cultural special

needs such as how death is handled; developing personal connections; using Pueblo language/s or translators); and exercising actions in delivering culturally-respectful care (e.g. using open-ended questions; not extracting information about Pueblo traditions). Providers were also aware that healthcare systems needed to take actions to be more responsive to AI/AN patients, including provider awareness of patient storytelling and eliciting responses through encouraging the story and the different cultural contexts that shape how AI/AN people might view illness. Providers generally acknowledged that being familiar with cultures and living in the area was helpful in developing positive relations with patients. One physician explained:

> Seeing health issues in the context of someone's life and someone's life includes their culture, it's easier to do when someone is from your culture. But when they're (provider) from a different culture, it's important to pay a little bit of extra attention to what you're saying, answer questions and also understand there is an inherent trust issues with Western medicine and Native patients (Provider, 9//17/18).

At the same time, providers conveyed "frustrations" associated with providing health care to Native patients. For instance, a provider described identifying who is Native as being a challenge. This provider's experience was that unless asked, patients did not willingly share being Native. Other interpretations that reflected some provider frustrations were "patients not disclosing what's happening with self, or patient having a negative perception of self because of health condition." Some providers associated these situations to patients being previously disrespected, being guarded and protective. Most

providers acknowledged the importance of trust but recognized that it "takes time to work through to gain someone's trust and pay attention to what you are saying and answering questions." A story shared by a Pueblo provider illustrated this sentiment:

> It's hard because we as Natives are often scared to ask questions about a medical condition they may have, and sometimes it's embarrassing because we think that it doesn't happen to everybody. But one thing I do make sure as a provider, is the patient has an understanding of the medical condition….pay attention to patient instead of just using the keyboard, talking to the computer, versus talking and touching the patient. I needed to make sure the patient felt safe and could trust me (Pueblo provider, 9//13/18).

Encounters described in this study are the "critical incidents" described by either the patient or provider. Patients selected a particular experience that stood out for them as either a negative or positive experience. Overall, the stories shared by both patients and providers provided insight to how they perceive their place in healthcare, their roles and responsibility. Key findings included, (a) Pueblo patients noting that labeling and negative stereotypes continued to persist with some the Pueblo patients. (b) Pueblo patients feel apprehension when it comes to seeking medical care due to concerns they will judged as being negligent of their health. Or, those managing their health responsibility may not be recognized for their good effort. (c) For both providers and patients, culture in healthcare is important. Patients understand that healthcare—being healthy, will contribute to the maintenance of the culture. For the providers, gaining the

trust of patients is important therefore, being patient and a good listener contributes to the maintenance of culture. (d) Clear communication and being compassionate are key to the patient feeling confident about making medical decisions. Patients pointed out that when providers display uncertainty or have different messages, making important medical decisions is difficult more so in the cases when a family member's life is at stake. (e) Providers acknowledge their professional knowledge will/had evolved into perceptions of what they should know when providing health services for Pueblo patients. They see the benefit of health systems taking action to be more responsive to the needs of the diverse populations.

Encounters consisted of medical appointments, hospitalization, medical home visits, or emergency room visits. Whatever the encounter, the situation affected actions, feelings and interpretations of both providers and patients. Including encounters was necessary to distinguish the unique circumstances that described patient-provider communications for this study. What takes place during a medical appointment is vastly different from what takes place in the emergency room, hence perceptions will differ.

Discussion

A primary goal of this study was to gain perspectives from Pueblo patients and their interaction experience with medical providers in the context of obtaining healthcare. The study found interpersonal trust as most significant in the interactions between Pueblo patients and health care providers. Consistent with literature describing trust as integral in patient-provider relations, this finding suggests that without trust patients will approach interactions and communications cautiously. Therefore, the provider has the task of

establishing trust. Patients in this study identified conditions of trust to be not being stereotyped or labeled; being culturally sensitive, which I suggested is recognizing the importance of Pueblo values, beliefs and practices in their lives; and being treated in a kind and caring manner.

Results suggested that experiences in seeking or delivering health care defined how interactions would play out for patients. Some Pueblo patients noted they entered into the medical encounter with certain expectations and depending on the interactions from the beginning of the encounter, such as the receptionist greeting to the actual exam, lasting impressions are made that may be a factor in the person continuing their medical care. For instance, the young man who mentioned he expected a long wait to be seen by the doctor was ultimately pleased that he did not have to wait long, and he was 'satisfied' with the interactions with the nurses and doctors who were "nice."

Interpretations of these findings suggest that current conditions of communication between health care providers and Pueblo patients result from sociocultural mismatches between patients and providers, including providers' lack of knowledge regarding the patients' health beliefs and life experiences, and providers' unintentional and intentional processes of racism (Saha, Arbelaez, & Cooper, 2003). Some Native patients have taken responsibility for their health but still do not expect to be recognized or credited for "knowing my body and being responsible for my health." For instance, one Pueblo woman shared the story of her reluctance to meet her new provider. Her previous provider was with her for 25 plus years. She did not trust the new provider would acknowledge she had a "good grasp of her disease management." She noted that most

providers did not expect that Native patients could manage their diabetes, "in their eyes we (Native people) are irresponsible and don't want to change." She was surprised the new doctor listened to her describe how she managed her diabetes. She felt "good" when the doctor said, "sounds like you have your diabetes under control, keep it up."

Most Pueblo patients indicated they wanted to know about their health conditions; they expected the providers to be "honest" and at the same time to respect the patient enough to allow patients to communicate in ways they felt comfortable. The ideal situation would be an atmosphere that enables and does not obstruct the patient's telling of his/her own illness or wellness story. This eliminates the need for complete mastery of every groups' health beliefs and other concerns because the patient in the ideal scenario is encouraged to communicate how little or how much culture has to do with a particular clinical encounter (Kalbfleisch, 2009).

After investigating existing gaps in communication, particularly how uncomfortable patients were in sharing sensitive matters, I noted the following general observations: First, Pueblo participants feared seeing the doctor due in part to their perceived neglect of their own personal health care, or expecting to be stereotyped or judged, or encountering negative attitudes from medical staff.

Second, Pueblo peoples' distrust of the healthcare system is often related misunderstandings related to previous negative medical encounters, or individuals concerned about being stereotyped. One individual suggested that misunderstandings or negative encounters are based on what the health providers are not aware of, she stated, "A lot of them [providers] don't know our history [Pueblo history] and how things have

changed. They just tell us, ‘don’t do this, don’t do that.’ They don’t realize it’s their government that changed our lives.”

Third, Pueblo patients often viewed the importance of their illness differently than medical providers. Some of providers acknowledged that storytelling a culturally appropriate information gathering method for learning more about the patient therefore they able to provide the best medical treatment for the patient. One provider noted that he encourages his patients to tell their stories using words like, “tell me more,” which helps patients to build confidence and trust.

Fourth, positive outcomes for Pueblo patient health are contingent on communication that allows the patient to be engaged while the provider takes the time to get to know the patient. Individuals coming together in medical dialogue bring with them individual personalities, social attitudes and values, race, ethnicity, gender, sexual orientation, age, education, and physical and mental health (Saha, Arbelaez, & Cooper, 2003).

The challenge in transferring the practice of medicine to more effectively meet the needs of ethnically diverse patients will include the generation of racial and ethnic-neutral social norms regarding patient expectations and judgments of physician conduct, as well as the establishment of medical practice norms that value communications skills, interpersonal sensitivity and cultural competence (Ulrey & Amason, 2001, p. 461).

Despite efforts to address racial and ethnic differences to improve access to health care, individuals continue to report barriers to care revolving around issues of trust, respect, and discrimination. Kalbfleisch (2009) argued that “trust is important in

communication between providers and patients… the distrust by Native Americans contributes to the difficulty of developing information" (p. 160) as well as is a barrier to seeking health care. That said, the most prevalent condition that determines a positive interactions or negative interactions outlined in this study is the presence or absence of trust. Responses from both Pueblo patients and healthcare providers noted that trust is central to effective patient-provider relations, which determines the degree of success in the health care process. Patients described situations where trust played a vital role in how and what they communicated with a health care provider. If trust was established, communication was open, and the patient was comfortable in revealing medical concerns to the provider. On the other hand, providers noted that having trust with the patients enabled them to determine the best treatments for the medical conditions. Trust is important for medical knowledge, recommendations, and protocols to be sought, understood, and used by members of Native communities (Simonds et al., 2011; Simonds, Goins, Krantz, & Garroutte, 2013), emphasizing the importance of valuing relationships, becoming familiar with community, and respecting cultural beliefs and practices.

Conclusion

Health in Indigenous societies as we understand it today is impacted by settler colonialism which is demonstrated in the discussion of the major challenges for contemporary Indigenous and Pueblo health in the U.S. Relationships and distinctions between individual beliefs and practices as well as community beliefs and practice highlight the diversity with and among Indigenous communities. I suggest that Native

health challenges relate to science and industry with the health industry, federal and state governments' controlling the health narrative through the publication of health reports that are strictly based on Western scientific data and limited information about the people themselves. Additionally, I argue that Native patients today view their well-being based on limited bio-physical assessments to gauge health which contradict their own Indigenous philosophies of health based on values, beliefs and practices. Western scientific definitions on Native American health reinforces the values and beliefs of the larger dominant society while minimizing the importance of Native culture, practices, and beliefs or in some instances, are ignored.

Theoretically, Pueblo philosophies conceptualize "the Pueblo way of life" describing knowledge and practices that sustain Pueblo cultures and contexts. Shifts from Indigenous philosophies of a Pueblo way of life to the more Western focus on human physiology are illustrated in the health research on Native peoples today. As Native peoples' health is of grave concern in health research and practice, work is also being done to incorporate Indigenous knowledge and practices in health interventions, recoveries and revitalizations. Indigenous ways of knowing and doing are applied in methods to address the health issues Pueblo people are dealing with today.

Being a Pueblo researcher, I did not set out define Pueblo culture but to better understand the shift by examining what is distinct and common in patient/provider interactions. My research concentrated on what Pueblo people said was is important for their medical care and if they mentioned culture we did not get into elaborate discussions about what the term culture entailed. When I introduced myself as a Pueblo person, I

sense they "knew" (without saying) I understood what they meant when they used the term "culture." For most of the Pueblo participants "culture" meant being engaged in the ceremonies that take place throughout the year—dancing, singing, running, cooking, cleaning, and all other family and community duties. Knowing that I was Pueblo, some expected that I knew what it meant to be prepared, using phrases such as "you know how hard it is," or, "you what we need to do." With that said, I learned from the Pueblo participant the importance they place on their cultural beliefs and practices and their physical ability was critically important in taking part in the ceremonies. Most of the Pueblo participants acknowledged the importance of participating in the ceremonies and prided themselves on maintaining their culture. Therefore, being in good physical health meant having a trusting relationship with their health provider.

Providers recognized that gaining the trust of the patient would influence the outcomes of the treatment and acknowledged the benefit of knowing why Pueblo people may appeared apprehensive during a medical encounter. Providers, both Pueblo and non-Pueblo agreed that having this awareness would help in the methods they use to deliver health services. Rather than being judged for being a teen mother, the new mother should be embraced by the provider who could guide her tending to her child's medical needs. Pueblo people should not have to worry about being treated differently because of race, like the Pueblo woman who feared having to be seen by a non-Native doctor: "I think dealing with your own race is much easier because they understand the values of what you are and what you believe in…" Most of the health providers understood that trust and culture are crucial aspect of healthcare today and as the health care needs of Pueblo

people expands more effort is needed to incorporate strategies that support diverse cultures. One Pueblo health provider eloquently stated this sentiment with the following: “It’s just a fact that it (culture) goes hand in hand with our well-being and health. Both seek the same goal, making everybody health and well” (Pueblo health provider, 9/13/18).

A crucial aspect of this study is the application of the knowledge gained from the research to a policy with recommendations that engages the Pueblo patient and the healthcare provider in a meaningful exchange with each controlling medical treatment and strategies for their health care. The health policy chapter includes policy recommendations for provider training and education intended to Pueblo people’s access to healthcare and advance quality healthcare for Pueblo patients.

CHAPTER III

HEALTH POLICY: DIVERSITY TRAINING FOR HEALTHCARE PROVIDERS FOCUSED NATIVE AMERICAN POPULATIONS IN NEW MEXICO

Introduction

This chapter is a policy paper that focuses on key issues that emerged from my dissertation research examining the medical provider-patient relationship in one medical institution in the state of New Mexico and focusing specifically on local American Indian patient care. In this chapter, I provide observations as a Pueblo health care specialist and a Native community member, which are parts of my identity that compelled me to explore this topic in the first place. I provide an overview of my dissertation research revealing major findings regarding the roles of trust, communication, and Indigenous culturally-sensitive knowledge in the provider-patient relationship before moving on to outline some recommendations to address problematic gaps in these relationships.

Prior to engaging my dissertation research, based on informal conversations with patients, Pueblo community members, and my own family members, as well as explorations of the research literature, I speculated that the quality of the medical provider-patient relationship and communication affects health. For example, good communication between patients and providers has been demonstrated to lead to good health outcomes for patients (U.S. DHHS, 2015). Communication behaviors found to be positively associated with health outcomes include empathy, reassurance and support, sensitive methods for questioning, positive reinforcement, humor, information sharing, friendliness, courtesy and clarity (Kagawa-Singer & Kassim-Lakha, 2003). This is such

an important issue that the Accreditation Council for Graduate Medical Education identified interpersonal and communications skills as areas medical staff need to demonstrate competency (Committee on Patient and Quality Improvement; Committee on Health Care for Underserved Women, 2014).

Although "good communication" is popularly considered a vital aspect in providing health care today, *effective communication* in health care and specifically with American Indian/Indigenous patients and other minority and immigrant community members has been found to be challenging due to a number of interrelated dynamics, including provider perceptions of patient needs that are limited to professional discipline (Dingley, Daughtery, Derieg, & Persing, 2008). Moreover, providers' education curricula for most health care professions persists in focusing primarily on individual technical skills, paying little attention to communication skills and what it takes to develop these skills for historically marginalized populations (Dingley, Daughtery, Derieg, & Persing, 2008). Communication learning opportunities for non-Indigenous providers, for example, serving Indigenous patients are too often limited, and gaps in care may occur that are the result of miscommunication or the provider dismissing patients' cultural needs in relation to their health care.

This chapter ultimately focuses on the need to examine Native American cultural diversity education in health care for New Mexico. Advancing improvements in the training of medical providers is a complex and political endeavor, so the brief discusses a recommendation for a health institution to agree serve as a pilot to launch the examination. The future goal is to establish a New Mexico Native American medical

training curriculum for medical staff who practice in New Mexico and in areas where large populations of Native Americans reside.

Culturally Responsive Health Care

I begin this section, outlining gaps in care as the result of lack of effective communication and miscommunication that takes into consideration Native cultural factors. In my work in a hospital I have observed how the systems pose difficult challenges for person(s) seeking healthcare. The following vignette is appropriate here to illustrate this:

> *A hospital is located in an area where patient populations are of various racial and ethnic groups, diverse socio-economic and educational backgrounds. The hospital's immediate surrounding communities are situated in urban settings, but the hospital also serves small rural communities where patients need to travel a good distance to be seen. A 65-year-old Native American man arrives by ambulance to the local hospital emergency room, 73 miles from his residence. The son asks permission to ride in the ambulance with his father because dad has needs the assistance with language translation. Furthermore, dad's primary language is his Native heritage language. Ambulance staff deny the son's request, emphasizing policies that only allow the ambulance staff to ride in the ambulance. The Elder man is alone when he arrives at the emergency room (ER). Diagnosing him turns out to be challenging due to the limitations with his speech and language abilities. Doctors determine*

that the Elder had suffered a stroke. While in the ER, the Elder starts to have trouble breathing, so doctors immediately perform an emergency procedure, inserting a tube through his mouth to his lungs to open up the airway (tracheotomy-trach). When the family arrives four hours later, the family is able to explain the Elder's medical history, including the fact that he had suffered two previous strokes that affected his speech and caused a partial paralysis from his waist down. The Elder man's wife and son learn about breathing episode and the emergency procedure that was done to restore the Elder's breathing. They were told the trach was temporary, and it would have to be removed to avoid an infection. Doctors tell the family that the stroke has had serious effect on the father's physical health, and that he faced the possibility of another life-threatening episode. Then the family is asked if "advance directives" were in place for their dad. (An advance directive is a living will that states the wishes of the patient and family when the patient is unable to communicate them to a doctor). Uncertain about what this means, the son asks if the dad is dying, and staff explain that the advance directives inform the staff on action to take in the event dad's heart stops or he stops breathing. Staff need family to decide whether to perform cardiopulmonary resuscitation (CPR). Doctors also explain that removing the tracheotomy tube could lead to his death. Knowing the tube kept dad alive, the wife and son do not want to remove the tube. Later in my

conversations with the family, the son explained that when the medical team asked about removing the tube, they understood it as permitting their father to die. They did not want the tube removed, because they did not want to cause his death. The son explained to me that their Native beliefs mandate that people should not do anything to cause the death of someone, and by them agreeing to remove the trach tube, they would be doing that.

In the beginning, the family visits their father at the hospital regularly. According to the son, each time they visit, a medical staff person would ask if the family if they were ready to remove the tube. Staff then start to notice that the family visits decrease, and soon, no one visits for several days, and then a whole week. Hospital staff perceive this behavior as lack of concern about dad. Doctors want to meet with family to discuss the status of dad's condition and the removal of the trach tube. Staff are unable to contact the family, and as a last resort call on the assistance of the Native American advocate for the hospital. She reaches the family and arranges a meeting. The family picks the day and time for meeting, however, when the time comes, they do not appear. By the time the family does arrive, the attending doctor is not on duty. Finally, a week later a meeting is held. A medical language interpreter was included to translate the information in the family's Native language she participates by phone.

Doctors explain that their father is not getting better, and it is time for the trach tube to be removed, otherwise infection will start. When asked again if the family would agree to have the trach tube removed, they do not agree.

With the family not wanting to remove the trach tube, doctors explain that the dad had to be transferred to a nursing facility where he could be better monitored with the trach tube. Sadly, a few days after being transferred to a nursing facility, he dies. Later, in a follow up conversation with the patient advocate, the son expressed anger and disappointment for the way his family and father were treated by them medical staff. He told the patient advocate his father did not get proper treatment, saying, "Doctors gave up on him the moment he was brought here." He was angry at the doctors and nurses' constant questioning about removing the trach tube, stating—"My mother and I were badgered to agree to take the trach tube out, and the staff did not care even when I explained the reason we could not do that is it was not up to us to decide if he lives or dies, The spirits will decide." The family felt pressured by the hospital staff to do something they did not want to do, so they stayed away from the hospital and did not answer calls from the hospital staff. The son also said his family did not trust white doctors and nurses because "they don't understand our culture." The family also took issue with the language

interpreter, pointing out that she did not relay correct information from the doctor.

This vignette illustrates an important point, which is that a common complaint that Native people have with accessing health care and being treated is the lack of culturally supportive health care approaches, which include practitioner and staff understanding of their cultural contexts, histories, behaviors and circumstances (Garroutte, Kunovich, Jacobsen, & Goldberg, 2004). Research examining barriers to delivery of health care services to diverse populations identified language and cultural differences as the major issue (Toms, Hodge, & Pullen-Smith, 1998; Ha, Anat, & Longnecker, 2010; Institue for Health Care, 2011; Kagawa-Singer & Kassim-Lakha, 2003; Kevanagh K., 1992; Smedley, Stith, & Nelson, 2003). Today, challenges that the health care system faces with delivering health care services to diverse populations are not only focused on language and cultural differences, but also include other key factors related to some Native people's contemporary realities, like rural location, isolation, and poverty, which are interplayed with health disparities and unequal access to health for Indigenous peoples (Marrone, 2007).

A composite of these factors explains the breakdown in family-patient-provider relations and missed opportunities for a better outcome. Problems that surfaced in the vignette, for example, cannot be attributed to the family because they made an initial and ongoing effort to inform providers about their dad's limited speech ability, as well to try to convey that their cultural beliefs conflicted with what the doctors wanted them to do. In this case, providers missed key opportunities for *connection* with the family and at

important times, especially at the start of the relationship. The family ultimately became frustrated and defeated, and they dealt with this by avoiding the medical staff and staying away from the hospital, which meant not visiting their father. When the family tapered off visits to their father, medical staff again missed an opportunity for connection and understanding and instead developed a judgement by assuming the family did not care, so little effort was made to communicate with the family and provide them support during this difficult time.

Research has already demonstrated that health can improve if patients receive care through people they trust, who are respectful, compassionate and show they care (Kevanagh K., 1992; Marrone, 2007; Toms, Hodge, & Pullen-Smith, 1998). Various training and educational strategies have been proposed for the training of health professionals to deliver culturally appropriate care. Like health care becoming more complicated with changes in systems and policies, training in culturally appropriate care today calls for careful examination of understanding and explaining health disparities, understanding the distinct values and belief systems of the diverse groups, and comprehension of cross-cultural communications. Thus, what I am calling for may not be a new proposal in the broader scheme of practitioner-patient relationship-building, but in the case of New Mexico's tribal nations and specifically, Pueblo peoples, I do believe that by looking at communities as distinct, this is an inherently unique proposal towards exploring what those relationships can seek to repair, what they mean to Pueblo people, and how they can be co-constructed in Pueblo homelands.

Research-based Recommendations

My dissertation examined Pueblo patients and health care provider perceptions of the patient-provider interaction and is aimed at helping to prepare medical staff to recognize and act accordingly in acknowledgement of cultural differences when providing health services for the Native people upon whose traditional homelands these hospitals sit. Language and understanding the differences between Pueblo, Navajo, and other tribes were identified as the major areas. Having providers speak the Native language was a "wish" of many participants in my study who articulated sentiments like, "It would be cool to have Native doctors and nurses who spoke the language. Hispanics get to talk in Spanish, how come we can't?" Participants also hoped that providers could learn why Native people are distrustful of Western medicine, stating, "This [understanding] may help them be better at finding *meaningful* treatments."

Medical providers participating in the study also recognized the value in having knowledge of the Native American populations they treat regularly. Therefore, the calls for understanding across patients and provides are shared. One doctor explained that his medical expertise is in gastroenterology, which is not an area many people want to see a physician for, and unfortunately, a leading health condition associated to Native Americans is related to the digestive system. He expressed that if he had a better understanding why patients wait until their condition has advanced, he could seek different strategies that addresses fears and apprehension.

My dissertation research was ultimately aimed at suggesting improvements in health care services—a need confirmed by all study participants who recognized in one

form or another the implications of racial and ethnic diversity in patient care today. Relatedly, I note that cultural competence in medical training is a loose concept in practice, with various interpretations and various tactics for defining competence. I recommend a tightening of this concept, along with critical local participation in defining what competence in the provider-patient relationship looks like according to local terms. I also argue that improvements in our health care system begin with knowing something about the populations the health care system served, as well as knowledge of the communities of the patient populations. However, this information is complex, and Pueblos in particular are cautious regarding what type of information to share with non-Pueblo peoples. These are questions, issues, and conversations that need to be organized within Indigenous communities and in equal collaboration with providers.

Sociocultural mismatches between patients and providers include the lack of knowledge regarding patients' health beliefs and life experiences, and providers' unintentional and intentional acts of racism, classism, homophobia and sexism (Kevanagh K., Kennedy, P. 1992). The 2010 Patient Protection and Affordable Care Act (ACA), is the catalyst that lead to the development of methods for culturally and linguistically appropriate care. Title III of the ACA, *Improving the Quality and Efficiency of Health Care, subtitle F, section 3502,* introduces the patient centered medical home model (PCMH), which is the latest approach of health care delivery where patient treatment is coordinated through their primary care physician (PCP). The intent of PCMH is to ensure the patient receives all the necessary care including medical, behavior and social care when and where they need it, and they can understand (U.S. Congress, 2015).

According to the improved approach, a primary consideration factors or social determinants that affect a person's health and well-being. Social determinants are defined as part of the person's medical treatment. With this approach, medical providers will be expected to have some knowledge of populations, different cultures, philosophical values, practices and traditions, lifestyle and so on, if they do not, it would be their interest to learn. PCMH is the health care delivery model used by health care centers throughout the country as well as healthy systems in New Mexico. Being that health data lists diverse populations have experiencing the greatest health disparities in NM (NM Dept. of Health, 2014), it makes sense to examine the training and education of health care providers.

On the surface, advanced cultural diversity training is recognized as a need for medical staff in New Mexico and other national organizations such as The Office of Minority Health (OMH) created in 1986, which was established to ensure racial and ethnic minority populations' health needs are addressed and that organizations are held accountable for eliminating health disparities. Additionally, national health policies exist to support advanced training in cultural diversity for medical providers. The National Standards for Culturally and Linguistically Appropriate Services (CLAS) developed by the OMH described how medical providers will address minority health care quality and health equity (U.S. DHHS, Office of Minority Health, 2016). The National CLAS standards are the tests required for the accreditation of a health care facility, another opportunity for validating the need to examine medical provider Native American cultural diversity training.

Interestingly, CLAS underscores the importance of culture emphasizing that "culture defines how health care information is received, how rights and protections are exercised, what is considered to be a health problem, how symptoms and concerns about the problem are expressed, who should provide treatment for the problem, and what type of treatment should be given" (HHS, Office of Minority Health, 2016). Opportunities to expand accountability is needed at this juncture—moving superficial policies towards deeper practices and application. As I have discussed elsewhere in this dissertation, medical care relies predominantly on western science and methods, and despite increases in attention towards Indigenous knowledge, incorporating Indigenous healing and treatments are still less likely to be included in medical care in the places like that where my dissertation research was conducted (Sandoval County, New Mexico). So I argue that the best approach in Native American health care at this time is to ensure that medical providers are first knowledgeable about Native American populations and respect cultural diversity, which require local tribal agency and oversight in this process. However, this is a difficult process, especially as the responsibility to oversee takes time, energy, and expertise; so the question then becomes how appropriate knowledge transmission to medical providers can be institutionalized within health care systems that serve Pueblo populations in New Mexico.

Policy Recommendations

Institutionally speaking, Native American cultural diversity training for medical professionals may include a variety of topics, but the most important consideration is aligning the proposed methods with an existing medical training policy. By doing so, new

strategies are supported with sanctioned standards. Examining cultural training on these levels is vital for understanding the concepts of cultural sensitivity and identifying information that to prepare medical providers and staff to work with diverse Native populations and cultures. The results of this would be two-fold: information gathered could be applied as a baseline for Native cultural training, and Native people will explain why health is important describing a concept that may be slightly different from the general notion of Native culture in health.

For medical training, the CLAS is the existing policy that defines the nationally approved standards for cultural competency in medical treatment, and health care providers must adhere to. CLAS standards describe evidence-based methods for use in the patient centered medical home model. The medical home model has five primary functions: comprehensive care; patient centered care; coordinated care; accessible care; and, quality and safety. Multidisciplinary teams made up of physicians, nurse practitioners, physician assistants, nurses, pharmacists, nutritionists, social workers, educators, and care coordinators facilitate care that extends beyond medical care. For example, besides health, other matters such as housing, behavior or mental, employment and so on, are things that also need to be addressed.

Team members are taught the importance of creating positive relationships between the patient and the health team. Positive relationships establish trust between patient and providers creating opportunities for providers to better understand the patient's needs as well as develop respect for diverse culture, values, and preferences. Patient care coordination is expected to reach outside the health care systems into places

where the patient lives, works and plays such as tribal communities. Understanding the policy and identify the areas that address cultural competency and diversity are tools can be used to leverage the need for a training program that includes topics that can expand the awareness of diverse groups health needs and, it is the mechanism to maintain accountability.

At the state level, there are policies that address health care provider training. Like the national policy, the state policies can be reviewed for implementation methods and evaluation, training content, and lists of medical teaching institutions that include Native American cultural education as topic all students must take. In 2007, New Mexico legislature created a task force to develop cultural competence education requirements for health training programs for medical providers in NM[5]. This effort intended to address the issue of diverse populations accessing health care with the focus on health care providers to expand their knowledge specifically of Native populations in New Mexico. The plan was to create curriculum standards for medical education programs at New Mexico's two four-year post-secondary academic institutions. Unfortunately, the project was not completed and the academic institutions continue to waver on developing meaningful Native American cultural diversity training.

At the local level, the examination would focus on matters relevant to the Native American populations in New Mexico—what is important for a medical provider to know about Native patients. Information from tribal communities will guide the development of a teaching tool. The University of New Mexico School of Medicine has not adopted a

[5] New Mexico Senate Bill 600 2007.

formal Native American cultural diversity education program in any of the medical program curriculums. However, programs like the UNM hospital pediatrics program on their own adopted a mandatory four and half hour training program for all staff working in the pediatrics department. The training titled, "Cultural Humility: A Best Practice for Serving American Indians in New Mexico" was developed by a former Pueblo tribal leader who works at the UNM Health Sciences, Center for Native American Health, Institute for Indigenous Knowledge and Development (IIKD).[6] The training described is a highly interactive, multi-method orientation to the needs, cultural and social interactions of Native people residing in Albuquerque and the tribal communities in NM in general. Topics covered in the training include:

- New Mexico Native American demographics
- Historical events associated with federal policies to described influences on the lives of American Indians in NM
- Social determinants of health, healing, and well-being;
- Protocols when visiting tribal lands;
- Discussion of cultural humility versus cultural competence;
- Exploration of the unconscious biases that exist in relation to perceptions about Native Americans;

[6] UNM HSC Center for Native American Health, 2015

- Examples of historical traumas that continue to influence American Indian health and well-being.

Staff at the UNM Center for Native Americans approached the UNM Medical School and the Diversity, Equity and Inclusion program to adopt the training as part of the medical education curricula as well as competency training for the staff. However, to date as I submit this dissertation, both programs have not agreed to this.

Clearly, there is a need to revisit materials, resources, and connections that bring together constituents who have been working on culturally-relevant sharing opportunities and curriculum and/or program development. Drawing from my dissertation, I would recommend that we not only reassess the work that has been done and explore why it has not been adopted or institutionalized in ways envisioned by Pueblo people, community members, and practitioners, but also consider some of the gaps in the patient-provider relationship that have emerged from my study. Underlying all of this work is the need for communities to also do the work within of exploring their own definitions of well-being and to raise awareness regarding how we have all been conditions to conceptualize health according to non-Indigenous standards. Our own self-development in this regard is the critical step.

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