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Walking in beauty: Responsive and responsible health and healing among  
Virginia American Indian people

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy at Virginia Commonwealth University.

by

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## Dedication

This dissertation is dedicated to the participants who generously opened their hearts and homes to me. Your stories were my fire during long, dark nights.

This dissertation is also dedicated to Archer Kenneth Custalow, a storyteller extraordinaire. Your love for life and storytelling was contagious; your spirit lives on in the stories you told. Mr. Ken, you walked a beautiful road.



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## Abstract

### WALKING IN BEAUTY: RESPONSIVE AND RESPONSIBLE HEALTH AND HEALING AMONG VIRGINIA AMERICAN INDIAN PEOPLE

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2017

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Little is systematically known about the collective health and well-being of Virginia American Indian people. When compared to the total U.S. population, American Indian and Alaska Native (AI/AN) peoples nationwide disproportionately experience health inequities across several Western informed health indicators including diabetes, cardiovascular disease, cancer, influenza, intentional and unintentional injuries, and mental and emotional illnesses. Given the widespread health inequities experienced by AI/AN peoples nationwide, it is reasonable to suspect that Virginia American Indian people may similarly experience health inequities, although with a collective health profile unique to their communities. A rurally located, reservation-based, non-federally funded health clinic in Virginia that serves the basic medical needs of American Indian

people was the context for this study. This study sought to explore the meaning of health and healing among Virginia American Indian people in the context of a reservation-based, non-federally funded health clinic. Using an emergent approach to qualitative research grounded in a constructivist inquiry paradigm and guided by Indigenous research principles, a total of 24 in-depth, semi-structured interviews were conducted with 17 American Indian service-users of the Clinic. Through an inductive thematic analysis of participant stories, a framework for understanding responsive and responsible health and healing was derived. The framework includes seven dimensions: spirituality, physical processes, mental and emotional processes, social relationships, access to resources, contextual factors, and the interconnection among the dimensions. Personal and collective identity was a significant element woven through the dimensions. From the stories told by participants, health seems to be a continuum and healing seems to be a cycle. With constant motion in each of the dimensions, health has to do with sustained engagement in healing processes that continually seek to bring about functional balance in one's whole health system. Ill health has to do with when a change in any one of the dimensions overtakes one's ability to bring about a functional balance in the whole health system. The framework is context-dependent, true for the people who participated in the study at the time of the study.

## Prologue

“Our own relationships with our environment, families, ancestors, ideas, and the cosmos around us shape who we are and how we will conduct our research. Good Indigenist research begins by describing and building on these relationships” (Wilson, 2008, p. 194).

*Relationality is the foundational belief that sits at the heart of an Indigenous paradigm (Wilson, 2008). Knowledge, therefore, is relational. This relationality transcends interpersonal relationships, and extends to include relationship with all of creation – with the cosmos, the animals, the plants, and the earth (p. 74). This dissertation seeks to tell the story of a group of people’s relationship to specific knowledges, namely health and healing. First, however, in the spirit of relationality, it is important for you to know a little about me so that you can better understand the work presented in this dissertation. My door is open. I invite you to come in, pull up a cozy chair, and enjoy a warm cup of tea.*

*My name is Amy Jule Prorock-Ernest. I am the biological daughter of Kathleen (Kathy) Siniawa and Gerald (Jepper) Prorock, and the adopted daughter of John Troiani. I am the mother of a beautiful son, a wife, a daughter, a sister, a granddaughter, a niece, a cousin, an aunt, a friend, a follower of the Good News, a lover of the wilderness, a dancer at heart, a first generation college student, a thinker, a life-long learner, an emerging researcher, and, at this point in my life, a doctoral candidate.*

*I was born and raised in Northeastern Pennsylvania (NEPA), particularly Lackawanna County, specifically the boroughs of Dickson City, Olyphant, and Throop. This region was my home for the first consecutive 18 years of my life, and inconsecutively for months at a time for an additional five years. NEPA lies at the northern edge of the Coal Region, with its roots deep in the anthracite coal mining industry and, consequently, coal mining culture. While coal mining is no longer an active industry in the region today, its influence is still present, evidenced in the popularity of the coal mine tour attraction, which every public school student in the region has visited at least once, and the popular hang-out spot for adolescents affectionately called “The Dump,” previously mined stacks of coal. As the coal industry faded away manufacturing took its place; however, with the recent economic downturn, many of the manufacturing jobs have dissipated, leaving in its place a high unemployment rate. Representative of the working class spirit, however, there is a strong will to work, but limited opportunities for employment, particularly employment paying a livable wage. Trade work (e.g. plumbing, carpentry, electrical, etc.) is also woven tightly into the labor/cultural landscape of my hometown. I come from a family that is well represented in the trades and construction.*

*My father is a licensed master plumber. He is proud of his knowledge and skills. I used to be embarrassed by his rough hands, but, now, I, too, am proud of his in-depth knowledge of plumbing and heating systems, his ability to fix almost anything, and the high quality standard he applies to all his work. My mom worked hard in the familial sphere, exclusively taking care of our family until my brother and I were in middle school when she went to work in a factory, eventually, ending up doing event planning for a local family-owned banquet hall. I will always admire my mom’s unwavering dedication to her family. Growing up, trade-based knowledge and skills were the standard by which I judged all other knowledge systems. However, what was once*

*a standard for me became an embarrassment as I recognized that I was different from many of my college friends whose parents were “working class professionals.” I’ve come around though, learning to respect, and be proud of, my working class roots, and the knowledge and technical systems that underpin the work.*

*I grew up in a place where neighborhoods were largely defined by ethnicity, communities of first, second, third, fourth, and fifth generation immigrants primarily from various Central and Eastern European countries, with the exception of a vibrant Italian and Irish community. Knowing one’s ethnicity was important, it defined you as a person, as a family – which foods you ate, which ethnic/cultural events you attended, which church you attended, and even sometimes who you married. I can hear my Italian Noni (grandma) saying, “Do you know she’s running around with that Polish boy?” I am a third and fourth generation settler from Eastern and Central Europe (mostly). I am Lithuanian, Russian, Polish, Slovakian, and English (although there is little connection with our English heritage). And, while not Italian by bloodline, I was raised in an Italian family from a young age when my biological father passed away and my mother remarried into an Italian family. I grew up knowing that culture mattered. Holidays were always a feast and included homemade ethnic foods such as pierogi, kielbasi, kolachi, halushki, chrusciki, ravioli, polenta, risotto, and Italian wine. I also grew up in a place where hunting and fishing seasons have almost as much meaning as traditional Holidays. In fact, public schools were closed on the first day of the deer-hunting season, an occurrence I never would have thought was anything unique until I moved away from the area at age 18!*

*I am a part of a relatively large family. My mom is one of six siblings, my biological father was one of three, and my step-father is one of eight siblings. Growing up I learned the importance of family. It was a rarity to go a day without seeing someone from my extended*

*family. Christmas day was a bustle of activity with four different family events spread throughout the day. As a family we celebrate together; as a family we mourn together; as a family we support each other; as a family we fight with one other; and as a family we fight for one another. Collectively, my family identifies with Christian traditions and values. Individually, some members identify by culture and some by practice and belief.*

*I was born, raised, and educated in a worldview informed by European/Western philosophy, values, and customs. I was educated in the public school system, and while I performed well overall in school, I struggled in certain subjects such as math that worked from rote memorization rather than understanding. For example, I couldn't grasp the concept of geometry by memorization of postulates and theorems, I needed to understand how they worked. Apparently my need for understanding was not appreciated by my teacher who advised my parents to encourage me to "just trust" what he was teaching, rather than challenge it. While I was an inquisitive youth, I continually received feedback from various environments in which I was situated to just fall in line. In retrospect, I longed to think critically about the world around me, yet I lacked the mentorship to teach me how to do it.*

*Fortunately, from a young age I started dancing – ballet, tap, and jazz. Faithfully, I cried every class during my first year of dance instruction. My mom, however, determined to make me stick it out for the year, encouraged me to stay in class until the end when we would dance to the Ghostbusters song. I loved to move my body to that song. "Who ya gonna call? Ghostbusters!" It was just the right amount of motivation. The joke in my family became that my mom should have let me quit dance that first year because what did not begin as love at first sight, turned into an all-consuming passion. By high school, I was dancing with a pre-professional ballet company. I had dreams of dancing professionally in Europe, a lofty dream for a girl with working class*

*roots. In the summers I attended intensive ballet training programs away from home, and during the school year, training, rehearsals, and performances consumed every moment that I was not in school or sleeping. Movement provided a way for me to learn about myself and explore the world around me, as well as a way in which to express myself and to engage with people, ideas, emotions, and elements of an emerging spirituality. Movement provided an avenue for me to be and be in relationship, on multiple levels.*

*While ballet and I eventually suffered quite a terrible breakup in college, which totally rocked my world, the relationship afforded me opportunities that would not have otherwise been available to me. While scholarships and work-study opportunities helped make my engagement in ballet financially more affordable for my family, most of the people with whom I danced were from more affluent families. Being in relationship with people from a much different social class opened my eyes to a world much larger than reflected to me by my working class exposure. Further, most of the summer intensive dance programs in which I participated during grade school were held on college campuses. Being on college campuses during the summer, although not for formal collegial activities, normalized the college experience for my family and me. These opportunities were invaluable to me (and arguably my family) in making the transition between a working class world and the world of academia.*

*My parents, although not college-educated (actually, my dad went to a two-year technical school), were adamant about my brother and me going to college. I can't say they were exactly excited that my first declared college major was ballet, but it was at least a foot in the door to college. Five colleges/universities later, I found my academic home at Prescott College in sunny Prescott, Arizona. As I mentioned earlier, I love learning, so I enjoyed being in a college environment, but Prescott College was the first formal learning space where I thrived,*



*where I could breathe. Prescott College is a small, private liberal arts college whose motto is, “For the Liberal Arts, the Environment, and Social Justice.” Prescott College has a unique approach to education that is largely experiential. Classes were limited to fourteen students, a limit enforced so all students could fit into a van to partake in regularly scheduled field trips. This environment was favorable for building relationships with students and professors. The educational philosophy of Prescott College strongly encourages self-direction within a protected environment. For the first time, I was able to ask the question “Why?” In fact, I was encouraged to ask “Why?” Prescott College offered a supportive learning environment for me to explore my world experientially, through dialogue, through instruction, and through personal reflection. I was given permission to, and even encouraged, to connect a cerebral learning experience to my heart and spirit. I was taught to take ownership of my learning. Learning became alive, fully integrated – mind, body, soul, and spirit.*

*It’s important to also note that during my breakup with ballet, I turned to nature for healing. While I loved being outside as a kid, I had never really taken the time to listen to nature. During my breakup, I would find quiet places to sit under a tree, on a rock, in a field of tall grass, or near a river. I would sit in stillness, and listen. I felt most accepted in nature, nature accepted me for who I was (whoever I was), not who someone else wanted me to be. While living in Prescott, Arizona, I encountered my first wilderness experiences, true wilderness. I was in love – the solitude, the peacefulness, yet, at the same time, the liveliness of nature. Formal coursework through Prescott College introduced me to the wilderness, and continued experiences by myself and in the company of friends deepened my relationship with nature. I learned that nature is alive, and that relationships with its members (rocks, water, rich soil) can be rich, fulfilling, healing, and long lasting.*

*The experiences I have shared thus far, however seemingly unrelated to the research presented in this dissertation, have been instrumental in shaping the ways in which I understand and engage with the world, and shed light on the person I bring to this study. You may be wondering what led me to my interest in, and work with, Indigenous peoples, particularly Virginia American Indian peoples. Let me explain.*

*Since childhood I have had an interest in the tradition and culture of Indigenous peoples. Initially, my knowledge and understanding of Indigenous peoples was founded on a romanticized ideal of “Indian” fabricated and promoted by our mainstream culture. It wasn’t until college that education began to expose the grave injustices and deep deception lurking behind the clichéd images of feathers, tepees, drums, and Native American spirituality. Formal and informal education opened my eyes (and pulled at my heart) to a history plagued by sustained acts of violence systematically waged against Indigenous peoples. Particularly relevant to my journey as an emerging scholar/researcher, I learned about the devastating role a European/Western research agenda has played in initiating and perpetuating injustices against Indigenous peoples.*

*As a settler, I have come to acknowledge the role my European ancestors played in systematically initiating and perpetuating a system of injustices waged against Indigenous peoples who, prior to colonization, dwelled richly and successfully on Turtle Island. I want to stand on a different side of history from my ancestors: I want to stand in solidarity with Indigenous peoples as they work to heal their communities and reclaim their place on the world stage. Despite centuries of adversity as a result of colonization, I have come to know a resilient people who have stood strong, and continue to stand strong, collecting strength to (re)claim what has been taken, (re)build what has been broken, and (re)value what has been preserved.*

*In 2004 I graduated from Prescott College where I received a bachelor's degree in Cultural Studies. In 2009, I graduated from Virginia Commonwealth University (VCU) with a dual masters degree in Social Work and Public Health. In 2011, I entered the doctoral program in the School of Social Work at VCU. At each academic phase, I focused my assignments on learning about the worldviews, traditions, customs, beliefs, and practices of Indigenous peoples; the history of various Indigenous groups of people (nationally and internationally); how policies and legislation influenced, and continue to influence, the lives of Indigenous peoples; and "culturally relevant" ways in which to engage with Indigenous peoples. Whenever possible, I refer to resources created by Indigenous people, as well as learn through personal relationships. By no means am I suggesting that I am an expert in Indigenous studies/peoples, nor is this something I aim to become; I only share this to show that I have done my best to prepare myself to engage intelligently, respectfully, and creatively with Indigenous peoples in general, and Virginia American Indian people specifically, and to limit to the greatest extent possible repeating abuses of past researchers/practitioners. It is this knowledge and these experiences I bring with me to my relationship with Virginia American Indian people.*

*I hope this narrative provides a window for you, the reader, to gain insight into who I am as a person, and the knowledges, perspectives, and experiences I bring with me to this study as a researcher. Throughout the dissertation, I have incorporated segments of narrative as related to the section at hand. It is my hope that the way in which I have included my voice and experiences in the co-constructed narrative concerning the meaning of health and healing among a group of Virginia American Indian people is done in a way that is respectful of the multiple relations that have been established along the way.*

## Chapter One: Overview

Little is known about the collective health and well-being of Virginia American Indian people. When compared to the total U.S. population, American Indian and Alaska Native (AI/AN) peoples nationwide disproportionately experience health inequities across several Western informed health indicators including diabetes, cardiovascular disease, cancer, influenza, intentional and unintentional injuries, and mental and emotional illnesses (IHS, 2016a; IHS, 2014b; Jones, 2006; U.S. Commission on Civil Rights, 2004). A steadily growing body of health-related research regarding Indigenous populations suggests that persistent health inequities present in Indigenous communities are largely attributable to a complex matrix of various factors including socioeconomic, political, historical, cultural, and environmental determinants (Brave Heart, 2003; Czyzewski, 2011; Duran & Walter, 2004; Greenwood & de Leeuz, 2012; Hill, 2009; IHS, 2016a; Jones, 2006; King, Smith, & Gracey, 2009; Lowe, 2008; Mawbray, 2007; Reading & Wein, 2009; U.S. Commission on Civil Rights, 2004). Given the wide-spread health inequities experienced by AI/AN peoples nationwide, as well as Indigenous peoples globally, it is reasonable to suspect that Virginia American Indian peoples similarly experience health inequities, although with a collective health profile unique to their communities. Investigating and understanding the multiple dimensions that influence health is paramount to suitably supporting the health of individuals, families, groups, and communities, as this understanding directly impacts how health is defined, measured, treated, experienced,

researched, legislated, and funded. Using an emergent approach to qualitative research grounded in a constructivist inquiry paradigm and guided by Indigenous research principles, this dissertation research explores the multiple meanings of health and healing held among Virginia American Indian people connected to a rurally located, reservation-based, non-federally funded health clinic.

Foundational to both Indigenous and constructivist approaches (which inform the methodology) is the central role of context (Charmaz, 2014; Guba & Lincoln, 1994; Kovach, 2010; Kovach, Carriere, Montgomery, Barrett, and Gilles, 2015; Lincoln & Guba, 2014; Wilson, 2008). In both Indigenous and constructivist approaches, the context in which the phenomenon of interest is situated is critical to the inquiry process, with the context implicitly and explicitly shaping the form, flow, and content of the process. Findings that emerge from the inquiry process are held as tentative and representative only of the people involved in the inquiry process, at the time of the inquiry engagement, in the place and space of engagement. While a more in-depth discussion concerning the methodology will be discussed in Chapter 3, for now, it is important to acknowledge the central role that context plays in this study in order to justify the form and flow of the remainder of Chapter 1.

To situate the study in context, it is important to provide you, the reader, with the context that frames and informs the focus of the research, people involved in the study, the methodology, and findings. In the sections that follow, Virginia American Indian people will be introduced in broad sweep strokes, presenting demographics, as well as stories that are particularly relevant to the context of the research question. After unfolding the context as related to the study, the current study will be briefly introduced, followed by a discussion of the significance of the study to both the profession of social work, as well as to the community engaged in the research. Prior

to beginning a conversation about context, it is first important to come to a shared understanding of the way in which certain identifying terms will be used in this dissertation.

### **Description of Terms**

The following are terms used to refer to groups of people in this dissertation: *Indigenous*, *American Indian/Alaska Native*, *Virginia American Indian*, *state-recognition*, and *federal recognition*. Before I identify how the before-mentioned terms are used in this dissertation to refer to groups of people, it is first important to recognize that the naming process of a group of people and the establishment of parameters around who is and who is not included in a specific group shifts and changes in response to the people, organization, and agency doing the naming and/or setting the criteria. Table 1 describes the general ways in which I use the terms *Indigenous*, *American Indian/Alaska Native*, *Virginia American Indian*, *state-recognition*, and *federal recognition* to refer to groups of people, but I am not ignorant to the fact that there is great variation among and between how the groups to which I refer name and describe themselves.

Table 1

*Description of Identifying Terms*

---

**Indigenous**

The term *Indigenous* is a broad term used to refer to all Original Peoples who identify with the following characteristics as set forth by Battiste & Henderson (2000):

- a) priority of time, with respect to the occupation and use of a specific territory; b) the voluntary perpetuation of cultural distinctiveness, which may include the aspects of language, social organization, religion and spiritual values, modes of production, laws and institutions; c) self-identification, as well as recognition by other groups, or by State authorities, as a distinct collectivity; and d) an experience of subjugation, marginalization, dispossession, exclusion or discrimination, whether or not these conditions persist (p. 64).

**American Indian/Alaska Native (AI/AN)**

Indigenous peoples (inclusive of the characteristics addressed above in the Indigenous description) whose ancestors originally inhabited Turtle Island, the land now known as the United States of America, prior to the legacy of colonization.

**Virginia American Indian**

Indigenous peoples whose ancestors originally inhabited the land now known as the Commonwealth of Virginia prior to the legacy of colonization.

**State-recognized Tribe**

A tribal entity that has been formally recognized by the Commonwealth of Virginia as a tribe who was living on a site in which is now the Commonwealth of Virginia at the time of the arrival of the first European settlers, and whose current members are Indian descendants of those Indigenous tribes with appropriate records and historical documentation. At present time there are 11 state-recognized tribes in Virginia.

**Federally-recognized Tribe**

As per the Bureau of Indian Affairs (2017): “A federally recognized tribe is an American Indian or Alaska Native tribal entity that is recognized as having a government-to-government relationship with the United States, with the responsibilities, powers, limitations, and obligations attached to that designation, and is eligible for funding and services from the Bureau of Indian Affairs. Furthermore, federally recognized tribes are recognized as possessing certain inherent rights of self-government (i.e., tribal sovereignty) and are entitled to receive certain federal benefits, services, and protections because of their special relationship with the United States” (n.p.).

---

Before moving on, I would first like to say a word about why I chose to use the term

Virginia American Indian in lieu of others, as well as a clarification about the parameters around

the term. I chose to use the term Virginia American Indian to refer to the Original Peoples of the land currently known as the Commonwealth of Virginia because it is the term that I most commonly hear participants using to describe themselves and their people; however, the Original Peoples in Virginia refer to themselves in a variety of other ways. For example, Dr. Linwood “Little Bear” Custalow, late historian of the Mattaponi Indian Tribe, advocated the use of *First Americans* (Daniel, 2003, p. 1). It’s important to note that the use of the term Virginia American Indian does not include Indigenous Peoples who reside in Virginia but whose ancestors inhabit(ed) lands outside of the territories now known as the Commonwealth of Virginia.

### **Situating the Study in Context**

#### **Virginia American Indians: We Are Still Here**

When asked about my area of research by Virginians, as well as non-Virginians, the most common response I receive is, “There are Indians in Virginia?” This question is accompanied by a look of disbelief or surprise. The allure and legacy of a cherished Disney princess, Pocahontas, a descendant of the Original Peoples of Virginia, overshadows the contemporary lives of the descendants of her ancestors. This section introduces Virginia American Indian people in broad sweep strokes, addressing demographics and stories that are particularly relevant to the context of the research question.

According to the 2010 U.S. Census, approximately 29,000 (0.37%) people living in the Commonwealth of Virginia identify as American Indian/Alaska Native. The number of American Indian and Alaska Native people in Virginia is higher when accounting for people who identify as American Indian and Alaska Native in combination with one or more races. The majority of American Indian and Alaska Native people living in the Commonwealth of Virginia, however, are not indigenous, or native, to the lands of Virginia, but rather they are the



descendants of ancestors who originated from land outside of what is today known as the Commonwealth of Virginia.

Today, there are approximately 6,000 members on the tribal registries of state-recognized tribes in the Commonwealth of Virginia (Stebbins, 2012). This number is likely higher when accounting for Virginia Indian people associated with one or more of the 11 state-recognized tribes who, for various reasons, are not enrolled members of the tribe from which their ancestors originated. The Commonwealth formally recognizes 11 tribes (Stebbins, 2012) whose ancestors and cultural connections can be traced directly to groups documented to have been living on the lands currently known as Virginia in 1607 at the time of initial English colonization (Virginia Indian Tribal Alliance for Life [VITAL], 2014). Additional groups such as the Wolf Creek Cherokee who assert their ancestry dates back to Virginia during the time of English colonization continue to petition the Commonwealth for state recognition (Daniel, 2007; Giddens, 2015). Two of the 11 state-recognized tribes, the Mattaponi and Pamunkey, remain in possession of reservation land that was issued to the tribes through treaties with England in the late 17<sup>th</sup> century (Stebbins, 2012; Wood, 2007). Several tribes have purchased, or were given, land in areas closely associated with their ancestors, mostly rural, on which tribal centers have been constructed and serve as gathering places for community meetings and events, as well as educational outposts for tribal members and the public (Stebbins, 2012; Waugman & Moretti-Langholtz, 2006). Refer to Table 2 for a list of state-recognized tribes in Virginia.

Table 2

*Virginia State Recognized Tribes, Location, Land Acreage and Estimated Enrollment*

<b>Virginia State-Recognized Tribes</b>			
<b>Tribe</b>	<b>Location</b>	<b>Land (acres)</b>	<b>Est. Enrollment</b>
Cheroenhaka (Nottoway)	Courtland, South Hampton County	100**	272
Chickahominy Tribe	Charles City County	110**	840
Eastern Chickahominy Tribe	New Kent County	41**	164
Mattaponi Indian Tribe	Mattaponi River, King William County	150*	450
Monacan Indian Nation	Bear Mountain, Amherst County	180**	2,000
Nansmond Tribe	Cities of Suffolk and Chesapeake	73**	200
Nottoway Indian Tribe of VA	Capron, South Hampton County and Surry County	0	120
Pamunkey Tribe	Pamunkey River, King William County	1,200*	200
Patawomeck	Stafford County	0	770
Rappahanock Tribe	Indian Neck, King and Queen County	120**	500
Upper Mattaponi Tribe	King William County	32**	575

Note. Information from "Meet the State-Recognized Virginia Indian Tribes," by S. Stebbins, 2012, *National Park Service: Historic Jamestowne*, Retrieved August 25, 2014 from <http://home.nps.gov/jame/historyculture/Virginia-indian-tribes.htm>

\*Reservation land established in 1646 and 1677 via treaties signed with the English.

\*\*Tribally-owned land.

### **Historical Overview of Virginia American Indian People**

The presence of Indigenous peoples on the lands now known as Virginia began prior to 1607 and English colonization, and is still strong today in 2017, contrary to what many accounts may report (Waugaman & Moretti-Langholtz, 2006). According to archeologists, Indigenous peoples have lived in the area now called Virginia for as many as 15,000 years; however, "if you ask Virginia Indians how long our people have been here, they will probably say, 'We have always been here'" (Wood, 2007, p. 8). Initially hunter-gatherers who followed the migratory patterns of large game, the Indigenous peoples in Virginia later settled into specific regions, usually along riverbanks, developing sophisticated agricultural techniques that were practiced for more than 900 years (Wood, 2007). In addition to their distinguished agricultural practices, the Indigenous peoples in Virginia also developed notable *cultural landscapes*, where "hunting and

fishing areas alternated with townships and croplands arranged along the waterways” (Wood, 2007, p. 8). Karenne Wood (Monacan) describes:

Our people developed intimate, balanced relationships with the animals, plants, and geographic locations that characterized our homelands...Virginia was not a wilderness to us; it was a known and loved home place, a managed environment, and we shared our resources with strangers who came among us, as well as among our communities. That is the Native way (2007, p. 8).

Dr. Linwood “Little Bear” Custalow (Mattaponi) asserts that the Original Peoples of the lands now known as Virginia also had a highly organized form of government that was influential in shaping the current governmental structure of the United States (Custalow, 2007).

Post-European contact, Virginia American Indian people share a similar story with American Indian people nationwide, a story of deliberate and systematic attempts by a dominant group of people (predominantly, at first, the colonial powers of Western Europe, followed by the U.S. federal government, as well as state and local governments) to exterminate “uncivilized” groups of people perceived as a threat to “civilized” society (Egloff & Woodward, 2006; VITAL, 2013; Waugman & Moretti-Langholtz, 2006). This was accomplished by means of systematic killing, deliberate introduction of disease (in addition to the proliferation of “naturally” occurring diseases), and inflicted starvation, followed by centuries of oppressive and repressive social and economic policies that have tremendously impacted the ways in which Virginia American Indian communities, families, and persons navigate life. These policies permitted such acts as displacement from sacred land, segregation, forced assimilation, and restricted such rights and fundamental freedoms as the right to an “Indian” identity, the right to an education, the right to marry freely, and the right to observe traditional beliefs and practices (Egloff & Woodward,

2006; VITAL, 2013; Waugman & Moretti-Langholtz, 2006). Although most Virginia Indian people signed and adhered to the Peace Treaty in 1677 with England, and fought in nearly every American war, they, along with Indigenous peoples nationwide, were not granted U.S. citizenship until 1924 (Daniel, 2007; Kimberlin, 2009).

**The eugenics movement and racial integrity laws in Virginia.** At the turn of the 20th century, eugenics was internationally heralded as “the thinking man’s science” (Fisk, 2004b). The term *eugenics* was coined in 1883 by English scientist Francis Galton, a cousin of Charles Darwin, who defined eugenics as the science of “race improvement” (Fisk, 2004b, n.p.). What began as a science focused on promoting selective marriages to eliminate hereditary disorders, became a “science” aimed at perpetuating a superior class (Fisk, 2004; Wolfe, 2015). Fisk (2004b) describes eugenics as “the perfect way to deal with race and the underclass” (n.p). Gregory M. Dorr explains Virginia’s relationships with eugenics, “Virginians thought of themselves as more progressive than their neighbors to the south. There was a feeling that we don’t need to do lynching or the KKK. We’re not savage. We can handle our problems in a rational way” (as cited in Fisk, 2004b). Although 31 states would pass eugenics laws, Fisk (2004b) describes none other being tougher than Virginia’s.

In Virginia, in the same year American Indian and Alaska Native people nationwide were granted citizenship, Virginia Indian people were denied the right to an “Indian” identity. In 1924, Virginia passed a series of racial integrity laws to “protect ‘whiteness’ against what many Virginians perceived to be the negative effects of race-mixing” (Wolfe, 2015, n.p.): *The Racial Integrity Act of 1924* (SB219) and *An ACT to Provide for the Sexual Sterilization of Inmates of State Institutions in Certain Cases* (SB218).

*The Racial Integrity Act of 1924.* Spearheaded by Walter Ashby Plecker, the first Registrar of the Bureau of Vital Statistics in the Commonwealth of Virginia, and a strong proponent of the eugenics movement, the *Racial Integrity Act of 1924* (SB219) was meant to preserve racial integrity by prohibiting racial inter-marriage (Daniel, 2007; Dorr, 2014; Waugman & Moretti-Langholtz, 2006). Effectively, the *Racial Integrity Act of 1924* divided Virginians into two strictly defined racial categories: “white” and “colored.” The legislation mandated that all persons register as “white” or “colored” on all official records including marriage certificate, death certificates, and birth certifications (Waugman & Moretti-Langholtz, 2006; Wolfe, 2015).

Plecker believed there were no longer full-blooded Indians in Virginia. He believed that the tribes had become a “mongrel” mixture of black and American Indian blood (Fisk, 2004b, n.p.). This piece of legislation denied Virginia American Indian people the right to an Indian identity, mandating that Virginia American Indian people with over one-sixteenth of Indian blood register as “colored” on all official records including birth records, marriage licenses, and death certificates. This made it impossible for anyone to register as “Indian” on any official record without facing severe penalty (Waugman & Moretti-Langholtz, 2006; Wolfe, 2004). Further, Plecker also saw to it that official records of generations of Virginia American Indian people were altered to reflect their race as “colored.”

Plecker was gravely concerned about the existence of Virginia American Indian people and was convinced that “mulatto” offspring would slowly seep into the white race. Plecker wrote, “Like rats when you’re not watching,” they “have been sneaking in their birth certificates through their own midwives, giving either Indian or white racial classification” (as cited in Fisk, 2004b). He called native people “the breach in the dike” (as cited in Fisk, 2004b). Accordingly,

in 1943, Plecker compiled a “hit list” with surnames historically held by Indian families, and distributed the list to hospitals and schools. Anyone with a surname that appeared on the list was not to be admitted to white facilities (Waugman & Moretti-Langholtz, 2006). Hospitals detained Native newborns until parents signed birth certificates designating their child as “colored” (Kimberlin, 2009).

As color is the most important feature of this form of registration, the local registrar must be sure there is no trace of colored blood in anyone offering to register as a white person. The penalty for willfully making a false claim as to color is one year in the penitentiary (Virginia Department of Health [VDH], 1924).

In 1946, when Plecker left the Bureau of Vital Statistics, Virginia’s harsh treatment toward Indians began to wane (Waugman & Moretti-Langholtz, 2006). In 1967, the U.S. Supreme Court in its ruling on *Loving v. Virginia* struck down part of the *Racial Integrity Act of 1924* that banned interracial marriage deeming it unconstitutional. Eight years later, in 1975, the Virginia General Assembly repealed the rest of the *Racial Integrity Act of 1924* (Fisk, 2004b). The aim of the *Racial Integrity Act of 1924*, and its subsequent effects, have been referred to as “documentary genocide,” “paper genocide” (Kimberlin, 2009), and “eugenic homicide” (Waugman & Moretti-Langholtz, 2006).

***An ACT to Provide for the Sexual Sterilization of Inmates of State Institutions in Certain Cases.*** In the same year Virginia passed the *Racial Integrity Act of 1924*, the Virginia legislature also passed a eugenics sterilization statute, SB 281, entitled *An ACT to Provide for the Sexual Sterilization of Inmates of State Institutions in Certain Cases*, hereafter referred to as *The Sterilization Act*. Similar to the *Racial Integrity Act*, the *Sterilization Act* sought to preserve the racial integrity of the “white” race. Although Plecker had no role in administering the

*Sterilization Act*, as he did the *Racial Integrity Act of 1924*, Plecker strongly supported sterilization laws, “arguing that feeble-minded whites were prone to mate with Indians and blacks” (Fisk, 2004b, n.p.).

Between 1924 and 1979, it is estimated that 8,300 people (Fisk, 2004b) “afflicted with hereditary forms of insanity that are recurrent, idiocy, imbecility, and feeblemindedness or epilepsy” in Virginia were sterilized without their consent (*An ACT to Provide for the Sexual Sterilization of Inmates of State Institutions in Certain Cases*, 1924. n.p.). Among those who were subjected to forced sterilization were people who were predominantly poor and uneducated, deemed mentally incompetent, physically disfigured, of ill repute, and/or persons of color, including Virginia American Indian people (Daniel, 2007). Many of those sterilized were not aware of their sterilization (Wong, 2013). For women, many came to the hospital for reasons such as childbirth, and doctors sometimes sterilized them without their knowledge or consent (Kevles, 1985). According to a contemporary eugenics expert and professor at the University of Virginia Law School, Paul A. Lombardo, “the eugenics statue [sic] spelt, ‘racism, pure and simple’” (cited in Daniel, 2007, p. 10).

The racial effects of the program in Virginia can be seen by the disproportionately high number of black and American Indian women who were given forced sterilizations after coming to a hospital for other reasons, such as childbirth (Kevles, 1985). The number of American Indian people who were sterilized against their will, however, is uncertain. Because the *Racial Integrity Act of 1924* mandated that Indians register as “white” or “colored,” it is impossible to approximate from medical records how many Virginia Indian people were among the estimated 8,300 people who were sterilized. Given Plecker’s blatant abhorrence for Indian people, it seems reasonable to suspect that perhaps Virginia Indian people were well represented among the 8,300

people who were sterilized. Nonetheless, the story of sterilization of Indian people is on the collective memory of Virginia Indian people (Daniel, 2007).

**Ripple effects of racial integrity laws.** While the eugenics movement and subsequent racial integrity laws that governed Virginia for nearly half a century have been repealed for decades, the ripple effects of these policies still run deep and wide in Virginia American Indian communities today. Many of these ripples effects are directly and indirectly related to the health and well-being of Virginia American Indian communities.

*Little is known about the collective health of Virginia Indian communities.* To escape the repressive racial integrity laws, many Indian families left Virginia, resettling in surrounding states (Fisk, 2004b; Waugman & Moretti-Langholtz, 2006). Kenneth Adams, Chief of the Upper Mattaponi Indian Tribe, recounts, “The worst thing about Plecker is how he screwed up the community. People just left” (as cited in Fisk, 2004, n.p.). For those who stayed in Virginia, families who could “pass” as “white,” created a new identity and narrative. Some Virginia Indian families took such measures as changing their last name, shedding every possible layer of Indian identity (Waugman & Moretti-Langholtz, 2006). Thus, it is not uncommon today for people with Virginia Indian ancestry to not learn of their ancestry until well into their middle years of life, for their families’ survival depended upon this secret (Waugman & Moretti-Langholtz, 2006). As I’ve heard from Virginia American Indian people through casual conversation, to this day, it is also not uncommon for Virginia Indian people, similar to Indigenous peoples nationwide, to refrain from identifying as “American Indian/Alaska Native” on official paperwork, instead identifying as a different race. While meant as a contextually derived protective/survival measure, an indirect effect is that little is systematically known about the collective physical, behavioral, social, and economic wellbeing of Virginia Indian people through official



repositories of records and/or surveys (e.g., U.S. Census Bureau, Virginia Department of Health, Center for Disease Control Behavioral Risk Factor Surveillance System).

***Fear and distrust.*** Distrust and fear among Virginia Indian people of the government (federal and state), and its subsequent services, as well as distrust and fear of mainstream health care entities, and their subsequent services, are ripple effects of a history of repressive and oppressive government policies (Daniel, 2007). Daniel asserts, “There is an overriding fear of the government among Indians” (p. 8). For example, from my time as a volunteer at the Clinic that serves as the context for this study, I am familiar with a particular Virginia Indian woman who lives on a severely limited income and whose health and well-being is fairly compromised. Until rather recently, this particular woman refused to apply for federal welfare programs for which she was eligible for fear of perceived consequences of her personal information being on the radar of federal and state governments. She also resists charitable donations, for which she is always grateful, wanting to independently support herself. It took the continued assurance of someone the woman closely trusts, and the patience of a government employee, for her to finally consent to the application process for government assistance. Additionally, I have witnessed fear and distrust of mainstream health care in my work with the health Clinic. There are some service-users who refuse to pursue recommended health care services at particular mainstream health care facilities for fear of discrimination and distrust of “outside” providers and procedures.

***Denied federal recognition.*** A significant ripple effect of the *Racial Integrity Act of 1924* is its controversial impact on Virginia state-recognized tribes’ pursuit of federal recognition. Fisk (2004b) asserts, “From the grave, Plecker is frustrating the efforts of Virginia tribes to win federal recognition and a trove of accompanying grants for housing, health care and education” (n.p.). Until 2016, not one Virginia-state recognized tribe had been extended federal-recognition.

Current regulations governing procedures for establishing that an American Indian group exists as an Indian Tribe are based on a set of seven criteria including, but not limited to, continuity of a group's existence since 1900 (BIA, 2017). Plecker, by purging Indians as a race, has made the fulfillment of that requirement nearly impossible (Fisk, 2004b). Several Virginia Indian tribes have been unable to adequately document this specific criterion because of the gap in records as result of the *Racial Integrity Act* (Fisk, 2004a). "Despite the integral role the tribes played in American history and the unique cultures they have continued to maintain for thousands of years, they have faced barriers to recognition due to extraordinary circumstances out of their control," said Timothy Kaine, U.S. Senator and former Governor of Virginia (as cited in Heim, 2015)

Without federal recognition, Virginia Indian tribes are ineligible to receive federal benefits available to federally-recognized tribes, including, but not limited to, health-related services through Indian Health Services (VITAL, 2013; Waugman & Moretti-Langholtz, 2006). As a result, there is no centralized repository of health data for Virginia American Indian people, further inhibiting a collective understanding of the health and wellbeing of Virginia Indian people. Lack of access to Indian-centered health care, also prohibits, or severely limits, access to culturally responsive care.

It is important to note, during the life of this dissertation research, the Pamunkey Indian Tribe received federal recognition by way of the U.S. Bureau of Indian Affairs (Heim, 2016). While it is well documented that the Pamunkey people inhabited the region for hundred of years prior to the English settlement at Jamestown, greeted English settlers on the shores of what is now known as Virginia in 1607, were among the Original Peoples who provided the colonists with food and aid (Custalow & Daniel, 2007; Heim, 2015; Rountree, 1996; Waugman & Moretti-Langholtz, 2006; Wood, 2007), and claim Disney's beloved and celebrated princess

Pocahontas among their ancestry (daughter of a father who is Pamunkey) (Custalow and Daniel, 2007), federal recognition was extended only after three decades of petitioning for federal recognition (Sky News, 2015), costing the tribe over \$2 million (Piven, 2015).

The Bureau of Indian Affairs initially announced that the Pamunkey had met its requirements for federal recognition in January 2014 (Heim, 2015); however, the decision was fiercely challenged by non-profit organizations and private companies opposed to casinos or directly involved in casino management, as well as from members of the Congressional Black Caucus, delaying the Bureau of Indian Affairs' formal announcement (Heim, 2015). In February 2016, the Pamunkey received a court victory over a challenge to their right to exist (Brauchle, 2016), making it the 567th federally recognized tribe in the U.S (Heim, 2015).

***Limited access to health care.*** A history of oppressive and repressive policies aimed at eliminating Virginia Indian people from the racial and cultural landscape of Virginia has largely constrained the access Virginia Indian people have to gainful employment, both in the past and present. Therefore, as a whole, the economic prosperity of Virginia Indian people is low, even when compared with other “minority” groups in Virginia (M. S. Sargent, personal communication, March 11, 2014; Waugman & Moretti-Langholtz, 2006). Consequently, as a whole, Virginia Indian people largely lack access to health care and resources needed to be healthy (M. S. Sargent, personal communication, March 11, 2014), greatly inhibiting their collective and individual health and well-being. While empirical data to justify these assertions are lacking, given issues addressed previously, the assertions are supported anecdotally by the stories I’ve heard and witnessed as a volunteer at the Clinic that serves as the context for this study, as well as in the writings of Virginia American Indian authors. It is important to note, however, despite the seemingly overwhelming obstacles stacked against Virginia American

Indian communities, several people from Virginia American Indian communities have gone on to attend training schools, colleges, and universities, practicing in such professions as medicine, accounting, education, mainstream politics, law enforcement, etc.

It is from these ripples –fear and distrust of the government and mainstream health care and lack of federally funded, Indian-centered health care, and limited access to health care, that the Mattaponi Healing Eagle Clinic origin story emerges.

**Resilience in spite of hardship.** In spite of a long history of hardship, a strong thread of hope and resilience is woven throughout Virginia Indian communities (Waugman & Moretti-Langholtz, 2006). Virginia Indian people are working diligently to reclaim and preserve their heritage and cultural traditions including dancing, drumming, pottery, beading, basket weaving, flute making, woodwork, canoe making, painting, and storytelling (American Heritage Voices, 2012; Egloff & Woodward, 2006; Waugman & Moretti-Langholtz, 2006; Wood, 2007). Projects that seek to remember, preserve, celebrate, and share tribal histories have emerged and are continually developing (Adkins & Adkins, 2009; Bradby, 2008; Custalow & Daniel, 2007; Daniel, 2007b; Waugman & Moretti-Langholtz, 2006; Wood, 2007). Virginia Indian people stand today ready to (re)claim what has been taken, (re)build what has been broken, and (re)value what has been preserved. According to Dr. Linwood “Little Bear” Custalow (Mattaponi), “It is only by the indomitable spirit of the Indian people, as to why we are still here” (as cited in Daniel, 2007, p. 12). The Mattaponi Healing Eagle Clinic is a tangible example of the resiliency, creativity, and tenacity of Virginia Indian people to internally address an important need within their communities: health care.

## **The Mattaponi Healing Eagle Clinic**

The Mattaponi Healing Eagle Clinic (MHEC) is housed in a historical school house situated on the Mattaponi Indian Reservation, King William County, Virginia. MHEC opened its doors in 1999 with a vision to provide quality health care for American Indians and their families. According to Daniel (2007), MHEC is a volunteer-run, donation-based clinic, with services available to all American Indians and their families. No “proof” of Indian identity is required. Clinics operate on a first come, first served basis. All services are free of cost to service-users. MHEC serves as the primary medical home for a majority of service-users, and for many, the only medical care they receive. It is not uncommon for service-users to travel four hours round-trip to receive care at the Clinic. MHEC operates as an informal training site for medical (and pre-medical) students and pharmacy students from a local university. MHEC is a 501(c)3 non-profit organization with its own Board of Directors, Medical Director, and bank account. The Clinic abides by the protocol of the Mattaponi Indian Reservation and its governing body.

It’s important to note here that other than a written history of the Mattaponi Healing Eagle Clinic by Angela L. Daniel (2007), documentation of Clinic services, operations, and management, to the best of my knowledge, does not exist. Therefore, information about MHEC presented in the following section is largely informed by my experience as a volunteer with the Clinic over a seven-year period, as well as accounts from Daniel’s written history of MHEC.

The oversight and management of MHEC, as well as available services, has shifted throughout the life of MHEC, with rather significant changes occurring during the life of my dissertation research. During my time at MHEC, I have witnessed how a slow shift in oversight and management of MHEC, in addition to outside shifts in policy and funding, have largely

impacted the availability of services at MHEC. The former Administrative Director of MHEC, also co-founder of the Clinic, was relentlessly dedicated to the success of the Clinic and unwaveringly committed to the people it serves. The former Administrative Director “ran a tight ship,” as volunteers and service-users would say, ensuring that the Clinic ran smoothly and that the needs of service-users were met to the very best of her ability. Through my relationship with the former Administrative Director, I witnessed the long hours she invested in staffing clinics, soliciting donations, and communicating with service-users during non-Clinic hours, ensuring the best quality of care was available to service-users. She offered a friendly, genuine greeting to all who entered the doors of the Clinic, and extended a listening ear to anyone who sat beside her at the Clinic wanting to share what was on their hearts and minds. In 2009, the physical health of the former Administrative Director began to waiver, sometimes making it difficult, and increasingly not possible, to be physically present at the Clinic. Although her physical presence at the Clinic diminished, the work she did behind the scenes did not waiver. However, as her physical health deteriorated, so did her ability to invest in the oversight and operations of MHEC, until she officially announced her retirement from the Clinic in 2016.

During its prime, MHEC offered three clinics per month (two primary care and one podiatry) staffed by a diverse, rotating team of volunteer medical professionals including an internal medicine doctor/pulmonologist, family medicine doctor, nurse practitioners, nurses, medical students, pharmacy students, and non-medical volunteers of varying backgrounds and skills. At its prime, MHEC boasted a roster of approximately 450 service-users, representing over 13 different tribes, with nearly 50 to 60 service-users frequenting each Clinic (M. S. Sargent, personal communication, March 11, 2014). According to Daniel (2007), this is a far cry from MHEC’s early days when clinics were held once per month and attended by perhaps five or

six people. Trust between MHEC staff and community members developed over time, through consistent, committed relationships, which the former Administrative Director orchestrated so beautifully. At its prime, MHEC offered services such as medical exams; cholesterol, sugar, and blood pressure screenings; foot care; flu and pneumonia vaccinations; medications and vitamins from MHEC's pharmacy (prescription and over-the-counter); medications through the Healing Spirit Fund, a partnership between MHEC and a local community pharmacy that helps MHEC service-users access medications not available through the Clinic and otherwise not accessible to service-users; and medical supplies (i.e. supplement drinks, incontinence products, wound care products, wheelchairs, walkers, etc.) (Daniel, 2007). The long-term commitment of MHEC to supporting the health and wellbeing of Virginia Indian people largely explains the exponential growth in MHEC's patient roster since the opening of its doors in 1999.

Currently, however, the number of clinics per month have decreased, attendance has dropped, and services are limited. MHEC now hosts one primary care clinic per month, attended by approximately ten to twenty service-users. Services currently offered include medical exams; annual flu and pneumonia vaccinations; medications and vitamins from MHEC's pharmacy (prescription and over-the-counter); and medical supplies (i.e. supplemental drinks, incontinence products, wound care products, wheelchairs, walkers, etc.). The availability of prescription drug samples in MHEC's pharmacy (donated by various community-based medical practitioners to MHEC), on which several MHEC service-users depend, has waned significantly due to rather recent policies (at the federal, state, and/or medical institution level) restricting, and in some cases prohibiting, prescription drug samples. Also, relationships between the former Administrative Director and medical practitioners in the community who donated samples are compromised due to the ill health of the former Administrative Director. Additionally, the

Healing Spirit Fund has largely dried up without the oversight of the former Administrative Director. Therefore, MHEC service-users do not have the same level of access to free medications, important to the maintenance and promotion of their health, as they once did. Perhaps one of the most impactful changes at MHEC influencing the operation of MHEC and service-users' experience engaging with MHEC is the absence of a committed, strong, hospitable presence that regularly greets volunteers and service-users alike as they walk through the doors of MHEC. The former Administrative Director leaves a set of big shoes in need of filling.

**The beginning of my relationship with MHEC and Virginia Indian people.** I began volunteering with MHEC in the fall of 2009. Having recently graduated from my masters of social work and masters of public health programs, I felt I was ready to responsibly engage with the communities I had spent so much time learning about. Volunteering with MHEC seemed like an optimal way to begin building relationships with the Virginia American Indian community because it met an expressed need of the Clinic for volunteers, and the setting was congruent with my academic study concerning health in marginalized communities, particularly Native communities. Greeting service-users upon their arrival to the Clinic and visiting with them in the community waiting room while they waited to see a medical practitioner were among the first tasks assigned to me as a volunteer. In this role, I had the opportunity to listen to hundreds of stories and see almost as many pictures. This experience afforded me the opportunity to develop relationships with Virginia Indian people, relationships that were at first limited to the parameters of the Clinic, but then extended to the lives of service-users outside of the Clinic. This role also provided an opportunity for me to become familiar with the management and operation of the Clinic, as I was attentive to both while visiting with service-users, and I was often asked to perform any number of organizational tasks during Clinics. As a trust began to



build between the service-users and me, I began to help service-users with various observed and expressed needs such as navigating a pharmaceutical company's medication assistance program and helping an elder who was ill plant his annual vegetable garden.

When the health of the then Administrative Director had declined to the point where she was no longer able to be physically present at the Clinic, at her request, I stepped in as Assistant Administrative Director. At this point I had been a volunteer with MHEC for three years. The relationships I had developed during my time greeting and visiting service-users, as well as with the medical professionals, were invaluable in helping me transition into this position. As the Assistant Administrative Director, I assumed responsibility for much of the oversight and management of the Clinic, with the Administrative Director assisting me as much as her health would allow. I acted in the role of Assistant Administrative Director for two years until a major life event occurred and required me to relocate to another state. However, despite the distance, I maintained relationships with MHEC service-users through extended visits to Virginia where I would help out at the Clinic as needed, as well as through casual, long-distance relationships with service-users.

Just prior to stepping into the role of Assistant Administrative Director, I had returned to the university to begin the doctoral program in social work. The relationships I developed through MHEC with service-users and medical practitioners alike inspired me to continue my education to explore how better to support the health and well-being of Virginia American Indian families and communities, as well as Indigenous communities nationally and globally. This dissertation is a culmination of what I set out to do – learn how to better support the health of Virginia American Indian communities. Further, this dissertation is a way for me to give back to the Virginia American Indian people who welcomed me into their hearts and homes.

## **The Current Study**

As someone who has been in relationship with people from Virginia Indian communities for over seven years, particularly within the context of MHEC, I often wonder in what ways MHEC meets the health needs of the people it serves, based upon the ways in which service-users think about health. For example, health care provided through MHEC is largely based on a Western biomedical perspective of health, which differs along several dimensions from more traditional Indigenous conceptualizations of health. When available, “culturally relevant” health promotion and disease prevention information, such as materials created by the Centers for Disease Control specifically for American Indian and Alaska Native populations, is shared with service-users. Knowing that conceptualizations of health are culturally, socially, economically, politically, and historically situated, I wonder whether material that is intended to be culturally relevant for American Indian and Alaska Native peoples is relevant to the ways in which MHEC service-users think about health. This web of wonder serves as the motivation for my dissertation research.

This study explores the ways in which Virginia American Indian people connected to a rurally located, reservation-based, non-federally funded health clinic think about health and healing. Given the nature of the research question, as well as consideration of the worldview of the community engaged in the research, a methodology was needed that centralizes the role of context, recognizes and accounts for the existence of multiple co-occurring realities, honors subjectivities of the inquirer and participants alike, and allows for the design to emerge in response to inquirer-community engagement. Indigenous scholars the world over call for grounding research with Indigenous peoples in Indigenous ways of knowing and being in the world (Bishop, 2005; Caldwell et al., 2005; Cochran et al., 2008; Kovach, 2009; Smith, 2005;

Smith, 1999; Wilson, 2008), an urgent call which I respect. For reasons that I extensively discuss in Chapters 2 and 3, I decided to ground my dissertation research in a Western paradigmatic tradition, however, a paradigmatic tradition with philosophical assumptions closely aligned with Indigenous ways of knowing and being.

Using an emergent approach to qualitative research grounded in a constructivist inquiry paradigm and guided by Indigenous research principles, I engaged in seventeen initial in-depth, semi-structured interviews with select MHEC service-users and eleven follow-up interviews. Together, participants and I engaged in the co-creation of stories concerning participants' life experiences related to health and healing. This study did not seek to label, pathologize, or romanticize Virginia American Indian people, but rather learn from the stories told by Virginia Indian people regarding their lived experiences concerning health and healing. Additionally, this study was not intended to be an evaluation of MHEC services, but rather an investigation of a particular phenomenon within the context of MHEC.

The aim of this study was multi-fold. The first aim was to learn how to more responsively support the health of Virginia American Indian communities for today and seven generations to come. The second aim of the study was to create a space for dialogue among a group of people whose voices have for too long been silenced, because, as I was reminded, "There is healing in the sharing." The third aim of the study was to contribute to the social work literature more responsive and responsible ways to engage with Indigenous peoples in helping relationships.

### **Significance of the Research**

The significance of my dissertation research extends to both Virginia American Indian communities, particularly the community connected with the Mattaponi Healing Eagle Clinic, as well as the profession of social work. The significance of this research study to Virginia Indian

people, particularly people associated with MHEC, was two-fold. First, this is the first known study to explore and document (particularly in a systematic fashion) the meaning of health and healing among Virginia American Indian people. The product of the inquiry will be documentation of a story co-constructed by Virginia Indian people regarding their lived experiences concerning health and healing. Second, the study created space for a historically marginalized group of people to tell a story important to their communities, a story that celebrates the diversity of voices represented in their communities.

The significance of this research to the discipline and profession of social work was also multifold. First, a plethora of the limited research in social work literature regarding Indigenous peoples is conducted with Indigenous peoples from federally recognized tribes. This study (a) contributes to the limited social work literature concerning Indigenous peoples; and (b) represents the voices of Indigenous peoples often not heard from in the literature, the voices of non-federally recognized Indigenous people. Second, as the profession of social work strives to be culturally competent in a world of increasing diversity (NASW, 2015), the context-embedded nature of this study presents the social work profession with an understanding of health from a cultural perspective that is more complicated, contested, and fluid than previous models suggest.

### **Dissertation Overview**

Chapter 1 sought to identify the focus of this dissertation research and provide justification for the research. Important to this conversation was constructing the context connected to this research, as the context is central to all areas of the research including framing and informing the focus of the research, people involved in the study, the methodology, and findings.

Chapter 2 explores the literature relevant to identified web of inquiry. The chapter begins with asserting that little is currently known about the health of Virginia American Indian people, and considers reasons for this lack of information. This discussion further builds justification the identified web of inquiry. Two theories of health will be explored – an Indigenous theory of health and an Indigenous informed social determinants of health theory, and a discussion of their relationship to the research question and subsequent elements of the study will be presented. Next, inquiry paradigms will be addressed – dominant, received, and Indigenous, and their role in informing both the methodology and research design.

Chapter 3 will present the methodology informing this dissertation research, and the subsequent research design. The chapter also seeks to ground methodological and design decisions in the literature. The chapter concludes with a discussion of challenges connected to the methodology and design.

Chapter 4 will present the findings of this dissertation research via two forms: a visual representation and narrative. The chapter concludes by addressing *learnings* derived from study findings.

Chapter 5 will discuss implication of study findings and derived learnings for social work education, practice, policy, and research.

## Chapter 2: Literature Review

The focus of Chapter 2 is to provide a review of the literature relevant to the research question, as well as to build further justification for the focus of this work. The chapter begins with setting up the assertion that little is known as the health of Virginia American Indian people, and considers reasons for this lack of information. Next, two theories of health will be explored – an Indigenous theory of health and an Indigenous informed theory of social determinants of health, and a discussion of their relationship to the research questions and subsequent elements of the study will be presented. Lastly, inquiry paradigms will be addressed – dominant, received, and Indigenous, and their role in informing both the methodology and research design.

### **Health of Virginia American Indian People**

When compared to the total U.S. population, American Indian and Alaska Native people nationwide disproportionately experience poor health outcomes across several Western informed health indicators, including diabetes mellitus; cardiovascular disease; malignant neoplasms; influenza; intentional injuries (including suicide) and unintentional injuries (including automotive accidents); sexually transmitted diseases; and mental and emotional illnesses (Indian Health Services [IHS], 2016a; Indian Health Services [IHS], 2014b; Jones, 2006; U.S. Commission on Civil Rights, 2004). American Indians and Alaska Native people continue to die at higher rates than other Americans in many categories, including chronic liver disease and

cirrhosis, diabetes mellitus, unintentional injuries, assault/homicide, intentional self-harm/suicide, and chronic lower respiratory diseases (IHS, 2016a).

Findings from the U.S. Commission on Civil Rights' report *Broken Promises: Evaluating the Native American Health Care System* reports that American Indian people are 770 percent more likely to die from alcoholism, 650 percent more likely to die from tuberculosis, 420 percent more likely to die from diabetes, 280 percent more likely to die from accidents, and 52 percent more likely to die from pneumonia or influenza than the U.S. general population (U.S. Commission on Civil Rights, 2004, p. 8). The IHS report *Trends in American Indian Health 2014 Edition* reports comparable disparities in mortality across several of the same conditions as reported in the *Broken Promises* report, with inequities as staggering as, although slightly lower than, those identified in the *Broken Promises* report published ten years earlier (IHS, 2014b). Generally, non-Hispanic American Indian men and women have not experienced the decreases in mortality that have been documented and widely heralded for the US population overall (Bauer & Plescia, 2014). American Indian and Alaska Native peoples born today have a life expectancy that is 4.4 years less than the U.S. all races population (73.7 years to 78.1 years, respectively; 2007-2009 rates) (IHS, 2016a). However, although the numbers tell a story of heavy burden of morbidity and mortality shouldered by American Indian and Alaska Native people, it also tells a story of the strength and resilience of Indigenous people as they seek to not only survive, but also thrive under adverse circumstances

Although a current phenomenon, Jones (2006) asserts, "Disparities in health status between American Indian and Alaska Native people and other groups in the United States have persisted throughout 500 years since Europeans arrived in the Americas" (p. 2122). From the earliest years of colonization, American Indian people have suffered more severely whether the

prevailing diseases were smallpox, bubonic plague, whooping cough, tuberculosis, alcoholism, or other chronic afflictions of modern society. Throughout the centuries, explanations for these disparities have run the gamut between providence; natural selection; genetic determinism; environment; nutrition; behavior (morally justified); physical, racial, and cultural differences; and socioeconomic factors (Jones, 2006). Jones asks the compelling question, “Do American Indians have intrinsic susceptibilities to every disease for which disparities have existed? Or does the history of disparity after disparity suggest that social and economic conditions have played a more powerful role in generating Indian vulnerability to disease?” (p. 2123).

A steadily growing body of health-related research regarding American Indian and Alaska Native people, as well as Indigenous populations worldwide, suggests that persistent health inequities present in American Indian and Alaska Native communities, and Indigenous communities worldwide, are largely attributable to a complex matrix of various factors including socioeconomic, political, historical, cultural, and environmental determinants (Brave Heart, 2003; Czyzewski, 2011; Duran & Walter, 2004; Greenwood & de Leeuz, 2012; Hill, 2009; IHS, 2016a; Jones, 2006; King, Smith, & Gracey, 2009; Lowe, 2008; Mawbray, 2007; Reading & Wein, 2009; U.S. Commission on Civil Rights, 2004;). Additionally, the literature also attributes inequities in health within Indigenous communities to a conflict in the use of dominant biomedical models of health in Indigenous communities whose localized conceptualizations of health may differ from that of the dominant Western informed model (Cross, 1997a; Duran, Guillory, & Villanueva, 1990; Hodge, Limb, & Cross, 2009; Mawbray, 2007).

Little is known, however, about the collective health and well-being of Virginia American Indian people. The absence of health-related data about Virginia American Indian people is complex and ties together conversations about Virginia American Indian history,



particularly as related to the *Racial Integrity Act of 1924*; federal recognition; and access to federally-funded health care for American Indian and Alaska Native people. Much of what is known about the collective health of American Indian and Alaska Native people is largely based on data collected by Indian Health Services (IHS). The United States has a unique legal and political relationship with *federally recognized* American Indian tribes and Alaska Native entities as provided by the Constitution of the United States, treaties, court decisions, and Federal statutes. These special trust and government-to-government relationships entail certain legally enforceable obligations and responsibilities on the part of the United States to persons who are enrolled members of federally recognized tribes (BIA, 2017), one of which entails the provision of health care services.

Indian Health Services is an agency within the U.S. Department of Health and Human Services that provides a comprehensive health delivery system for approximately 2.2 million of the nation's 3.7 million American Indians and Alaska Natives (IHS, 2016a; IHS, 2016b). Operating with an annual budget of \$4.8 million (FY 2016), IHS services are administered through a system of 12 area offices and 170 IHS and tribally managed services (IHS, 2016b). IHS primarily serves American Indian and Alaska Native people (who are enrolled members of federally recognized tribes) who live mainly on or near reservations and in rural communities, mostly in the western United States and Alaska; however, there are 34 urban programs that provide services ranging from community health to comprehensive primary health care (IHS, 2016a; IHS, 2016b).

Until 2016, not one of the 11 state recognized tribes in Virginia had been extended federal recognition; therefore, Virginia American Indian people do not share a government-to-government relationship with the U.S. federal government. Thus, Virginia American Indian

people have been ineligible to receive federally funded services, including health related services through IHS. Although the Pamunkey Indian Tribe has entered into a government-to-government relationship with the U.S. federal government with its recent granting of federal recognition (Heim, 2016; Piven, 2015; Sky News, 2015), based on informal conversations I've had with people in the Pamunkey community, it seems its enrolled members have yet to benefit from this relationship. While enrolled members are technically now eligible to participate in federally funded services, the nearest IHS facility is approximately a two-hour drive from the Pamunkey Reservation, limiting access to IHS services. Therefore, Virginia American Indian people are not represented in a vast majority of the health statistics reported about American Indian and Alaska Native people.

Mattaponi Healing Eagle Clinic was created to meet an identified need for health care in Virginia American Indian communities. MHEC serves a broad array of people from various Virginia American Indian communities; however, the Clinic serves only a segment of the Virginia American Indian population. While MHEC maintains medical records of service-users, the record keeping is not as sophisticated as that of Indian Health Services. Therefore, there is a lack of a central repository of health information related to Virginia American Indian people. Further, as a residual effect of a sustained history of persecution aimed at Virginia American Indian people, it is not uncommon for Virginia Indian people to refrain from identifying as "American Indian/Alaska Native" on official paperwork. While meant as a contextually derived protective/survival measure, an indirect effect is that little is systematically known about the collective physical, behavioral, social, and economic wellbeing of Virginia Indian people through official repositories of records and/or surveys (e.g., U.S. Census Bureau, Virginia Department of Health, Center for Disease Control Behavioral Risk Factor Surveillance System).

Given the wide-spread health inequities experienced by American Indian and Alaska Native peoples nationwide, as well as Indigenous peoples globally, it is reasonable to suspect that Virginia American Indian people may similarly experience health inequities, although with a collective health profile unique to their communities. Also, in light of the body of health-related research suggesting that persistent health inequities in Indigenous communities are largely attributable to a complex matrix of adverse conditions present in Indigenous communities (e.g., poverty, limited education, oppressive history), it seems reasonable to suspect that Virginia American Indian people may be similarly impacted by the adverse conditions present in their communities as a consequence of a history of hardship. Without a systematic understanding of the health and well-being of Virginia American Indian people, it is challenging to know how to adequately support the health and well-being of Virginia American Indian communities. This dissertation research grows out of a need to better understand how to better support the health of Virginia American Indian communities for today and seven generations to come.

In the following section, various dimensions of the complex matrix associated with health among Indigenous peoples will be explored. This discussion will present a broader context for thinking about health than is typical of the dominant biomedical perspective of health. This conversation is important because it allows for a broadening of the way health is assessed in Indigenous communities, beyond a Western disease-centric model, such as reported in the brief overview of the health of Native peoples presented above. Therefore, a broader perspective of health will allow for a fuller, deeper consideration of the ways various dimensions may be impacting the health and well-being of Virginia American Indian people.

The perspectives presented in the following section represent prominent discussions in the literature regarding Indigenous peoples and health. First, a cultural dimension of health will

be explored, specifically considering an Indigenous cultural conceptualization of health. This will be followed by a discussion about the challenges inherent in focusing on the role of culture in addressing health. Next, consideration will be given to the ways in which social, economic, historical, and political dimensions interact to impact health, particularly that of Indigenous peoples, by considering an Indigenous-informed social determinants of health perspective. A review of the perspectives of health presented in this section will lead to a re-introduction of, and justification for, the proposed research question.

## **Theories of Health**

### **An Indigenous Conceptualization of Health**

Before beginning this section, it is important to mention that American Indian and Alaska Native peoples are not a homogenous group of people, but, rather, diverse groups of people with unique histories; relationships with the land; worldviews; and cultural beliefs, traditions, and practices (Cross, 2002; Hodge, Limb & Cross, 2009; Limb & Hodge, 2008; Weaver, 1999; Whitbeck, 2006). Further, there is “substantial diversity” represented within each American Indian and Alaska Native group (Limb & Hodge, 2008, p. 616; U.S. Census, 2012a; Weaver, 1999). Accordingly no singular construction of health exists among American Indian and Alaska Native peoples, but rather localized constructions of health based on each group’s unique story of worldview; history; relationship with land; cultural beliefs, traditions, and practices; and presence of socioeconomic and political determinants. However, despite the extensive diversity represented among and within American Indian and Alaska Native groups, as well as Indigenous peoples worldwide, there are some common elements that are represented in many localized conceptualizations of health and healing (Hodge et al., 2009). This section will consider these shared elements. Because research has shown that the conceptualization of health about to be

presented below shares common characteristics with localized conceptualizations of health held by Indigenous/Aboriginal peoples worldwide, the term *Indigenous* will be used to identify the construction, rather than American Indian and Alaska Native, unless a reference is specific to Indigenous peoples in the United States.

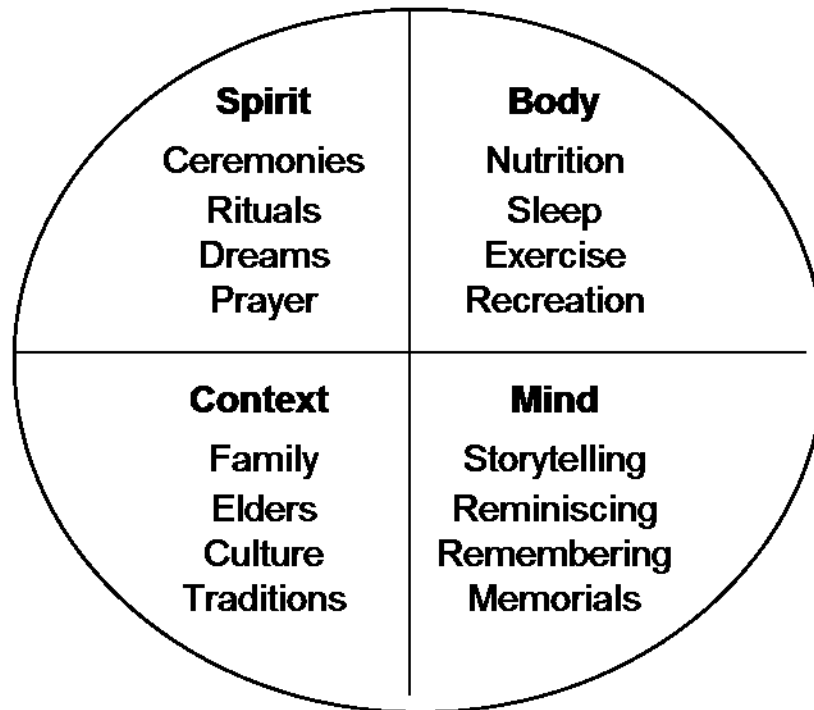
Indigenous conceptualizations of health are informed by a relational worldview. Health is conceptualized more broadly than physical health and extends beyond a mere absence of disease (Adelson, 2000; King et al., 2009; Mawhiney & Nabigon, 2011; Winkelman, 2009). Rather, health is a “complex interplay between the physical world (i.e. our bodies), our mental processes (our thoughts and emotions), our environment (our family, culture, etc.), and the spiritual forces outside of us and the spiritual learned practices that become part of us” (Cross, 2002, p. 22). King, Smith, & Gracey (2009) assert, “These four elements are intricately woven together and interact to support a strong and healthy person” (p. 76).

The concepts *balance* and *harmony* are integral to an Indigenous conceptualization of health. Balance is described by Hodge, Limb, and Cross (2009) as “a natural state that results from the normal processes of stimuli and response, drive and drive satisfaction, and complex system interactions” (p. 215). While balance is functional, it may not be optimal. For example, a person experiencing abuse by an intimate partner may develop coping strategies that bring balance to her/his life (i.e. alcohol and/or drug abuse, submissiveness, becoming withdrawn); however, the coping strategies may leave her/him vulnerable. “As long as humans survive, some form of balance exists naturally” (Hodge et al., 2009, p. 215). Harmony, however, requires intentional effort, and is the “active pursuit of more optimal or positive balance” (Hodge et al., 2009, p. 215). Harmony may include the use of various forms of cultural, spiritual, or cognitive/emotional practices, as well as Western informed interventions.

Good health, also referred to as well-being and wellness, is a balance between the mind, body, spirit, and context, in which these elements of life have equal weight (Cross, 2002). Wellness occurs when each element is functioning in harmony with the others (Hodge et al., 2009). Ill health is the consequence of an imbalance among the mental, physical, spiritual, and environmental aspects of one's life (Winkelman, 2009). Rather than considering a person experiencing ill health as having a "problem," ill health is viewed as being out of harmony and balance (Limb & Hodge, 2008). Ill health tends to refer to the absence of well-being (King et al., 2009).

"Healing is a lifelong journey and individuals strive constantly to create and recreate balance and harmony" (Mawhiney & Nabigon, 2011, p. 17). Indigenous approaches to healing seek to restore balance and harmony, and often include a communal approach to healing, rather than solely individualistic. Consultation of a medicine person, elder, or spiritual teacher who works in ways that honor a holistic perspective of health is often sought out for their provision, advice, council, storytelling, and dream work (for the mind); recommendation of herbs, fasting, sweat lodges, or specific diets (for the physical); and facilitation of ceremonies, healing rituals, and teachings (for the spiritual) (Cross, 1997b; Hodge, Limb, & Cross, 2009). "Always, they [medicine person, elder, or spiritual teacher] become part of the context of the person being helped and add to the balance with their presence and willingness to help" (Cross, 1997b). In some cases, the services of a Western-trained medical professional may also be sought. Figure 1 illustrates the ways in which balance and harmony are presented in pathways to wellness.

Figure 1. Balance and Harmony as the Pathways to Wellness



**Note.** Adapted from “Moving from colonization toward balance and harmony: A Native American perspective on wellness,” by D. R. Hodge, G.E. Limb, and T. L. Cross, 2009, *Social Work*, 54(3), p. 211-219.

While Indigenous conceptualizations of health are based on balance and harmony of four elements of life – physical, mental, spiritual, and contextual, spirituality is the “cornerstone of existence” (Cross, 2002, p. 22). Cross (2002) asserts, “We are not so much humans on a spiritual journey as spirits on a human journey” (p. 22). Spirituality is “the power of the human spirit” (p. 22), yet also transcends the human spirit to include relationship with the Creator and with what might be called positive and negative forces (Hodge, Limb, & Cross, 2009). Although American Indian and Alaska Native people are members of a vast array of spiritual communities, faiths,

and denominations, there is almost a “universal belief” of the importance of spirituality and spiritual forces in the balance of one’s life. Spirituality and health are interconnected and healing cannot be separated from spirituality (Limb & Hodge, 2008).

Health and identity in Indigenous communities are also closely bound to relationship with the natural environment (Mowbray, 2007; Nettleton et al., 2007). In 2003, health workers of the UK-based organization Health Unlimited, and researchers of the London School of Hygiene and Tropical Medicine, collaborated to explore the views of Indigenous peoples in twenty remote communities in five countries regarding their respective concepts of health and well-being. Across the Indigenous communities surveyed, health was not conceived of as an absence of disease, but was closely bound to relationships with community and the environment, in both a physical and spiritual sense (Nettleton et al., 2007). For example, Diang Phoek, a village elder in Rattanakiri Province, Cambodia, tells a story of the effects of the arrival of a gold mining company in the area without permission of elders:

Prior to the arrival of the miners we had seen little sickness in our village. Shortly after the mining started, villagers began to suffer from a range of health problems, which included diarrhea, fever, headaches and coughing and vomiting with blood. The sickness mainly affected children but a small number of adults were also affected. Twenty-five to thirty people became ill, of which thirteen eventually died. We feared that the village spirit had become angry, as outsiders were mining land, and this has been taboo for a long time (Nettleton et al., 2007, p. 464).

In an Indigenous conceptualization of health and well-being, “the health of the land and the health of the people are deeply connected” (Mitchell, 2012, p. 73).



Based on what we know from communities that have been involved in research concerning localized constructions of health, the way in which Whapmagoostui Cree of northern Quebec conceptualize the idea of health poignantly illustrates the identified elements of Indigenous conceptualizations of health, well-being, and healing presented above: balance and harmony of the physical, spiritual, mental/emotional, and contextual, including the natural environment. For the Whapmagoostui Cree, there is no word that translates into English as “health.” In her work with the Whapmagoostui Cree, Adelson (2000) found that the most fitting phrase is *miyupimaatisiun*, which translates as “being alive well.”

‘Being alive well’ constitutes what one may describe as being healthy; yet it is less determined by bodily functions than by the practice of daily living and by the balance of human relationships intrinsic to Cree lifestyles. ‘Being alive well’ means that one is able to hunt, to pursue traditional activities, to eat the right foods, and (not surprisingly, given the harsh northern winters) to keep warm. This is above all a matter of quality of life.

That quality is linked, in turn, to political and social phenomena that are as much a part of the contemporary Cree world as are the exigencies of ‘being alive well’ (Adelson, 2000, p. 15).

**Complexity of culture in relation to health.** In conversations regarding culture and health, it is important to exercise caution in two areas: (1) the ways in which we think about the nature of culture, and (2) the ways in which culture often becomes a proxy for other factors that influence health such as social and economic factors. Today, there are literally hundreds of definitions of culture, but, basically, culture is “that complex whole of values, art, law, morals, knowledge, and beliefs about the world...[that] are shared by members of a group...” (McGrath, 1998, p. 19). It is through the lens of culture, we make sense of our world (McGrath, 1998).

While any individual within a group has her/his own “personal interpretation of the collective cultural code,” an individual’s worldview has its roots in the culture – that is, in the group’s shared philosophy, values, and customs (Little Bear, 2000, p. 77). Simon and Mosavel (2008) ask the challenging questions: How unique or consistent are cultural beliefs, attitudes, and practices? and Where does one culture end and another begin? Responses to these questions are intricately woven into conversations regarding the nature of culture.

A commonly held perspective regarding the nature of culture is that “culture is an unchanging force that determines how members think and act” (McGrath, 1998, p. 19). From this perspective, the constellation of worldviews, belief systems, values, and behaviors of a particular culture are seen as unique, organic, concrete, uncontaminated, reasonably stable, and objective, and can be defined, validated, and shared with others (Simon & Mosavel, 2009; Williams, 2006). Culture is viewed as static and monolithic with defining characteristics that endure over time and in different contexts (Dean, 2001). “Culture is made knowable by privileging the experiences that are common to everyone [in a group] and asserting these experiences as the core of the cultural identity” (Williams, 2006, p. 211). This perspective of culture is consistent with a positivist/postpositivist view of the world which asserts that there is one “true reality” that exists “out there” which can be studied without influencing it, or being influenced by it (Guba & Lincoln, 1994). It is the “business of science” to discover the “true” nature of reality and how it “truly” works in order to predict and control the identified traits, behaviors, and expectations based on one’s identified culture (Guba, 1990, p. 19).

A positivist/postpositivist conceptualization of culture underpins the dominant perception of cultural competence espoused by many helping professions, whereby members of a group (identified by race, ethnicity, age, gender, sexual orientation, religion, able-bodiedness) are seen

as sharing some essential characteristics that define them (Dean, 2001). “If a group can be seen as a stable entity that can be characterized in certain ways, then it is possible for clinicians to develop schema that allow them to interact ‘more competently’ with members of the group” (p. 625). Guarnaccia & Rodriguez (1996) warn, however, against too simple of an understanding of culture. Simon and Mosavel (2008) assert a similar position, “This is an untenable definition in today’s world. Countries, regions, and people are growing too interconnected and are influencing one another to a degree that our definitions of ‘culture’ and ‘cultural competence’ need to account for” (p. 197).

Another way to think about culture is through a social constructionist view of reality. From this perspective, culture is “...not a static object of analysis but a multiplicity of negotiated realities within historically contextualized (and contested) communicative processes” (Salazar, 1991, p. 98). Cultural traits, beliefs, and expectations are shaped by social interactions that are local and specific to a particular context, becoming “more sophisticated forms by immersion in [a] dialectical process of knowledge construction” (Williams, 2006, p. 212). Culture is viewed as emergent, improvisational, transformational, and political; “above all it is a matter of linguistics or of languaging, of discourse” (Laird, 1998, p. 28-29). What makes cultural knowledge local and specific is its integration of issues emerging from specific social, economic, political, and historical contexts that are individually and collectively experienced. In regard to conversations concerning culture as related to Indigenous peoples, King et al. (2009) assert:

It’s important to recognize that identity and culture are not fixed in time or location but rather are in constant evolution. They are co-created and renegotiated within the context of broader society. And yet, the identities that have often been developed for Indigenous peoples generally incorporate colonial images (eg. The Noble Savage, an idealized notion

of exotic innocence, effectively renders Indigenous peoples as other, static, and fragile) (p. 78).

Because American Indian and Alaska Native people are not a homogenous group of people, but, rather, diverse groups of peoples with unique histories; relationships with the land; worldviews; and cultural beliefs, traditions, and practices (Cross, 2002; Hodge, Limb & Cross, 2009; Limb & Hodge, 2008; Weaver, 1999; Whitbeck, 2006), the way in which health is locally conceptualized within Indigenous groups, as well as the ways in which the conceptualization of health manifests in daily living, is influenced by the unique context of each group.

As cultural conceptualizations of health are socially, economically, politically, and historically located, similar sets of factors also interact to impact the health status of individuals and groups. *Essentialism* is an important concept in this discussion. Rooted in a positivist/postpositivist view of reality, essentialism, in relation to culture, is the tendency to overemphasize culture and normalize beliefs for ethnic groups based upon a static understanding of the ethnic group's "culture" (McGrath, 1998).

Important differences within groups are ignored at the expense of presenting a homogenous cultural unit with a set pattern of beliefs and values. The effect of essentializing culture is that it is used to account for, explain, and understand differences, while overlooking history, experiences, and circumstances. Culture in this case becomes a convenient catch-all category to explain all sorts of behaviors" (McGrath, 1998, p. 19). In regard to health, attempts to understand and assess individual or collective health based on the perceived culture of the individual or collective, particularly in regard to discussions concerning culturally competent care, often under-emphasize, or overlook, the impact of social, economic, political, and historical factors. However, as Green, Betancourt, and Carrillo (2002) caution,

“The distinction between cultural factors and social factors is not always clear-cut – in fact there is often overlap” (p. 194). The following theory of health – Indigenous informed social determinants of health, provides a theoretical lens in which to consider the ways in which social, economic, political, environmental, and historical factors work together to inform the health of Indigenous people.

### **Indigenous Informed Social Determinants of Health**

A steadily growing body of health-related research regarding Indigenous peoples suggests that persistent health inequities present in Indigenous communities are largely attributable to a complex matrix of various factors including socioeconomic, political, historical, cultural, and environmental determinants (Brave Heart, 2003; Czyzewski, 2011; Duran & Walter, 2004; Greenwood & de Leeuz, 2012; Hill, 2009; IHS, 2016a; Jones, 2006; King, Smith, & Gracey, 2009; Lowe, 2008; Mawbray, 2007; Reading & Wein, 2009; U.S. Commission on Civil Rights, 2004). Indian Health Services asserts, “Lower life expectancy and the disproportionate disease burden exist perhaps because of inadequate education, disproportionate poverty, discrimination in the delivery of health services, and cultural differences. These are broad quality of life issues rooted in economic adversity and poor social conditions” (IHS, 2016, n.p.). An Indigenous informed social determinants of health (SDoH) perspective provides a valuable lens in which to investigate and understand inequities in health, such as health inequities experienced by Indigenous peoples.

*Health inequities* are disparities in health (differences in health status among distinct segments of the population, including differences by race, ethnicity, gender, sex, disability, age) that are influenced by the political, social, environmental, and economic conditions in which people are “born, grow, live, work, age” (Commission on the Social Determinants of Health

[CSDH], 2008, p. 1) and receive health care (Mitchell, 2012). Referred to in the literature as social determinants of health, these determinants include, but are not limited to: socioeconomic status, race, ethnicity, discrimination, housing, education, physical environment, food security, child development, transportation, working conditions, social support, and democratic participation (Brennan, Baker, & Metzler, 2008; CSDH, 2008; Wilkerson & Marmot, 2003). Health inequities are a result of systemic, avoidable, and unjust social, economic, political, and environmental policies and practices that create barriers to opportunity. They are sustained over time and generations and are beyond the control of individuals (National Association of County & City Health Officials [NACCHO], 2006).

A SDoH theoretical perspective does not individualize the effect of each determinant unitarily whereby one plus one equals two. SDoH “relate, intersect, and mutually reinforce one another” in complex ways (Hankivsky & Christoffersen, 2008, p. 271). An intersectionality framework provides “a normative framework that captures the complexity of lived experiences and concomitant interacting factors of social inequity, which in turn are key to understanding health inequities” (p. 272). An intersectionality framework reflects traditional Indigenous notions of health that conceptualize health as an interrelated balance between physical, emotional, spiritual, and contextual dimensions of health (Reading & Wein, 2009).

Indigenous communities are overwhelmingly impacted by a complex web of various SDoH that largely account for the widespread health inequities experienced by many Indigenous communities: low socioeconomic status, low educational attainment, high rates of unemployment, lack of access to health care (quality or otherwise), lack of availability of culturally relevant health care, racism, discrimination, substance abuse, accidents, and violence (Duran, Guillory, & Villanueva, 1990; Gracey & King, 2009; Hodge et al., 2009; King et al.,

2009; Reading & Wien, 2009; Mowbray, 2007). Proceedings from the International Symposium on the Social Determinants of Indigenous Health (2007) demonstrate, however, that social, economic, and political determinants of Indigenous health differ from those of mainstream populations, and even other minority groups. This is in part due to the ways in which Indigenous and Eurocentric/Western conceptualizations of health differ, as addressed previously, but also because of “common elements that exist for all Indigenous peoples [that] affect every issue confronting [Indigenous people] as a collective: the history of colonization and the associated subjugation of Indigenous peoples” (Mawbray, 2007, p. 24). Czyzewski (2011) asserts that SDoH for Indigenous peoples extend beyond these general risk conditions and include cultural and historical factors such as colonial oppression (e.g. forced migration) and historical traumas (e.g. loss of land, language, and cultural identity). Mitchell (2012) elaborates:

The SDoH experienced by Indigenous people represent a complex interplay among various connections and conditions that influence the health status of the individual, family, community, and tribe...It provides a nonlinear perspective that is cognizant of Indigenous culture and acknowledges the forces of postcolonial oppression and historical trauma that have influenced the current health circumstances of American Indian and Alaska Native people” (p. 73-74).

A SDoH theoretical perspective compliments the use of a cultural perspective of health as it provides a way of considering the ways in which these broad-reaching determinants may account for health conditions present in Indigenous communities, rather than simply attributing the health conditions to culture.

## **Focus of Dissertation Research**

In light of little being known about the collective health and well-being of Virginia American Indian communities, possibilities for initial inquiry are boundless. Based on the above discussion concerning theories of health, two potential areas of inquiry emerge: (1) exploration of cultural constructions of health held by Virginia American Indian people connected to the Mattaponi Healing Eagle Clinic, and (2) investigation of social, economic, political, and historical factors impacting the health of Virginia American Indian people connected to the MHEC. The literature regarding health and Indigenous people verifies the importance of both potential inquiry areas and would seem to suggest the relevance of either inquiry area in Virginia American Indian communities.

Two particular considerations ultimately informed my decision concerning which area of inquiry to pursue for this dissertation research: (1) Reflection on the proceedings from the International Symposium on the Social Determinants of Indigenous Health (2007) that emphasized a connection between persistent health inequities in Indigenous communities and the incongruence between dominant biomedical models of health that often inform the health care provided in Indigenous communities and localized conceptualizations of health, and (2) Reflection on the model of health offered at the Mattaponi Healing Eagle Clinic in light of cultural constructions of health held by its service-users. Therefore, with an interest in wanting to explore how better to support the health of Virginia American Indian people, particularly within the context of MHEC, it seemed like an exploration of cultural conceptualizations of health held by MHEC service-users was a relevant and important line of inquiry. Therefore, the research question to be explored in this study is: What is the meaning of health and healing among Virginia American Indian people in the context of a rurally-located, reservation-based, non-



federally funded health clinic. This study is not intended to be an evaluation of MHEC services, but rather an investigation of a particular phenomenon within the context of MHEC.

Chapter 2 thus far has focused on grounding the research question of this dissertation research in the literature, as well as building further justification for the focus of this work. The remainder of Chapter 2 will focus on laying the groundwork for the methodology and subsequent design that guide this dissertation research. This section will begin with a discussion of the function and importance of paradigms in research, particularly when engaged in research that crosses boundaries of difference. Next, Western and Indigenous inquiry paradigms will be introduced and discussed. Lastly, the section will identify the paradigmatic positioning of this dissertation research, setting the groundwork for an introduction of and justification for the research methodology and subsequent design to follow in Chapter 3.

### **Paradigms that Guide Research**

The conversation of Indigenous and Eurocentric/Western paradigms is explicitly relevant to research, as sets of beliefs go together to guide the actions of researchers. Wilson (2008) asserts, “Any research represents the paradigm used by the researcher, whether the researcher is conscious of their choice of paradigm or not” (p. 33). The paradigm from which the researcher operates, whether acknowledged by the researcher or not, influences all aspects of the research process, including, but not limited to, identification of research question(s), methodology, methods, analysis, interpretation, and dissemination of findings. When a researcher works across boundaries of difference, particularly when the researcher and “subjects”/participants see the world through a different set of paradigmatic perspectives, several problems may be encountered. The way in which the researcher conceptualizes “the problem” may not be relevant to the way in which “subjects”/participants conceptualize “the problem.” This can lead to mis-

framed/disrespectful research questions, inappropriate methodology and research design, poor participation, mis-interpretation of results, mis-application of study findings, and a potentially overall harmful and/or hurtful experience for the “subjects”/participants involved. This is how even well intentioned research may become a source of distress for Indigenous peoples. Given the cross-cultural context of this study, it is important to carefully consider paradigmatic positioning in order to inform a methodology and design that are responsive to the community context. Before introducing the paradigmatic positioning of this dissertation research, however, an introduction to paradigms is needed.

### **Defining a Paradigm**

Although there are an infinite number of ways in which a paradigm has been, and continues to be, conceptualized (Guba, 1990), in its most general and generic sense, a paradigm is a set of underlying beliefs that guide our actions (Wilson, 2008). How we see the world, understand our relationship to the world, and how we learn about the world, shape and influence the ways in which we engage with the world. Although paradigms are integral to the way in which we move through the world, often we go through life completely unaware of the existence of paradigms. It is not until we bump up against someone or something guided by a different paradigmatic positioning that we may, first, be forced to recognize the existence of paradigms, and, then, be provoked to examine the philosophical assumptions that guide our lives (Burrell & Morgan, 1979). Cordova (2007) explains, “[A paradigm], once established, is unidentifiable to the user. A [paradigm] is exposed when people from two different cultures come together and experience challenges in communication, not so much based on language, but based on different frames of reference” (p. ?).

Paradigms are distinguishable by their responses to a set of three interrelated questions concerning the nature of reality (ontology), the relationship between a person and reality (epistemology), and how a person can go about finding out about reality (methodology). The integrity of a paradigm is based on cohesion among the responses to the identified set of questions. The questions are interrelated in so much as the way a person thinks about the nature of reality directly impacts the relationship that is possible between the person and reality, which in turn influences how the person can go about finding out about reality. Paradigms, often referred to as belief systems, cannot be proven or disproven in any foundational sense. Guba and Lincoln (1994) assert:

...[belief systems] are in *all* cases *human constructions*; that is, they are all inventions of the human mind and hence subject to human error. No construction is or can be incontrovertibly right; advocates of any particular construction must rely on *persuasiveness* and *utility* rather than *proof* in arguing their position [*italics* included in original text] (p. 108).

In conversations concerning culture, the terms *paradigm* and *worldview* are commonly used, and occasionally used interchangeably. There are multiple views regarding the relationship between a worldview and a paradigm (i.e. whether a worldview informs the construction of paradigms, paradigms inform worldviews, or the two are interchangeable) (Cordova, 2007; Cross, 1997b); however, regardless of how the relationship between worldview and paradigm is conceptualized, there seems to be a shared agreement that the two are related in a manner where one informs the other, although the direction of exchange is negotiable. The next section will explore Eurocentric/Western paradigms and Indigenous paradigmatic perspectives and worldviews.

**The basic beliefs of Western “dominant” paradigms.** The overwhelming majority of multiparadigmatic paradigmatic frameworks – including, but not limited to, Burrell and Morgan (1979); Guba and Lincoln (1994); and Lincoln, Lynham, and Guba (2011), are rooted in a Western philosophical tradition. Wilson (2008) refers to these paradigms as *dominant*.

Dominant is used as an adjective to describe the culture of European-descended and Eurocentric, Christian, heterosexist, male-dominated Canada or Australia. The term dominant, like the culture that it describes and the society created by this culture, is not meant to include those who fall “outside” the powerful majority, such people who are not men, heterosexual, physically or mentally perfect or white, or any other people who for whatever reason do not “fit in” to the dominant culture (p. 35).

Although Wilson specifically uses the term dominant to describe a culture and corresponding society in the nations of Canada and Australia, I propose to extend the use of the term dominant to include the United States, as European-descended and Eurocentric, Christian-centered, heterosexist, male-dominated culture similarly takes hegemonic precedence in the United States.

Two terms that further delineate dominant paradigms are *received* and *alternative*. Guba and Lincoln (1994) refer to *positivism*, which has “dominated the physical and social sciences for some 400 years” (p. 108), as the received view, and the paradigms that challenge the hegemonic dominance of positivism as alternative. Alternative paradigms include *postpositivism* (although Guba and Lincoln argue that postpositivism has risen to the ranks of positivism while remaining within essentially the same set of basic beliefs), *critical theory*, and *constructivism*. Given the similar philosophical assumptions that underpin positivism and postpositivism, both paradigms will be addressed together as the received view.

***Positivism and postpositivism.*** Ontologically, positivism/postpositivism espouse that there is a “real world” that is as hard and concrete as the natural world. (Burrell & Morgan, 1979, p. 4). It exists “out there” regardless of whether it is perceived by human cognition (p. 1). From a positivist/ postpositivist perspective, there is one “true” reality driven by natural laws that are absolute and undisputable (Guba, 1990); however, postpositivism acknowledges that due to the fallibility of humans, reality can only be apprehended imperfectly and probabilistically (Guba & Lincoln, 1994; Wilson, 2008). “Although one can never be sure that ultimate truth has been uncovered, there can be no doubt that reality is ‘out there’” (Guba, 1990, p. 20). Guba and Lincoln (1994) identify positivism’s ontological positioning as *naïve realism* and postpositivism’s positioning as *critical realism*.

A realist perspective of reality constrains the type of relationship allowable between the inquirer and reality. Epistemologically, a *dualist/objectivist* perspective perceives the inquirer as able to study that which is to be known without influencing it or being influenced by it (Guba & Lincoln, 1994). A positivist perspective assumes that it is both “possible” and “essential” for the inquirer to adopt a distant, non-interactive posture in order to “objectively” study that which is the focus of the inquiry (Guba, 1990, p. 20). The inquirer “must stand behind a thick wall of one-way glass, observing [the social world] as ‘she does her thing’” (p. 19). Postpositivism espouses a *modified dualist/objectivist* view of the relationship between inquirer and the focus on inquiry, recognizing the “absurdity” of assuming a condition of complete non-interaction between the inquirer and that which is being inquired of (Guba, 1990, p. 20). While objectivity remains a “regulatory ideal,” postpositivists realize that complete objectivity is not achievable (Guba & Lincoln, 1994, p. 110).

Accordingly, the “business of science” is to discover the “true” nature of reality and how it “truly” works in order to predict and control natural phenomenon (Guba, 1990, p. 19). The methodology employed by positivists and postpositivists share a similar approach.

*Experimental/manipulation* (Guba & Lincoln, 1994) seeks to discover universal laws of reality through the use of systematic protocol and technique, similar to those employed in the natural sciences. Empirical experimentalism seeks to “dissect and manipulate the smallest controllable bits of nature” (Wilson, 2008, p. 36). Given that research and researchers are “imperfect tools” (p. 36), and given the absurdity of a truly objective relationship between the inquirer and the focus of inquiry, a form of “elaborate triangulation” (Denzin, 1978) known as *critical multiplism* (Cook, 1985) becomes important to the postpositivist methodology. Critical multiplism calls for the review of inquiry “findings” by as many sources as possible – of data, investigators, theories, and methods, to lessen the likelihood that distorted interpretations will be made (Guba, 1990, p. 21). It’s worth noting that in some multiparadigmatic frameworks such as Burrell and Morgan (1979), positivism and postpositivism are collapsed into one paradigm and referred to as *functionalism*.

Although there are four dominant paradigms rooted in Western philosophical traditions (of which the two alternative paradigms will be discussed next), the philosophical assumptions of the received view – positivism and postpositivism, which have dominated the natural and social sciences for nearly 400 years, serve largely as the foundation on which a Eurocentric/Western worldview is constructed. The value system of a Eurocentric/Western worldview, informed by positivist/postpositivist belief systems, can be summarized as temporal (time oriented), linear, singular, logical, static, objective, and systematic (Cross, 1997b; Little Bear, 2000). In the United States, the form and functioning of most institutions (education, health, law, bureaucracy) are

largely influenced and shaped by a Eurocentric/Western worldview. Continuing the conversation regarding dominant belief systems, the next sections considers alternative views to positivism/positivism – critical theory and constructivism.

***Critical theory.*** Critical theory is an umbrella that encompasses several ideologically oriented movements, theories, and perspectives including, but not limited to, neo-Marxism, materialism, feminism, Freireism, participatory inquiry, postcolonialism, as well as critical theory itself. The common characteristic that draws these theories/perspectives together is their strong rejection of positivism and postpositivism’s dismissal of values in the inquiry process (Guba, 1990). “Because they are human constructions, paradigms inevitably reflect values of their human constructors” (p. 23).

Ontologically, critical theorists ascribe to a realist view of social reality, a reality which, once seemingly plastic, appears to have been “crystallized (reified)” over time by social, political, cultural, economic, ethnic, and gender values “into a series of structures that are now (inappropriately) taken as ‘real,’ that is, natural and immutable” (Guba & Lincoln, 1994, p. 110). *False consciousness* is a phrase commonly used within the vernacular of critical theorists, suggesting there is a “true consciousness” somewhere “out there,” presumably possessed by the inquirer or “some better-informed elite” (Guba, 1990, p. 24). Although informed by a realist ontology, Wilson (2008) espouses that reality is more “fluid” or “plastic” than one fixed truth (p. 36).

While critical theories share a realist ontological perspective with positivists and postpositivists, critical theories diverge from these two paradigms in their epistemological positioning. Critical theories view the relationship between the inquirer and reality from a subjective perspective. Values inform all elements of the research process, from the research

questions that are asked, to the paradigm that frames the question and ensuing methodology and methods, to the interpretations that are drawn from the data. “Nature cannot be seen as it ‘really is’ or ‘really works’ except through a value window” (Guba, 1990, p. 24). A critical paradigmatic perspective explicitly acknowledges and identifies the value systems that inform respective engagement in the research process.

Methodologically, transactions between the inquirer and the subject/participant seek to eliminate the false consciousness of participants and “rally participants around a common (true?) point of view” (Guba, 1990, p. 24). Dialog must be dialectic in nature “to transform ignorance and misapprehensions (accepting historically mediated structures as immutable) into more informed consciousness (seeing how the structures might be changed and comprehending the actions required to effect change)...” (Guba & Lincoln, 1994, p. 110). The aim of a critical paradigmatic positioning is facilitating participant recognition of false consciousness and raising awareness of a new “true” consciousness intended to provoke participant action toward the achievement of structural transformation, ultimately leading to liberation from the perceived oppressive and limiting conditions (the focus of the inquiry).

***Constructivism.*** Constructivism is differentiated from the three previous paradigms in its ontological orientation, yet shares an epistemological position with critical theorists. Unlike positivism, postpositivism, and critical theorists, constructivism espouses a relativist view of reality. Social reality is relative to the individuals involved and to the particular contexts in which they find themselves (Lincoln & Guba, 2014). Rather than one “true” reality that exists independent of human cognition, constructivism asserts that realities are “multiple, intangible mental constructions, socially and experientially based, local and specific in nature (although elements are often shared among many individuals and even across cultures), and dependent for



their form and content on the individual persons or groups holding the constructions” (Guba & Lincoln, 1994, p. 110-111). “Reality is what you make it to be” (Wilson, 2008, p. 37).

Epistemologically, constructivism takes a transactional subjectivist position. Since reality is a construction of the human mind, interaction between the researcher and participant is key: it is the only means by which to come to know about the reality of interest. Inquiry is a transactional process whereby the researcher and subject/participant are “interactively linked” and findings are “*literally created*” through the investigation process (Guba & Lincoln, 1994, p. 111). In constructivism, the conventional distinctions between ontology and epistemology dissolve.

Methodologically, constructions can only be elicited and refined through sustained interaction between the researcher and subject/participant whereby conventional hermeneutical techniques are used to interpret constructions which are then compared and contrasted through a dialectal interchange (Lincoln & Guba, 2014). The aim of research situated in a constructivist paradigm is to co-create a more informed, sophisticated construction than existed prior to the research engagement (Guba & Lincoln, 1994; Wilson, 2008). It’s worth noting that in paradigmatic frameworks other than Guba and Lincoln’s, such as Burrell and Morgan (1979), constructivism is sometimes referred to by an alternative paradigmatic label: interpretivism.

Having introduced the four dominant Western paradigms, the next section will address the basic beliefs of an Indigenous paradigm.

**The basic beliefs of Indigenous paradigms.** Before beginning this section, I must first express a word of caution. I am in an early phase of my journey in learning about, processing through, and trying to understand Indigenous/Aboriginal philosophy, paradigms, and belief systems; therefore, the section that follows is presented from my elementary understanding of

Indigenous/Aboriginal paradigmatic perspectives. In an attempt to avoid misinterpretation to the greatest extent possible, I rely on direct quotes from Indigenous/Aboriginal philosophers, scholars, practitioners, and elders, rather than attempt to paraphrase their words. For a more authentic and holistic presentation of Indigenous/Aboriginal philosophies, worldviews, values, and customs, refer directly to the writings and/or oral teachings of Indigenous/Aboriginal philosophers, scholars, practitioners, and elders including Battiste (2000); Cordova (2007); Cross (1997a, 1997b, 2002); Deloria (2004); Kovach (2009); Little Bear (2000); Smith, L. T. (2012); Waters (2004); Weaver (2005); and Wilson (2008). I take responsibility for any and all misrepresentations of Indigenous/Aboriginal philosophical assumptions, values, and customs presented in this dissertation.

An Indigenous paradigm is situated in the foundational belief that “knowledge is relational” (Wilson, 2008, p. 74). To grasp the philosophical principle of relationality, it is first important to understand that in Indigenous philosophy, existence consists of energy, and, therefore, motion (Cordova, 2007; Little Bear, 2000). It is also important to understand that in Indigenous philosophy *all* things are animate, there is not a dichotomy between animate and inanimate as in Western thought. In addition, *all* things are filled with spirit. “All things are animate, imbued with spirit, and in constant motion” (Little Bear, 2000, p. 77). In this type of world, “interrelationships between all entities are of paramount importance” (p. 77). It is through this system of interrelationships that “relationality seem[s] to sum up the whole of an Indigenous...paradigm” (Wilson, 2008, p. 73).

In an Indigenous paradigm, ontology and epistemology are inextricably interwoven, both grounded in relationality (Cordova, 2007; Wilson, 2008). Ontologically, multiple realities exist as and through relationships. Wilson (2008) explains,

...rather than the truth being something that is 'out there' or external, reality is in the relationship that one has with the truth. Thus an object or thing is not as important as one's relationship to it . . . reality *is* relationships or sets of relationships...Reality is not an object but a process of relationships . . . ( p. 73).

Epistemologically, we can only come to know about reality through being in relationship. Indigenous philosophy does not recognize human beings on an individual level, but rather, in relation – in relation to other human beings, to place, to ideas, and spirits. “Human beings do not exist as isolated solitary beings. They exist, except in rare and unusual circumstances, as social entities” (Cordova, 2007, p. ?).

Similar to ontology and epistemology, axiology and methodology are also inexplicably interwoven. Whereas the ontological and epistemological positioning of an Indigenous paradigm is relational, relational accountability represents the axiological and methodological positioning.

Right or wrong; validity; statistically significant; worthy or unworthy: value judgments lose their meaning. What is more important and meaningful is fulfilling a role and obligations in the research relationship – that is, being accountable to your relations (Wilson, 2008, p. 77).

Methodologically, the process must be rooted in accountability to the multiple relations one forms in the inquiry journey. Respect, responsibility, and reciprocity are key features of any healthy relationship and must be included in an Indigenous methodology (Weber-Pillwax, 2001).

Rooted in Indigenous/Aboriginal philosophical assumptions, an Indigenous/Aboriginal worldview is relational, and is sometimes also referred to as cyclical (Cross, 1997; Limb & Hodge, 2008). Although there are as many Indigenous worldviews as there are Indigenous groups of people, “...there is enough similarity among North American Indian philosophies to

apply the concepts generally, even though there may be individual differences or differing emphases”(Little Bear, 2000, p. 77). The value system of a relational, cyclical worldview includes wholeness (totality), balance, interdependence, independence, respect (noninterference), sharing, strength, harmony, beauty, honesty, kindness, spatial (rather than time oriented), and spirituality (Cross, 1997; Limb & Hodge, 2008; Little Bear, 2000). The elements of an Indigenous/Aboriginal worldview and its underlying philosophical assumptions may appear familiar, as an Indigenous/Aboriginal worldview and its corresponding philosophical assumptions underpin the Indigenous conceptualization of health addressed earlier. Refer to Table 3 for a summary of the basic beliefs systems of the five paradigms (four dominant and one Indigenous) addressed above.

Table 3

*Basic Beliefs Systems of Five Inquiry Paradigms*

<i>Item</i>	<i>Positivism</i>	<i>Postpositivism</i>	<i>Critical Theory et al.</i>	<i>Constructivism</i>	<i>Indigenous</i>
<i>Ontology</i>	Naïve realism – “real” reality but apprehendable	Critical realism – “real” reality but only imperfectly and probabilistically apprehendable	Historical realism – virtual reality shaped by social, political, cultural, economic, ethnic, and gender values; crystalized over time	Relativism – local and specific co-constructed realities	Relational – human beings, place, ideas, spirituality  Reality <i>is</i> relationships or sets of relationships
<i>Epistemology</i>	Dualist/objectivist; findings true	Modified dualist/ objectionist; critical tradition/ community; findings probably true	Transactional/ subjective; value-mediated findings	Transactional/ subjectivist; co-created findings	Relational – human beings, place, ideas, spirituality
<i>Methodology</i>	Experimental/ manipulative; verification of hypotheses; chiefly quantitative methods	Modified experimental/ manipulative; critical multiplism; falsification of hypotheses; may include qualitative methods	Dialogic/ dialectical	Hermeneutical/ dialectical	Relational accountability – to all relations

*Note.* Adapted from “Competing Paradigms in Qualitative Research,” by E. G. Guba and Y. S. Lincoln, in N. K. Denzin and Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117), 1994, Thousand Oaks, CA: SAGE; “Paradigmatic Controversies, Contradictions, and Emerging Confluences, Revisited,” by Y. S. Lincoln, S. A. Lynham, and E. G. Guba, in N. K. Denzin and Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 97-128), 2011, Thousand Oaks, CA: SAGE; *Research is ceremony: Indigenous research methods*, by S. Wilson, 2008, Black Point: Nova Scotia: Fernwood Publishing.

## **Paradigmatic Positioning of this Study**

Several factors were considered in deciding in which paradigm to situate this web of inquiry. I considered the call by Indigenous scholars to ground research with Indigenous peoples in Indigenous ways of knowing and being in the world (Bishop, 2005; Caldwell et al., 2005; Cochran et al., 2008; Kovach, 2009; Smith, 2005; Wilson, 2008), an urgent call which I hear and respect. In considering whether to ground the proposed study in an Indigenous paradigm, I thought through several factors. First, given my elementary, yet emerging, understanding of Indigenous paradigms, I considered the risk involved in inappropriately operating, however unintentional, from the paradigm. Would I potentially cause more harm than good, both in the process, as well as in the knowledge generated? Further, I questioned whether situating the study within an Indigenous paradigm, at this place in my journey, is a form of cultural appropriation, again, potentially causing more harm than good. Next, as my first research study in which I am in the role of primary investigator, I considered whether I am ready to be an “interpreter” for both worlds (Indigenous and academic), beyond what is already required of me in operating from a Western paradigm. Lastly, I considered the paradigmatic belief system of the particular group of Virginia American Indian people who would become participants in the study. Given the centuries of oppression, discrimination, and marginalization experienced by Virginia Indian people, to what extent does an Indigenous paradigmatic perspective still guide the lives (individually and collectively) of this particular group of people? Concurrently, however, I also considered Wilson’s (2008) assertion, “Even though many Indigenous people may be removed from the practices of their traditional lifestyle, the underlying beliefs are nevertheless carried on” (p. 94).

Additionally, in thinking through in which paradigm to ground the web of inquiry, I considered the research question underpinning the study: What is the meaning of health and healing among Virginia American Indian peoples in the context of a reservation-based, non-federally funded health clinic? Inquiring about meaning suggests interest in subjectivity, an interest in understanding the lived experiences of the lives of people connected to the phenomenon of interest. Inquiry into the lived experiences of people recognizes the presence, and celebration, of a multiplicity of realities, rather than an objective truth, “out there,” waiting to be discovered. Lived experiences, however, do not happen in a vacuum. Lived experiences are relational, they occur as we engage in relationships, relationship – with people, ideas, spirits, and the context the surrounds us, including natural, social, cultural, historical, and economic spheres. After much reflection, I decided against grounding this dissertation research in an Indigenous paradigm, and, instead, chose to situate the study within a constructivist worldview.

Although situated in a Western paradigm, there seem to be several parallels in the philosophical assumptions that underpin constructivist and Indigenous paradigmatic perspectives. Both constructivist and Indigenous paradigmatic perspectives assert the presence of multiple realities that are socially and experientially based, local and specific in nature, and dependent for their form and content on the persons and groups holding the constructions. Both perspectives assert that we come to know about reality through being in relationship, and both recognize the cyclical nature of coming to know about reality. However, as parallel lines may run closely together, they never intersect; accordingly, I recognize the distinctness of the two paradigms.

While being in relationship is essential to the co-creation process in both constructivist and Indigenous paradigmatic perspectives, in the constructivist paradigm, the relationship itself

is not the focus of the knowledge generation process, but rather a means to the end, that being the focus is on the co-created “truth.” Whereas in an Indigenous paradigm, the relationship involved in the co-creation of “truth” is valued as much as, or perhaps more than, the “truth” itself. As Wilson (2008) explains, “[in an Indigenous paradigm] reality *is* relationships or sets of relationships... Reality is not an object but a process of relationships . . .” (p. 73). It makes sense, then, that methodology in an Indigenous paradigm is grounded in relational accountability.

Constructivist and Indigenous paradigms also differ in the ways in which the two paradigms conceptualize the term *subjective*. Subjectivity is the epistemological positioning of several Western-informed paradigmatic perspectives, such as constructivism (Guba & Lincoln, 1994) and radical humanism (Burrell & Morgan, 1979). Subjectivity is also foundational to Cordova’s (2007) conceptualization of an Indigenous epistemology. However, subjectivity in the two belief systems is not conceptualized in the same light. Given the centrality of relationality in an Indigenous worldview, Indigenous philosophy does not recognize human beings on an individual level, but in relation – in relation to human beings, to place, to ideas, and spirits. “Human beings do not exist as isolated solitary being. They exist, except in rare and unusual circumstances, as social entities” (Cordova, 2007, p. ?). Therefore, the subjective nature of an Indigenous epistemology is not individualistic, as is characteristic of Western informed conceptualizations of subjectivity, but rather collective. An Indigenous conceptualization of a subjective epistemological position differs from that of a Western view that conceptualizes subjective as personal and individual. While constructivist and Indigenous paradigms share several common philosophical assumptions and values, it must be remembered that these two paradigms are unique and distinct, grounded in two different philosophical traditions. These



distinctions have implications for the selected methodological approach and design that will be presented in Chapter 3.

### **Theory**

Paradigms, with their corresponding set of philosophical assumptions, are the fertile ground in which theory takes root, and theory informs and shapes the inquiry process, namely methodology and research design. The philosophical assumptions that underpin a constructivist paradigm influence two similar, but distinct, theoretical perspectives – social constructionism and social constructivism. In seeking to understand the richness and fullness of the lived experiences of Virginia American Indian peoples concerning the meaning of health and healing, the role of context is paramount and cannot be ignored. Sociohistorical events addressed earlier in the chapter have largely influenced, and, arguably, continue to influence the lived experiences of Virginia American Indian peoples concerning health and healing. A critical social constructionist theoretical perspective (Witkin, 1995) seems well suited for taking into account the ways in which social, cultural, historical, and economic contexts shape and are being shaped by the stories of health and healing among Virginia American Indian peoples connected to the context of this study. Incorporating a critical element to the theoretical perspective allows for light to be shed on the ways in which seemingly immutable structural factors have, and continue to, contribute to constructions of health and healing. Additionally, a critical element explicitly acknowledges and integrates the role of values in all areas of the research process. Further, a critical social constructionist theoretical perspective allows for discussions concerning social and economic justice as pertaining to the phenomenon at hand, a hallmark of the social work profession (NASW, 2008). Further details of the selected design and methodological approach will follow in Chapter 3.

## Chapter Three: Methodology

The purpose of Chapter 3 is to present the methodology that informed the research presented in this dissertation, as well as the journey that unfolded in the process of exploring the research question: What is the meaning of health and healing among Virginia American Indian people in the context of a rurally located, reservation based, non-federally funded health clinic. In addition to presenting the methodology and identifying specific steps of the journey, this chapter also seeks to link the decisions that were made with the literature, providing justification for such decisions.

### **Methodology**

Arriving at a methodology that was responsive and accountable to the various relations involved in this dissertation research required considerable thought and creativity. Given my deep, but still emerging, intellectual understanding of an Indigenous approach to knowledge building, and out of a deep respect for participants, it was important that the methodology have a grounding in an Indigenous paradigm and approach to knowledge building. However, given that my academic journey has been housed within Western-informed institutions of learning, I also knew that I was expected to demonstrate specific skill sets based in Western inquiry systems. Therefore, a methodology that was flexible enough to honor both learning traditions was needed. What emerged is a methodology rooted in a Western paradigmatic structure and guided by Indigenous research principles.

This study is an emergent piece of qualitative research grounded in a constructivist inquiry paradigm and guided by Indigenous research principles. Although informed by different worldviews, and some variation in their subsequent ontological, epistemological, and methodological positioning, a constructivist paradigm and an Indigenous paradigm, in which Indigenous research principles are rooted, share a number of similar philosophical perspectives to work compatibly together. Both constructivist and Indigenous paradigms recognize and account for the existence of multiple co-occurring realities; honor the subjectivities of the inquirer and participants alike; and centralize the role of context. While both a constructivist paradigm and Indigenous principles informed many aspects of the methodology and design, based on the shared elements of their belief systems, Indigenous research principles, rooted in and informed by an Indigenous paradigm that centralizes relationship and relational accountability, offered guidance in engaging with participants and their respective communities in a relationally accountable way. In addition, the methodology also borrowed elements from constructivist research models when it seemed an element from the model was a particularly good fit in informing the design.

It's important to note here, that a paradigmatic perspective and principles grounded in a paradigmatic perspective guided the methodology and design, rather than a theory, as is more typically practiced. Because of working across two different beliefs systems, it seemed more relevant to operate from the most basic beliefs foundational to each belief system, rather than working from a more abstract place such as theory. So while a critical social constructionist theoretical perspective was identified and addressed in Chapter 3 as a relevant theoretical framework for guiding this dissertation research, to have more control over operating from two different worldviews, a paradigmatic perspective and principles emanating from a paradigmatic

perspective guided the methodology and design, rather than theory. The next section will present a fuller description of the methodological elements

### **A Constructivist Inquiry Paradigm**

A methodology grounded in a paradigm and theoretical perspective that recognizes social reality as “multiple, processual, and constructed” (Charmaz, 2014, p. 13), calls for an inquiry process that allows for the inquirer and participants to be intricately engaged in a collaborative, dialogic/dialectic process of meaning making. In this process, the inquirer and participants are engaged in a process of co-engagement, initiated by the inquirer, to investigate a wide array of perspectives, or realities, held by participants regarding the phenomenon of interest (Guba & Lincoln, 1989). The emergent approach to meaning making is not expert driven, but rather relies on a collaborative approach to mutually defining and understanding the phenomenon of interest. There is no fixed order, only directionality that allows for the unexpected to present itself (Netting, O’Connor, & Fauri, 2008), each step influencing the next, the design and structure emerging as the inquirer and participants interact together (Netting, et al., 2008; O’Connor & Netting, 2007). Values are central to the engagement process as values guide the design of the inquiry, (re)constructions of the phenomenon of interest, and relationships established in the process. “Every construction resonates to the values projected by the voice that shapes it” (Lincoln & Guba, 2014, p. 58). The context in which the phenomenon of interest is situated is critical to a constructivist inquiry process with the context implicitly and explicitly shaping the form, flow, and content of the process. Therefore, findings that emerge from the engagement process are held as tentative and representative only of the people involved in the engagement process, at the time of engagement, in the place and space of engagement.

The aim of inquiry based in a constructivist inquiry paradigm is the pursuit of a “continuously improved understanding and extended sophistication” of the phenomenon of interest” accomplished through the reconstruction or extension of existing constructions and/or the development of new constructions (Lincoln & Guba, 2014, p. 61). When the constructivist inquiry is skillfully implemented, all who participate in the inquiry process (inquirer and participants) ought to experience a raised consciousness regarding the phenomenon of interest (although a more organic approach to consciousness raising than the top down approach referred to in critical paradigmatic perspectives). When consciousness-raising is successful, everyone becomes smarter through engagement in the process concerning the focus of the inquiry, and, ultimately, an organically generated call toward action may emerge (Rodwell, 1998).

**Constructivist grounded theory.** Constructivist grounded theory is a systematic, non-linear, emergent approach to knowledge generation whereby participants and the inquirer are intricately engaged in a collaborative, mutual, and dialectic process of meaning making. While there is much controversy in the literature concerning what constitutes grounded theory work, Charmaz (2010) proposes a list of nine common strategies that are characteristic of grounded theory work across the grounded theory spectrum:

- 1) Conduct data collection and analysis simultaneously in an iterative process
- 2) Analyze actions and processes rather than themes and structure
- 3) Use comparative methods
- 4) Draw on data (e.g. narratives and descriptions) in service of developing new conceptual categories
- 5) Develop inductive abstract analytic categories through systematic data analysis
- 6) Emphasize theory construction rather than description or application of current theories

- 7) Engage in theoretical sampling
- 8) Search for variation in the studied categories or process
- 9) Pursue developing a category rather than covering a specific empirical topic (p. 11)

Rather than act as rigid steps requiring mechanical application, Charmaz (2014) asserts that grounded theory guidelines “describe steps of the research process and provide a path through it” (p. 16). Whether the intent is to engage in theory construction, the primary intent of grounded theory inquiry, or use select grounded theory strategies to complete a specific task, Charmaz (2014) holds that grounded theory strategies can be adopted and adapted to solve varied problems and to conduct diverse studies (p. 16). Charmaz challenges researchers to understand in which strategies they are engaging and explicitly identify the specific strategies employed during the process, rather than simply identifying the methodology as grounded theory (constructivist or otherwise).

**Positioning this research in a constructivist inquiry paradigm.** This dissertation research drew from several elements characteristic of a constructivist inquiry paradigm such as the recognition of a socially constructed reality; inquirer and participant engagement in a collaborative, mutual, and dialogic process of meaning making; emergent research design; acknowledgement of values; and centrality of context. These elements were central to the research design about to be introduced. While rooted in a constructivist inquiry paradigm, this dissertation research was not, however, a constructivist grounded theory study. Upon assessment, a constructivist grounded theory methodology did not seem to be responsive to the cultural context of this study, nor did there seem to be a goodness of fit for pragmatic reasons. For these reasons, in addition to grounding this study in a constructivist inquiry paradigm, the methodology also drew upon Indigenous research principles for guidance. That being said, this

study borrowed constructivist grounded theory strategies (Charmaz, 2010) where they seemed helpful for guiding the research design. In response to Charmaz's (2010) challenge, I will explicitly identify the specific grounded theory strategies employed during the inquiry process.

### **Indigenous Research Principles**

Although I chose not to ground this dissertation research in an Indigenous paradigm, I believed it was incumbent upon me to engage the Virginia American Indian community in a way that was culturally respectful and responsive. While identity and culture are complex and fluid concepts, it seemed that principles governing research with Indigenous peoples, although culturally specific, were based on a set of values that could be respectful of engagement with humankind at-large. So regardless of the extent to which a participant may have identified with his/her "Indigenous" or "Indian" identity and culture, operating from values of respect, reciprocity, and responsibility seemed universal enough to be applied to research with all peoples. Indigenous scholars have put forth various different, yet related, sets of principles concerning research engagement with Indigenous communities, I chose a set of principles proposed by Judy Atkinson (2001) to serve as guidelines for me in my engagement with Virginia American Indian people. Below is the set of principles proposed by Atkinson (2001) for engaging in a research relationship with Indigenous peoples:

- Aboriginal people themselves approve the research and the research methods;
- A knowledge and consideration of community and the diversity and unique nature that each individual brings to the community;
- Ways of relating and acting within community with an understanding of the principles of reciprocity and responsibility;

- Research participants must feel safe and be safe, including respecting issues of confidentiality;
- A non-intrusive observation, or quietly aware watching;
- A deep listening and hearing with more than the ears;
- A reflective non-judgmental consideration of what is being seen and heard;
- Having learnt from the listening a purposeful plan to act with actions informed by learning, wisdom, and acquired knowledge;
- Responsibility to act with fidelity in relationship to what has been heard, observed, and learnt;
- An awareness and connection between logic of mind and the feelings of the heart;
- Listening and observing the self as well as in relationship to others; and
- Acknowledgement that the researcher brings to the research his or her subjective self (as cited in Wilson, 2008, p. 59)

Atkinson (2001) asserts, “By incorporating these principles and functions into the research, the researcher honours the worldviews of Indigenous peoples and does so with ethical responsibility and sensitivity” (as cited in Wilson, 2008, p. 59). It was my desire to honor the worldview of the Virginia American Indian people in a way that was ethically responsible and sensitive. There is discussion among Indigenous scholars pertaining to whether “dominant system researchers” are able to understand Indigenous concepts foundational to respectful research with Indigenous peoples, such as the concept of relationality (Wilson, 2008, p. 58). Given that I was born, raised, and educated in a European/Western context, it’s a reasonable assumption that I do not understand Indigenous concepts to the depth that some scholars agree is needed to engage in respectful relationships with Indigenous peoples (thus, why I chose not to



ground this study in an Indigenous paradigm); however, I did not walk into this research engagement blindly. I trusted that the pre-existing relationships I had with the community with whom I partnered in the study, as well as prior and continual engagement with Indigenous scholars, elders, and peoples, had prepared me to engage in this web of inquiry as respectfully as was possible in my journey. When introducing and discussing the research design, I will explicitly identify the Indigenous research principles employed during the inquiry process.

The methodology of this dissertation research was informed by both a constructivist inquiry paradigm and Indigenous research principles. While similarities between the two paradigms, constructivist and Indigenous, that guide this methodology have been drawn, differences among the paradigms have also been identified. Therefore, in making design decisions, the Indigenous research principles served as a screen in which to consider the appropriateness of a decision connected to the constructivist inquiry paradigm, or in consideration of the use of a constructivist grounded theory strategy.

### **Study Design**

The study design about to be unfolded sought to answer the research question: What is the meaning of health and healing among Virginia American Indian people in the context of a rurally located, reservation based, non-federally funded health clinic. The study design was informed by an emergent approach to qualitative research that was grounded in a constructivist inquiry paradigm and Indigenous research principles. The aim of the study was to co-create a more sophisticated understanding of participants' experience related to health and healing. Given the emergent nature of a methodology grounded in a constructivist inquiry paradigm and Indigenous principles, the structure of the design emerged through sustained engagement with

the participants. Accordingly, where appropriate, I comment on the envisioned design, the way(s) in which it emerged, and the reason for emergence.

### **Gaining Access**

**Building Relationships.** Relationships are important to the knowledge building process in both a constructivist inquiry paradigm and an Indigenous paradigm. While establishing and maintaining good relationships is important throughout the inquiry process, being in good standing with the community of interest prior to engaging in a research relationship is particularly important to the feasibility of a research engagement. Shawn Wilson (2008) asserts:

A key to being included in Indigenous communities is not only the work that you have done in the past but how well you have connected with others in the community during the course of your work. The strength of your bonds or relationships with the community is an equally valued component of your work” (p. 81).

Previously I have addressed the nature of my relationship with Virginia American Indian people, particularly as related to the Mattaponi Healing Eagle Clinic (MHEC), the context for this study. During the several years of my involvement in the Virginia Indian community, and particularly MHEC, I have been intentional about building and establishing strong relationships. I have done my best to follow through with things I said I would do, and not promise to do anything that I foreseeably could not carry out. When not able to carry out something that I said I would do, I addressed it directly, apologized, and helped to identify a “plan B,” when appropriate. I have continually tried to be thorough and timely in following through with what I promised, going the “extra step” whenever possible. I have done my best to respect each person with whom I’ve come in contact, valuing their unique story and situation. I believe that through the years, a rich trust has developed between many MHEC service-users (and their families) and

me. I hope they would agree. The former Administrative Director has repeatedly stated that it is the trust I have developed with MHEC service-users (and their families), and indirectly with tribal leadership, that has made this dissertation research feasible. I believe that my sustained, authentic engagement with MHEC service-users (and their families) served as a foundation for a healthy research relationship, one in which people could honestly choose whether it was in their best interest to participate, and one in which participants felt safe to authentically engage with the process, or walk away if feeling unsafe. I am not suggesting that this trust was a panacea for potential risk (identified later in the chapter), but, rather, I suggest that trust allowed for honest conversations around participation and authentic engagement.

**Cultural Interpreter.** In research contexts that require the researcher(s) to work across boundaries of difference (e.g., race, class, culture), research wisdom suggests the use of a *cultural interpreter* to guide the researcher in gaining access across boundaries, as well as helping to ensure that the research is relevant and responsive to the community of interest. A cultural interpreter should be someone that the researcher knows and trusts and someone who is known and trusted in the context (Rodwell, 1998, p. 120). The former Administrative Director of MHEC, who was in the Administrative Director position at the onset of this study, served as the cultural interpreter for this study. Over the years of volunteering at MHEC the then Administrative Director and I had developed a strong, healthy working relationship. Similarly, the then Administrative Director was known to be well connected with Mattaponi tribal leadership, the tribal leadership responsible for MHEC, as well as with MHEC service-users. The cultural interpreter played a critical role in helping me gain access to Mattaponi tribal leadership to solicit approval of this study, as well as in shaping the tenor and structure of the study. However, due to issues of availability and distance, the cultural interpreter became less available

as the project progressed. The role of the cultural interpreter in this study though was nonetheless of great importance.

**Tribal Approval.** Typically, research with Native communities requires tribal review and approval (Fisher & Ball, 2003; Gachupin & Freeman, 2014). While the tribes in Virginia do not have an established internal ethical review board, I submitted an abbreviated research plan and a personal narrative to Chief Emeritus of the Mattaponi Indian Tribe for his review. The Mattaponi Chief Emeritus was responsible for tribal oversight of MHEC, so it was important to have his approval before continuing. My cultural interpreter helped me to navigate this process, by reviewing my materials, writing a letter of support for me addressed to the Chief Emeritus, and delivering my materials. Prior to beginning any engagement in the Virginia American Indian community in a research capacity, I was granted full approval in writing from Mattaponi Chief Emeritus, as well as from the, now, former MHEC Administrative Director.

**Foreshadowed Questions and Probes.** Foreshadowed questions and probes are typical element of grounded theory. In an emergent design, inquiry begins with an initial set of questions and probes identified by the inquirer prior to the beginning of the data collection process. Questions are related to concepts of interest in an inquiry; probes seek to explore specificities related to the questions (Rodwell, 1998). Accordingly, questions are broader in scope than probes. The initial set of questions remains constant throughout an emergent web of inquiry; however, probes shift in response to emerging constructions in order to explore ideas held by participants; test new ideas that emerged through engagement with participants; and explore, test, and refine emerging themes. Given the aim of this dissertation research – to co-create a more sophisticated understanding of participants’ experience related to health and healing, I selected the use of foreshadowed questions and probes, instead of a structured interview protocol, to

allow for flexibility in exploring various nuances of the emerging construction. The following are the foreshadowed questions and probes I used to begin the inquiry:

Question 1: Talk to me about what it's like to be healthy.

Probe 1: Look?

Probe 2: Feel?

Question 2: Talk to me about healing.

Probe 1: Practices?

Probe 2: Promotes?

Probe 3: Gets in the way?

Probe 4: Relationship between health and healing?

Question 3: Talk to me about what it's like to be unhealthy.

Probe 1: Look?

Probe 2: Feel?

Question 4: Tell me about your experience with the Mattaponi Healing Eagle Clinic.

Probe 1: What led you to come (or not come) to MHEC?

Probe 2: Support your health?

Probe 3: Challenges?

In response to the iterative and emergent nature of the research design, probes shifted and changed throughout the inquiry process. For example, the probe concerning practices that support healing (Question 2, Probe 1), became more specific during the inquiry process to further explore, test, and refine ideas shared by participants. In one interview, a participant identified engagement in cultural activities as a practice that promoted healing; in future interviews, I

directly asked participants about the role of engaging in cultural activities in their lives as related to the promotion of healing.

### **Sampling and Recruitment**

**Inclusion/Exclusion criteria.** Mattaponi Healing Eagle Clinic serves American Indians and their families. While the vast majority of service-users identify as American Indian, there is a diverse representation of service-users based on “racial” grouping: people who identify as Virginia American Indians, people who identify as American Indians who descend from ancestors who originated from lands outside of what is now known as Virginia, people who identify as bi-racial, and people who identify as White. After much consideration, in consultation with my community consultants and committee, I defined the inclusion criteria as MHEC service-users who self-identify as American Indian – Virginia American Indian and otherwise, and who are 18 years of age and older. Exclusion criteria included people who are not MHEC service-users, MHEC service-users who are non-Indian, and MHEC service-users under the age of 18. Decisions concerning inclusion and exclusion criteria were difficult to make, as identity is fluid and complex, and my decision ultimately excluded people who were interested in participating, some people who are non-American Indian but very closely connected to the Virginia Indian community, and some who are American Indian but not MHEC service-users. The decision to include only people who identify as American Indian was guided by the research question that sought to understand the meaning of health and healing among Virginia American Indian people within the context of MHEC.

Sampling purposefully is key to the pursuit of a holistic construction of the phenomenon of interest (Rodwell, 1998). Pursuing a holistic construction of a phenomenon through the incorporation of multiple realities held by various people connected to a phenomenon is

representative of an Indigenous worldview that recognizes multiple realities, as well as honors an Indigenous worldview that values wholeness (Cross, 1997; Limb & Hodge, 2008; Little Bear, 2000). When striving to achieve a holistic understanding of a particular phenomenon, Patton (1980) suggests sampling for various types of cases: extreme or deviant cases (in search of the unusual, troublesome, or the enlightening), critical cases, politically important cases, typical cases (perceived as normal in the context), maximum variation cases, and/or convenience cases (Lincoln & Guba, 1985; Rodwell, 1998). Drawing on prior ethnographic work, two primary stakeholding groups – groups of people with a shared common interest in the phenomenon of interest, were identified at the onset of this study (Rodwell, 1998). One stakeholding group consisted of Virginia American Indian elders associated with MHEC, and the second stakeholding group consisted of groups of MHEC service-users based on self-identified tribal affiliation.

The study used a purposive sampling technique to identify and select 17 participants which comprised two primary stakeholder groups – Virginia American Indian elders connected to MHEC and MHEC service-users by tribal affiliation. Purposive sampling is an alternative type of sampling to the more commonly practiced random sampling whose goal is generalization. Purposive sampling serves “to expand the scope and the range of the discussion and subsequent co-construction” (Rodwell, 1998, p. 66). When investigating the values and realities of multiple participants “to expand the scope and the range of the discussion and subsequent co-construction” (Rodwell, 1998, p. 66), purposive sampling is necessary to intentionally identify participants whose perspectives may add to the sophistication and complexity of the co-construction (O’Connor & Netting, 2007). In purposive sampling, each successive participant is selected based on his/her potential to extend information already obtained, to obtain other

information that contrasts with what is already known, or to fill in gaps in the information obtained so far (Lincoln & Guba, 1985).

The status of “Elder” in American Indian culture is not solely conferred based upon one’s age. An elder is a person usually, but not always, older than the others in a family or community, who, while not elected or appointed, is widely recognized and highly respected for their wisdom and cultural and spiritual leadership (M. S. Sargent, personal communication, March 11, 2014). At the onset of the study, the cultural interpreter and I decided it would be most appropriate to begin the investigation by interviewing Virginia Indian elders first. This decision was supported by several reasons. (1) Time was of the essence. There were several elders whose voices and stories we believed would be an important contribution to the co-construction of the meaning of health and healing. The health of several of these elders was perceived as a possible barrier to participation, and exceedingly so if the invitation to participate was delayed. Connecting with the elders sooner than later was essential to having their voices represented in the co-construction. (2) Elders in Indigenous cultures are highly respected and hold a position of honor in the community (M. S. Sargent, personal communication, March 11, 2014). To first invite elders to participate in the study is respectful of the social position of elders in the community. (3) Intergenerational transmission of knowledge (from older to younger) serves as a primary method of teaching culture, history, language, and moral lessons in Indigenous cultures (M. S. Sargent, personal communication, March 11, 2014). Inviting elders to participate first is respectful of Indigenous methods of knowledge transmission. Recognizing that our lived experiences shape and are shaped by our understanding of the world, efforts were made to purposively sample along various lines of diversity.



The second primary stakeholding group was based on the self-identified tribal affiliation of MHEC service-users, to assess for potential commonalities, variations, and/or peculiarities of lived experiences among MHEC service-users based on their self-identified tribal affiliation. Currently, there are 11 state-recognized tribes of the Commonwealth of Virginia; however, not all tribes are represented among the service-user population. Similarly, not all MHEC service-users are associated with one of the 11 state-recognized tribes, as some service-users are associated with tribes whose ancestral origins are from lands outside of what is currently known as the Commonwealth of Virginia. Selection of participants by tribal affiliation was approximately representational to tribal representation among MHEC service-user population. Therefore, tribes with a higher number of service-users represented among the service-user population at MHEC will have a higher number of participants represented among the inquiry sample than tribes with lower service-user representation. Efforts were made to purposively sample along various lines of diversity.

At the onset of the study, I estimated the elder stakeholder group would include five participants, and the tribal affiliation group would include thirty participants, with the number of participants in each tribal affiliation group to range between three to seven, drawing a total of approximately thirty-five participants.

**Recruitment.** Recruitment occurred via several routes. The primary mechanism for recruitment was direct contact by the researcher. Recruitment occurred mainly by phone, and, in some cases, in a face-to-face engagement. In all cases, I using an IRB-approved script (see Appendix A), whereby I explained the purpose of the study and foreseeable expectations of participation, answered any questions, and invited the person of interest to participate in the study. In the instances where I did not have a familiar pre-existing relationship with a particular

person of interest, and where it would not have been culturally or socially appropriate for me to directly approach the person, an IRB-approved third-party recruitment script was given to a person with whom both me and the person of interest had a relationship (see Appendix B). If interested in being contacted by me to learn more about the study, the third-party recruiter solicited a consent to contact, written or verbal, determined by whichever was logistically possible (see Appendix C). I then contacted the person of interest directly. I also handed out a recruitment flier that contained my contact information to participants so they could share the flier with anyone they thought might be interested in participating (see Appendix D). Two participants heard about the study via word of mouth from people who had already participated in the study and contacted me to learn more about the study. In an effort to make a clear distinction between the study and medical care provided through MHEC, a flier was left on an information table at the Clinic, but recruitment did not occur during clinic hours.

For people interested in participating in the study, an in-person meeting was scheduled. The soon-to-be participant selected the location for the interview based on convenience to, and preference of, the soon-to-be participant.

**Description of the sample.** The sample for this study consisted of 17 participants. Refer to Table 4 for demographic information pertaining to participants' tribal affiliation, place of current residence, gender, and age. Perhaps one of the most salient factors to consider about participants is the collective age of participants. Ages of participants ranged from 45 to 79, with the majority of participants in the age range of 70-79. Age is a significant factor that largely shapes the life experiences of participants and their subsequent perspectives represented in Chapter 4. The distribution of age in the sample is representational of the distribution of age among MHEC service-users.

Table 4

*Demographic Characteristics of Participants (n=17)*

	Number of participants (n)
<b>Tribal affiliation*</b>	
Chickahominy	6
Chickahominy Indians Eastern Division	1
Mattaponi	4
Pamunkey	1
Rappahannock	4
Upper Mattaponi	0
Non-Virginia Indian	3
<b>Place of current residence</b>	
On one of the two Reservations in Virginia (rural)	3
Ancestral lands (rural)	10
Rural areas on lands that are not reservation lands nor specifically cited ancestral lands	3
Urban	1
<b>Gender</b>	
Male	6
Female	11
<b>Age**</b>	
18-24	0
25-29	0
30-39	0
40-51	2
52-61	2
62-69	6
70-79	7
80 or older	0

\*Tribal affiliation was based on self-identification. The total *n* represented in the 'Tribal affiliation' section of the table exceeds the total number of participants. Several participants identified their tribal affiliation as more than one tribe. Therefore, tribal representation was recorded for each tribe that a participant self-identified. For example, if a participant self-identified as Pamunkey and Mattaponi, the person was counted in the tally for both Pamunkey and Mattaponi respectively.

\*\*Ages were grouped according to life events connected to particular ages. For example, 40-51 is on the footstep of being senior citizen; 52-61 is beginning senior citizen; 62-69 is beginning Social Security and Medicare benefits; the age groups 70-79 and 80 or older seem like symbolic age groups in the aging process.

You might remember that at the outset of the study, I initially estimated the sample would include 35 participants. With a total sample of 17 participants at the conclusion of the data collection phase, it is clear that the sample is significantly lower than that initially estimated. During the data collection phase of the study, several unforeseeable circumstances and events

influenced the sample and the sample selection process. These unforeseeable circumstances and events included an unseasonably high number of winter storms; the passing on of several people in the Virginia American Indian community; controversy concerning the, then, recent publication of an unauthorized resource about one of the tribes; and a delayed start to the shad fishing season due to Virginia's late winter. These circumstances and events affected the sample and sample selection process in the following ways. At the onset of the study, I estimated the elder stakeholder group would include five participants; however, at the conclusion of the data collection phase, two elders (n=2) participated in at least one interview. Given the small sample size for the Elder stakeholder group, I decided to collapse the two stakeholder groups (i.e. Elder and Tribal Affiliation) into one group. Second, the Tribal Affiliation group sample is considerably smaller in number than initially estimated (n=15 v. n=30, respectively), however, the sample is still fairly representative of tribal affiliation of MHEC service-users.

In addition to the unforeseeable circumstances and events identified above, the lower than estimated sample size is also due, in part, to a slightly overly ambitious read of the community context. A sample of 17 participants seems to methodologically fall short when compared to the goal of 35 participants often recommended for reaching the point at which no new information is being added to the emerging construction (Rodwell, 1998). However, when considered in light of the context of the study, 17 participants told a different story. Both the cultural interpreter and participants were surprised upon learning that "so many" people had participated in an interview. The context did not seem to support the estimation. Further, the unforeseen circumstances and events constricted the sample pool; thus, limiting the degree to which maximum variation could be pursued.

## **Data Collection**

Data was collected using *qualitative methods* grounded in a constructivist paradigmatic perspective and Indigenous research principles. Suited for research that seeks to explore a topic about which little is known, qualitative methods generally are person-centered (rather than variable-centered), allow for an “insider” perspective (rather than outsider perspective), are holistic in nature (verse particularistic), are contextual (rather than decontextualized), and allow for an exploration of depth (rather than breadth) (Padgett, 2008, p. 2). Further, qualitative methods grounded in constructivist paradigmatic assumptions created a space for meaning making that is contextualized and localized. Specifically, qualitative methods informed by Indigenous inquiry principles provided a way of engagement with participants that was responsive to and respectful of their culturally nuanced ways of knowing and being in the world. The methods of data collection were used: (1) a quantitative participant information survey, and (2) a qualitative “conversational approach” to in-depth, semi-structured interviews) (Kovach, 2010).

**Participant information survey.** The participant information survey was a brief survey meant to collect selected quantitative information about participants as related to the context of the research question (See Appendix C: Participant Information). Information solicited included: tribal affiliation, gender, age category, religion/spiritual practice, form of health coverage. The participant information survey was used to take inventory of characteristics related to maximum variation. It was also used in creating a collective description of participants in their role as characters in the narrative presented in Chapter 4.

**A conversational approach to data collection.** A conversational approach to semi-structured, in-depth interviews was used to collect qualitative data relevant to the research

question. Kovach, Carrierre, Montgomery, Barrett, and Gilles (2015) assert that different Indigenous scholars, “the world over,” have proposed the use of a conversational approach to gathering knowledge in Indigenous communities (p. 18). A conversational method is “a dialogic approach to gathering knowledge that is built upon an Indigenous relational tradition” (p. 18). A conversational approach is used in Indigenist research to facilitate the telling of stories.

**Wave I of data collection.** Two waves of interviews took place. The first wave of interviews occurred during March 2015 and April 2015. A total of fifteen interviews (n=15) occurred with seventeen participants (n=17). At the request of four participants, two of the fifteen interviews (2 of 15) occurred with two participants. Interviews occurred at locations selected by participants and varied greatly, including at the residence of homes, in a private space at the local library, in a church, at restaurants, and in a car parked in the parking lot of a supermarket. The length of interviews ranged between thirty-seven minutes and two hours, with the average length of time around one hour and thirty minutes; however, most interview engagements, were approximately three to four hours in total duration with several participants inviting me to share a meal with them either before or after the formal interview, or serving me tea and dessert before or after the formal interview.

Prior to the commencement of all interviews, I engaged in a process of informed consent with each participant (See Appendix G: Informed Consent Form). Some participants wanted to review it on their own and some wanted to walk through it with my guidance. In all instances, I stressed the fact that their decision to participate, or not, in the study was in no way linked to their care at the Mattaponi Healing Eagle Clinic. In all instances, I asked if there were any questions, and answered all questions that came up. All people who participated in the informed

consent process signed the informed consent document. Sixteen of the 17 participants gave written consent to audio record the interviews.

All interviews were conversational in nature. The conversation was guided by four primary questions that remained consistent throughout all seventeen interviews; an initial eleven probes shifted and changed throughout the knowledge gathering process in response to participant narratives and the collaborative process of meaning-making (See Appendix F: Interview Questions and Probes). To begin the co-construction process, interviews were initially more open-ended in nature and broadly explored participant experiences, beliefs, feelings, and practices concerning health and healing, “uncovering” constructions held by the various “knowers.” This process is known as hermeneutics, whereby constructions are successively disclosed through dialogic engagement between the inquirer and participants whereby all parties are equal contributors to the process (Kovach, 2010; Lincoln & Guba, 1985, 2014; Rodwell, 1998).

In some models of research, such as grounded theory, once initial constructions have been identified, the inquirer engages with participants in a manner known as dialectics whereby competing constructions (conflicting, contradictory, or non-isomorphic) among participants are juxtaposed and examined, in ways intended to move the constructions toward some common consensual construction (Lincoln & Guba, 1985, 2014; Rodwell, 1998). In seeking to co-create a narrative of participants’ understanding of health and healing that captured nuances and variations in perspective, I had initially intended to engage in a dialectic process with participants. However, engaging with participants in a dialectic way felt uncomfortable to me as the inquirer, as it did not feel respectful of my relationship with participants.

During the data collection process, I was a mid-thirty-something-year-old woman; the participants were, for the most part, my elders. At various points in the inquiry process prior to engaging in the dialectic element of knowledge gathering, I experienced discomfort in taking what seemed to me to be an assertive and/or authoritative role (e.g. in pressing to schedule an interview, or in facilitating the informed consent process), but I always tried to walk humbly and respectfully through the process. But when I began to engage in the dialectic process of bringing awareness to potentially conflicting or contradictory ideas, either internal to the participant's construction or in juxtaposing participant constructions with other emerging constructions, I often perceived a discomfort experienced by the elder. After much reflection in my reflexive journal, I sensed the discomfort was not only in being made aware of the contradiction or conflicting idea, but also in a potential violation of cultural norms (i.e. Native, rural, southern) around intergenerational interaction. As an inquirer, I could learn to engage in the tension often associated with the consciousness raising process, but I did not feel as though it was respectful of my pre-existing relationships with the participants to engage in a dialectic process that often felt confrontational and disrespectful.

Trusting my observation and inferential feelings, I scaled back, but did not abandon, the dialectic process. Interviews continued to be hermeneutic in nature, drawing from the same set of four questions to open space for exploring newly identified constructions. Probes, however, became more specific, used to test emerging constructions, as well as to explore identified gaps in the emerging constructions. When appropriate, I gently explored conflicting, contradictory, and/or non-isomorphic constructions, although engagement in a dialectic process was used sparingly. Individual interviews concluded when all foreshadowed questions and probes appeared to have been explored, information became redundant, or when the participant or



researcher, for various reasons (i.e. researcher or participant fatigue), called the interview to a close (Rodwell, 1998).

Prior to the conclusion of each interview, I summarized the main topics of discussion that occurred during the interview and asked each participant if the recounting sufficiently captured the ideas they intended to convey. Each participant was asked if there were any new ideas, or clarification/correction of already addressed ideas, he/she would like to add. The formal conversation drew to an end with asking each participant if there were any questions that they felt I was missing in seeking to gather a holistic understanding of the meaning of health and healing. In the spirit of relationality and reciprocity, I presented each participant with a gift bag that included a handcrafted ceramic mug made by a local non-Native artist, a box of tea made by a Native American-founded company, and a bundle of tobacco prepared in red cloth. When possible, preliminary analysis of interview material was performed after each interview to assess for any potential patterns of meaning within the interview and across the data set; any new information that needed follow-up; and any gaps in the emerging constructions the need follow-up.

In May 2015, following the conclusion of the first wave of data gathering, I experienced a major life event that temporarily halted my engagement in the research process. Between January 2016 and July 2016, all interview audio files were personally transcribed verbatim. During August 2016 and September 2016, the full set of transcripts were reviewed three times, providing an opportunity for me to (re)familiarize myself with the breadth and depth of the content of the stories (Braun & Clarke, 2006), informally observe possible patterns within and between the stories, and identify potential gaps within and across the stories in need of further follow-up.

**Wave II of data collection.** Because of the pause in in the research process, it seemed a second wave of interviews was needed to assure that the first wave data remained relevant and worthy of analysis and to bring the discussion up to the present in light of a significant event that had occurred in the Virginia American Indian community during the pause in the study – the Pamunkey receiving federal recognition. The following questions guided Wave II of interviews:

Question 1: Talk to me about anything new that may have happened since our interview that has influenced the way you think about health and healing. Events? Ideas? Beliefs? Attitudes?

Question 2: Talk to me about what federal recognition means to you in relation to health and healing.

Wave II of data collection occurred October 2016 though December 2016. Eleven of the original total 17 participants were found to be available to participate in the second interview. Those who were available continued to represent the original dimensions of the desired maximum variation.

Wave II interviews were much shorter in duration than Wave I interviews, ranging in time from 17 minutes to one hour, with interviews averaging 40 minutes. The same two questions guided all nine interviews. I transcribed all interviews verbatim directly following each interview. Transcripts were informally reviewed following each interview for possible patterns within and across the interviews; however, it was not the intention of Wave II to allow for probes to emerge in response to emerging constructions as they did in Wave I. While I was/am incredibly grateful for participant prolonged engagement in the study, gifts were not given during Wave II.

## **Rigor**

Rooted in a constructivist inquiry paradigm and Indigenous research principles, rigor in this study must be flexible enough to account for a methodology that is emergent, iterative, and relational. It must account for a methodology where subjectivity and values (of the researcher and participants) are acknowledged for playing an integral part in shaping the meaning-making process. Rigor in this study must account for findings that are contextual and localized. Rigor associated with this study must account for an assessment of the trustworthiness of the product, as well as the relational accountability of the process. This section will address the various activities that were put in place prior to the commencement of the study, and practiced throughout the study, to serve as a guide in pursuing trustworthiness and relational accountability in my research endeavors. The following elements and activities were used to attend to rigor in the study: 1) Relational accountability, 2) Locating one's self, 3) Reflexivity, and 4) Prolonged engagement.

**Relational accountability.** When engaging with Indigenous inquiry principles that are grounded in a paradigm that is relational, engagement in a process that adheres to relational accountability is essential. Wilson (2008) asserts, “Right or wrong; validity; statistically significant; worthy or unworthy: value judgments lose their meaning. What is more important and meaningful is fulfilling a role and obligations in the research relationship – that is, being accountable to your relations” (p. 77). Respect, reciprocity, and responsibility are “key features in any relationship” (p. 77), and serve as the foundation of a series of questions Weber-Pillwax (2001) asserts a researcher must ask when engaging in an Indigenous paradigm. I’ve chosen several of the questions proposed by Weber-Pillwax (2001) to guide my consideration of the ways in which relational accountability is upheld in the study. For example: How do my methods

help to build respectful relationships between the topic that I am studying and myself as a researcher (on multiple levels? How can I relate respectfully to the other participants involved in this research so that together we can form a stronger relationship with the idea that we will share? My reflexive journal and peer review sessions served as spaces in which I explored the ways and degree to which an environment of respect, reciprocity, and responsibility was created during the study, as well as listened to and tried to implement shifts that were needed.

**Locating one's self.** While not commonly practiced in Western research, even within many types of qualitative research, locating one's self is foundational to Indigenous research. "It is our opinion that one of the most fundamental principles of Aboriginal research methodology is the necessity for the researcher to locate himself or herself" (Absolon & Willett, 2005, p. 97). Writing about one's self and positioning one's self at the onset of one's work is an opportunity for the researcher to clarify her/his perspective on the world. This is important as "we can only interpret the world from the place of our existence" (Kovach, 2009, p. 110). Grounded in a relational ontology and epistemology, location is about relationship to "land, language, spiritual, cosmological, political, economical, environmental, and social elements in one's life" (Absolon & Willett, 2005, p. 98). Locating one's self is important because it says, "This is just my view" (Absolon & Willet, 2005, p. 105). "The only voice I can represent is my own and this is where I place myself" (p. 99).

The prologue included at the beginning of the dissertation is an attempt to locate myself in relation to my family, geographical and cultural upbringing, knowledge orientations, the natural environment, and the community which is engaged in this research, all as related to the context of the study. Narratives regarding personal location as related to the topic at hand are

also incorporated at various strategic junctures throughout the dissertation in an effort to uphold rigor associated with locating one's self.

**Reflexivity.** Qualitative research, particularly the kind informed by constructivist and Indigenous principles, acknowledges the role of researcher subjectivity in the inquiry process (Davies & Dodd, 2002; Kovach et. al., 2015; Padgett, 2008; Rodwell, 1998; Charmaz, 2014; Wilson, 2008). Although there are differing perspectives regarding the degree to which subjectivity should influence the inquiry process, there seems to be agreement around the belief that researchers should be engaged in a process whereby personal subjectivities are accounted for, and consideration given to the ways in which subjectivities influence the inquiry process. The practice of reflexivity provides a way for researchers to take account of personal subjectivities and the role they play in the inquiry process.

Rodwell (1998) defines reflexivity as “the ability of the human mind to turn back on itself, and therefore know that it is knowing” (p. 262). Reflexivity involves a “reflective self-examination” (Davies & Dodd, p. 286) of personal biases, interests, positions, and assumptions, and how they influence the inquiry process (Charmaz, 2014). Reflexivity provides a space for the researcher to explicitly bring her/himself into the inquiry process, as, “A reflexive stance informs how the researcher conducts his or her research, relates to the research participants, and represents them in reports” (Charmaz, 2014, p. 344).

Regularly maintaining a *reflexive journal* chronicling my personal journey through the research project provided a space for me to process through and record a variety of information about myself and the inquiry process (Lincoln & Guba, 1985; Rodwell, 1998). Reflective conversations with the pages of my reflexive journal allowed me to explore “possible meanings from what [was] happening in relation to [my] values and interests” (Rodwell, 1998, p. 105).

Ultimately, journaling provided a space for catharsis, for reflection upon and consideration of the ways in which my values and interests may be impacting the inquiry process, and for speculation about growing insights (Lincoln & Guba, 1985).

In addition to regular maintenance of a reflexive journal, I also engaged in regularly scheduled formal *peer review and debriefing* with my committee, as well as informal peer review with fellow peers. Peer review sessions, formal and informal, provided a space for methodological guidance, as well as a cathartic outlet (Lincoln & Guba, 1985), both of which were important in assisting me in bounding my subjectivity (Rodwell, 1998), exploring aspects of the inquiry that might otherwise have remained “implicit” in my consciousness, testing emerging hypotheses; developing and testing next steps in the emerging methodological design; and processing emotions and feelings regarding the inquiry (Lincoln & Guba, 1985, p. 308).

Another reflexive activity I engaged in regularly was consulting the writing of Indigenous scholars and/or engagement in various other avenues for further learning about Indigenous ways of knowing and being in the world. Working in a cross-cultural setting, I knew/know it was/is important to be held accountable to Indigenous scholarly traditions, as well as Western; however, for various reasons, my committee did not include an Indigenous scholar. Further, the progressively ill health of my community consultant, as well as the passing of elders with whom I was in relationship, presented a situation where I had limited opportunities to be held accountable to Indigenous scholars and knowledge-keepers. Therefore, I regularly consulted the writings of Indigenous scholars and/or attended events where I could learn more about Indigenous ways of knowing and being in the world. I used these engagements as an opportunity for reflection, considering the ways in which the design of the study, as well as my engagement in the study, “checked out” in relation to an Indigenous worldview. While the study was not

grounded in an Indigenous worldview, I was/am still relationally accountable to Indigenous ways of knowing and being in the world, as well as to the American Indian participants in my study. I used my reflexive journal, as well as peer review sessions, to process through my learning and the ways in which this learning could (and could not) play out in the study.

**Prolonged engagement.** Prolonged engagement is the investment of sufficient time in the context of the research to achieve certain purposes such as learning the “culture,” testing for misinformation introduced by distortions either of the self or of the respondents, and building trust (Lincoln & Guba, 1985, p. 301). Rodwell (1998) asserts that prolonged engagement “increases the probability of credible findings, including learning about the working, living, and interacting patterns of inquiry participants in their environment by being in the environment over time” (p. 260). Prolonged engagement allows a trusting relationship between participants and the researcher to develop, important for the sake of relationship building during the inquiry process, as well as increasing the motivation for honesty and authenticity in the engagement process (Padgett, 2008).

The five years of engagement with Virginia American Indian peoples, particularly in the context of the Mattaponi Healing Eagle Clinic (MHEC) prior to any involvement in a research capacity, was invaluable. The prolonged engagement prior to engagement in a research capacity provided time to build trust with Virginia American Indian peoples; become familiar with their localized culture, including language; and learn about the context in which the study is situated. Prolonged engagement was instrumental in receiving tribal approval to engage with MHEC service-users in a research capacity, cultivating support for the inquiry from MHEC service-users, informing the research questions and shaping the research design, soliciting participation, authentic engagement on behalf of participants throughout the inquiry process, knowing how to

field certain interview responses and questions, and particularly in interpreting meaning. As my gatekeeper and cultural interpreter said, this research project would not have been feasible without having built trust and rapport with MHEC service-users and Clinic and tribal leadership during the years prior to research engagement. Narrative accountings of my relationship with Virginia American Indian communities, particularly in the context of MHEC, incorporated throughout the dissertation allows for a transparent assessment of prolonged engagement.

### **Data Analysis**

In emergent research, it is important to differentiate between informal and formal data analysis. Throughout the knowledge gathering process, I was continually engaged in an iterative process of knowledge gathering and informal analysis. Field notes, expanded field notes, audio recordings and my reflexive journal were reviewed on an ongoing basis for loosely-knit patterned responses or meaning within and across interviews, competing constructions, and gaps in the data in need of further investigation. Informal analysis allowed me to test emerging constructions in subsequent interviews and gave me clues about the relevancy of the questions and probes guiding the interviews. Formal data analysis began once interviews were complete and all audio recordings were transcribed.

**Inductive thematic analysis.** Inductive thematic analysis was used during the formal data analysis process to identify, analyze, and report patterns (themes) within the data (Braun & Clarke, 2006). The goal of the formal analysis was to provide a rich thematic description of the entire data set, seeking to identify and examine the underlying ideas, assumptions, and conceptualizations that shape and inform the themes, as well as theorize the relationship among the themes (Braun & Clarke, 2006). Throughout the analysis process, I was not interested in truth-telling (positivist leanings) nor creative-writing (preference-based rather than data-based),



but rather I sought to create a narrative that provided a best order to capture the greatest meaning, such that all voices were honored (M. K. O'Connor, personal interaction, October 6, 2016).

Before moving on to a description of the strategies employed in the formal analysis process, it is important to address the difference between inductive and deductive analysis.

Given the context-embedded nature of an emergent research design informed by constructivist guidelines and Indigenous principles, an inductive data analysis approach, rather than a deductive approach most characteristic of positivist and postpositivist research, was employed. "Just as the design unfolds in the context, so, too, do the results of data analysis" (Rodwell, 1998, p. 59). Inductive analysis begins from the bottom up, starting analysis in the data and moving from the specific toward the general, with the construction of theory as a product of the analysis process. In inductive analysis, theory is developed independent of preexisting parameters, it is informed by, or grounded in, the data from which it emerged. Deductive analysis, on the other hand, begins with the abstract and moves toward the specific, whereby data is analyzed through the lens of an existing theory (Boyatzis, 1998).

Inductive and deductive theories differ in their role and function. Inductive theory, particularly the type rooted in a constructivist inquiry paradigm, seeks to tentatively tell a story concerning the phenomenon of interest that is bound within the limits of the time and context of the investigation (Rodwell, 1998, p. 154); whereas deductive theory is derived for the function of prediction, control, and/or explanation of a phenomenon (Rodwell, 1998). The thematic analysis strategies employed in this study sought to identify a full distribution of themes woven through participant stories relating to the construction of a grand narrative concerning the meaning of health and healing among Virginia American Indian people connected to the Mattaponi Healing Eagle Clinic in the second decade of the twenty-first century.

The inductive thematic analysis plan for this study borrowed from the phases of thematic analysis proposed by Braun and Clarke (2006). Phase 1 of the thematic analysis included familiarizing myself with the data. I personally transcribed all interviews, which provided a space in which to become familiar with the data. After all interviews were transcribed, I reviewed the full set of transcripts three times to become familiar with my data. Because Wave I interviews were transcribed months after the interviews occurred, referring back to the entry in my reflexive journal that corresponds with the date that each interview occurred was helpful in connecting with my frame of mind during the data collection process, as well as to review loosely identified connections I was picking up on during the data gathering process. While re-familiarizing myself with the data, I made notes in my reflexive journal concerning initial ideas about the analysis. Each interview was assigned a unique identifier.

It's important to note that I did not use a qualitative data analysis software program, but rather used a combination of tools for analysis including customizing analysis templates in Microsoft Word and using note cards to organize codes into themes and sub-themes. While multiple tools for analysis were used, an electronic audit trail of each piece of raw data was established in the process of analysis. Refer to Appendix H for excerpts from the four electronic files that were used in the analysis process to track the progression of data from concrete through abstraction

Braun and Clarke (2002) identify Phase 2 as generating initial codes, which involves “coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code” (p 87). Rather than develop new codes, a framework established by the emerging interview protocol guided my initial step of coding. I created a table that included each of the four questions, as well as corresponding various probes that emerged during ongoing

engagement with participants. Refer to Appendix H, Step 1. As I read through each transcript, I collated segments of the raw data corresponding to the question/probe-informed code identified in the table. It is important to note that each segment of raw data was not directly collated to the question/probe-informed code that solicited the response, but rather to the questions/probe-informed code most closely represented in the segment of data. Because the framework was created based on the questions and emerging probes, not the responses, the framework was unable to accommodate the full spectrum of responses. Accordingly, a ‘Not Sure, Yet’ category was created in the framework to catch all segments of data that did not “fit” into any of the question/probe-informed codes in the framework. Each segment of data was tagged with the unique identifier of the respective interview from which the segment of data originated, as well as the line number connected to the data segment’s location in the transcript. Therefore, each segment of data could be traced back to the respective interview from which it originated and exact line in the interview, even as it moved through more abstract groupings during later phases of analysis.

During the initial stage of Phase 2, a document with the initial analysis framework was created for each interview, whereby there is a document with collated data specific to each interview. After all twenty-four interviews (15 Wave I interviews and 9 Wave II interviews) were collated according to the framework, collated data across all interviews was combined. A table was created for each question/probe-informed code, and data that had been collated to that particular code in each respective interview was transferred to the newly created table. Therefore, all segments of data that had been collated to a particular question/probe-informed code in a particular interview were transferred to a table corresponding to the respective code.

In the next stage of Phase 2, probes present under each of the questions were collapsed into one respective code. For example, the ‘Spirituality’ probe under Questions 1, 2, and 3 were collapsed into Code 22: Spirituality. Refer to Appendix H, Step 2. Combining data by code and collapsing codes across questions served as the first steps toward abstraction. Collapsed codes and their corresponding combined data segments were reviewed, assessing the degree to which the data segments were related to the respective code, shifting around data segments that did not appear to be connected with the initially assigned code. Analysis of each code was then performed, identifying patterns within each code and assessing for variability within the identified groups. Each code and group was then defined. Refer to Appendix H, Step 3. Each data segment was tagged with the name of the code to which it had been collated.

Phase 3 of formal analysis was marked by organizing codes into potential themes and sub-themes, eventually corralling all data under the identified themes and sub-themes (Braun & Clarke, 2006). The process of organizing codes into themes and sub-themes was done “by hand,” with the name of each code written on a notecard and the notecards being organized into piles based on perceived patterns and relationships among the codes. Groups of codes were reviewed, assessing the degree to which the codes were related (i.e. shared a theme), shifting around codes that did not appear to be connected to the group to which they were initially assigned. Refer to Appendix H, Step 4. Once groups of codes were temporarily stable, the corresponding data segments were collated under the respective theme and sub-theme to which they had been assigned. During this phase of analysis, I began thinking about the relationship between codes, sub-themes, and themes (Braun & Clarke, 2006), recording observations and thoughts in my reflexive journal.

Phase 4 of formal analysis entailed reviewing the potential themes identified in Phase 3, assessing whether the themes worked in relation to the coded data segments and the entire data set, and refining the themes as necessary (Braun & Clarke, 2006). A conceptual framework of themes and the relationships among the themes was created.

Once a conceptual framework was created, I began to consider how to present the themes and relationship among the themes in a narrative format.

### **Inquiry Product**

A case study report was used as a way in which to report the shared collaborative construction that was derived from the inquiry process (Guba & Lincoln, 1989). The case study report can be thought of as a grand story constructed from individual stories. The primary goal of a report is to create understanding, to enable readers to see how the constructors made sense of the construction, and why (Guba & Lincoln, 1989; Rodwell, 1998). According to Guba and Lincoln (1989), the best way to generate understanding is to create a case study report that provides “a vicarious experience of the situation, allowing the readers to ‘walk in the shoes’ of the local actors” (p. 223). This narrative type approach to the case study report is congruent with Indigenous ways of sharing information and facilitating understanding. While writing the case report, I was continually engaged in an iterative process of analysis and writing, constantly considering the ways the data “fit” together in light of the emerging case report narrative and re-arranging groups of data as needed.

In the case report, participants chose to be identified with their thoughts and stories in different ways. Some participants chose to use their legal names, some chose to use their Native names, and some chose to create a pseudonym. All of these options were IRB approved, and

participants went through a multi-layer decision making process. This will be further addressed in the following Human Subjects Protections section.

### **Human Subjects Protection**

Although a discussion concerning ways in which to protect participants and the community involved in this dissertation research appears toward the end of a chapter about research design and methods, it in no way suggests that human subjects protection was an after-thought. Rather, consideration of human subjects protection was a topic for reflection and conversation at the very beginning stages of planning the study and continued throughout the inquiry process. Ethical considerations concerning protection of participants and their respective communities in research-based relationships, particularly in a cross-cultural context, are varied and diverse. Several of these considerations (i.e. paradigmatic placement, culturally-responsive research design, etc.) have been addressed previously. This section will specifically address an assessment of risk involved in working across boundaries of difference, particularly in a setting that serves as the primary health care center for a community, and strategies for mitigating the risk such as confidentiality, privacy, and informed consent. This section also will address institutional review board approval.

The Virginia Commonwealth University Institutional Review Board approved the study on February 20, 2015. The Virginia American Indian community does not have an established tribal institutional review board, nor are they a part of a consortium with an institutional review board, so I did not engage in a tribal institutional review process. However, with guidance from my cultural interpreters, I submitted a formal request to Mattaponi Indian tribal leadership, including a personal narrative and my interest in partnering with the Mattaponi Healing Eagle

Clinic in a research capacity, as well as a summary of the research question and research design. I received a letter of support from Mattaponi Indian tribal leadership in July 2014.

The involvement of people (i.e. service-users) in a research study who receive medical care at the place which serves as the primary context for the research study, specifically a health clinic that serves as the primary source of medical care for an overwhelming majority of its service-users, runs some inherent risk. To mitigate these risks, the following efforts were taken. The focus of the study explored the meaning of health and healing which may be perceived as low risk to jeopardizing one's care than, say, an evaluation of MHEC services. In an effort to reduce coercion to the greatest extent possible, recruitment did not take place during MHEC clinic hours. Further, the then Administrative Director refrained from involvement in recruitment activities. During the informed consent process, I stressed that a person's decision to participate in the study, or not, was in no way connected to their care at MHEC. The informed consent also clearly stated that participation in the study was in no way connected to one's medical care at MHEC. Refer to Appendix G.

As for anonymity of research participants, research has shown that it is not uncommon for participants to want their names associated with their particular story or contribution to the inquiry process, particularly when systemic societal efforts to silence certain voices have limited or prohibited a group of people from telling their stories. For example, in a study that sought to explore the views of Indigenous peoples in twenty remote communities in five countries regarding their respective concepts of health and well-being (Nettleton et al., 2007), all 35 respondents preferred to be acknowledged by name, and, in some cases, respondents requested their position in the community also be included. Participants of this study were given the option to remain anonymous (in which case they were given the opportunity to select a pseudonym) or

to have their “real” names associated with their contribution to the inquiry. Overall, nine participants chose to use their legal name and eight chose to use either their Indian name or a pseudonym. Documentation of participants’ decision of how they preferred to be identified with their contribution to the study was included in the informed consent. Refer to Appendix G. During follow-up interviews, I revisited the question pertaining to how participants would like for their identification to be connected with their story. In follow-up, three participants shifted their response, either making changes to their “real” name or changing their pseudonym; however, no one changed their decision about whether they wanted to remain anonymous or not. Regardless of whether a participant chose to remain anonymous or have their “real” name associated with their story, all participants were given a unique identifier which was used at all stages of the inquiry process prior to the final write up to ensure confidentiality was upheld as long as possible, in the event that any participant who initially chose to use their “real” name decided later to remain anonymous. The decision to use unique identifiers until the final write-up protected the identity of all participants (to the greatest degree possible) by giving each participant multiple opportunities throughout the life of the study to change their minds.

Prior to any knowledge gathering activity with participants, I engaged in a process of informed consent with each participant. Given that elements of informed consent have been addressed elsewhere in this Chapter, the only unaddressed information has to do with the signature required. The informed consent form solicited four signatures: (1) consent to participate (or not); (2) consent for the interview to be audio recorded (or not); (3) consent for researcher to contact participant with any follow-up questions and/or future opportunities related to the study (or not); and (4) consent for real (legal) name to be connected to one’s story (or not). The form contained multiple signature lines under consent for real (legal) name to be connected



to one's story (or not), so this question could be revisited multiple times during the study. Refer to Appendix G.

## **Limitations**

Given the emergent nature of the design, shifts and changes in the design in response to engagement with participants and the context of the study were expected. However, some changes in the context could not be reconciled and resulted in two particular study limitations: limited maximum variation and reduced sample size, and the absence of a formal member check process.

**Limited maximum variation and reduced sample size.** When seeking to understand a phenomenon in all of its complexity, it is critical to purposively sample along various axes of diversity to explore the breadth and/or depth of perspectives held among the population of interest regarding the phenomenon of interest. In this type of inquiry, sampling typically concludes when interviews provide no new information to the emerging construction (Rodwell, 1998). Rodwell asserts that the point at which interviews cease to provide new information often occurs around interview thirty-five. As addressed earlier in Chapter 3 (section "Description of the Sample"), within the time period allotted for data collection for this study, various unforeseen circumstances and events occurred that limited both the axes of variation among the sampling pool and the total sample size. While tribal affiliation was largely representative of tribal affiliation among MHEC service-users, maximum variation along other lines of diversity was compromised. For example, the late shad-fishing season inhibited certain MHEC service-users from participating because of shad fishing responsibilities. It seems reasonable to suspect that perhaps the meaning of shad fishing for these MHEC service-users might have added a dimension of variation to participants' construction of health and healing that is not otherwise

represented. Age was also another dimension with limited variation. While the age of participants was largely representative of MHEC service-users, for various reasons, MHEC service-users older than eighty years of age were unable to participate in an interview. Given the way age seemed to be a factor in participants' construction of health and healing, it seems reasonable to suspect that perhaps elders may have added a dimension of variation to the construction that is not currently represented. Similarly, all participants were older than forty-years-old, and the construction is missing the voices of Virginia American Indian people under the age of forty. However, this is a limitation of the sampling pool, rather than the sample, because nearly all MHEC service-users were older than the age of forty. Relationship with nature, seasonal cycles, and age are dimensions along which diversity was limited.

**No formal member-checking process.** In community-based qualitative research, engagement in sustained member checking activities with participants is commonly practiced to ensure that the emerging construction is, indeed, rooted and grounded in the words and ideas of participants (Guba & Lincoln, 1985; Rodwell, 1998). Member checking is particularly important when engaging in cross cultural work to ensure the researcher is accurately understanding and interpreting ideas as intended by participants. Informal member checking was utilized throughout this study to explore, test, and refine emerging constructions during the data collection process, however, in the interest of time, only an informal member check of the conceptual framework was conducted with one participant. While the participant's feedback influenced successive iterations of the conceptual framework, the absence of a formal member check is a limitation of this study.

While this dissertation will draw to an official close without a formal member check, efforts are already in motion to continue this dissertation work at the community level. An event

is being planned with MHEC service-users to share findings and to solicit feedback about the findings. Future iterations of the conceptual framework and narrative will be informed by MHEC service-user feedback. This event will also solicit feedback from the community about their thoughts and ideas for preparing and distributing findings to participants and the wider Virginia American Indian community (if desired by participants) in a way that is relevant and meaningful to the community.

## Chapter 4: Findings

This is a story about responsive and responsible health and healing among Virginia American Indian people in the context of a reservation-based, non-federally funded health clinic. To be clear, this story is not an evaluation of the Clinic, but rather a story about what responsive and responsible health and healing looks like from the perspective of a variety of participants who are service-users of the Clinic. The voices in this story weave together a narrative of health and healing that is rich and complex. Broadly, the story tells of the ways in which various dimensions are woven together to create a holistic picture of health and healing that is responsive and responsible to the voices represented in the story. Specifically, the story tells of how physical processes, mental and emotional processes, spirituality, social relationships, access to resources, and contextual factors are uniquely related to health and healing. The richness of the story is informed and shaped by the diverse life experiences of participants.

### **Setting the Scene**

This story begins on a warm September day in 2009. Driving through the countryside, watching the first rays of the morning sun kiss the groomed rows of vegetation, I couldn't contain the excitement and wonder swelling inside. Today would be my first day as a volunteer at the Mattaponi Healing Eagle Clinic (MHEC), a rurally located, non-federally funded, volunteer-run health clinic serving American Indians and their families. Located on the Mattaponi Indian Reservation in rural King William County, Virginia, the commute from

Richmond provides ample time for admiring the scenery – beautiful open skies, rolling farm fields, weathered barns on the horizon, and thinking. Without fail, the drive away from the busyness of the city gently chisels away the closed exterior I unknowingly assume in the city and melts away the informality of a concrete jungle. With each mile outside of the city, my breath becomes fuller and deeper.

On this warm day in September, as the city residue melted away, an excitement and wonder swelled inside, and, if I'm honest, sheer nervousness. "What would the reservation look like? Was it as large as the reservations I've seen in Arizona? What would the clinic be like? What would the patients be like? What tasks would I be assigned? Would I insult or hurt a patient by unintentionally violating a cultural norm? I was most worried about this.

As I dropped down the steep hill into the Mattaponi Indian Reservation, my heart immediately fell in love. The Reservation was small, much smaller than any I'd seen out West. As I drove around the paved road that encircles the Reservation, I observed lush, green trees, humble houses of various structures, yards with vegetable gardens, and a beautiful river bordering the east side of the reservation. As I admired the river to my right, I was surprised to see a small, quaint church perched on top of the hill overlooking the Mattaponi River. At this point I was not, yet, aware of the role of the Baptist church in the lives of the Mattaponi Indian people, or in the lives of other Virginia Indian people. As I came around a bend in the road, on my left I spotted the community center in which the Clinic is held. The community center is an addition onto a renovated schoolhouse, where Mattaponi children received an education until the mid-1900s. I pulled into the grass parking lot and parked in the shade of a large tree. My heart beat quickly as I got out of the car and walked toward the community center door. I took a deep breath and opened the door.

Fast forward seven years, seven years which have rolled by with quickness. Since that first day of timidly pushing open the door of the Mattaponi Healing Eagle Clinic, I've greeted patients, provided lunch for volunteers, coordinated clinics, and developed rich relationships. I've helped plant gardens, clean houses, attend pow-wows, and participate in spiritual ceremonies. I've mourned the loss of loved ones, celebrated the birth of babies and grand-babies. I've admired the beauty of sunrises and sunsets while visiting with friends on their porch, shared meals, given gifts, received gifts, and even rode on the back of a four-wheel dirt bike driven by a teen on a terrifying ride through the woods and around the Reservation. I have been fortunate to listen to hundreds of stories and see almost as many pictures.

There's one particular story from the first day though that has stayed with me over the past seven years. MHEC operates on a first come, first served basis. Some patients arrive at the clinic nearly an hour before the clinic opens in order to get their name on a list. Patients wait in a community room until they are called into a small room where they go through an intake process with a medical student volunteer. When I say "small," I mean small – about a six-foot by ten-foot room containing a row of filing cabinets with Tupperware containers stacked on top holding medical charts, shelves of first-aid supplies, two small tables, four chairs, and a scale. After going through intake, patients return to the community room where they sit at long rows of tables while socializing with other patients (their friends and family) until they are called back to see a medical professional. The whole process from signing one's name on the list to seeing the medical professional and picking up prescriptions, if needed, can be as fast as an hour or as long as three to four hours, depending upon how many patients are on the sign-in sheet.

As I observed how the Clinic operated that first day in September, I was appalled to see two patients going through intake at one time. That's four people (two patients and two student

volunteers) in a six-foot by ten-foot room filled with furniture and supplies. No curtain separated the two patients simultaneously going through intake, not that a curtain would do much in the way of concealing one's voice. "What about privacy," I thought. "This is certainly in violation of HIPPA standards!" "This is compromised patient care!" But as I watched closely, patient after patient coming out of the intake room sat down at the long row of tables among other patients (their friends and family) and shared with others their "condition." Similarly, as patients came out from seeing the medical professional, they would share with one another their discussion with the medical professional. I observed this clinic after clinic. I have to admit, seven years later I still feel a little uncomfortable with the lack of privacy, by Western standards, but as a Mattaponi woman recently told me, "Amy, there is healing in the sharing."

Having set the scene of this narrative with a personal story regarding my relationship with the Mattaponi Healing Eagle Clinic and the people it serves, it is now time to let the participant voices do the talking. What follows is a story of responsive and responsible health and healing among a particular group of Virginia American Indian people as informed by the voices of participants.

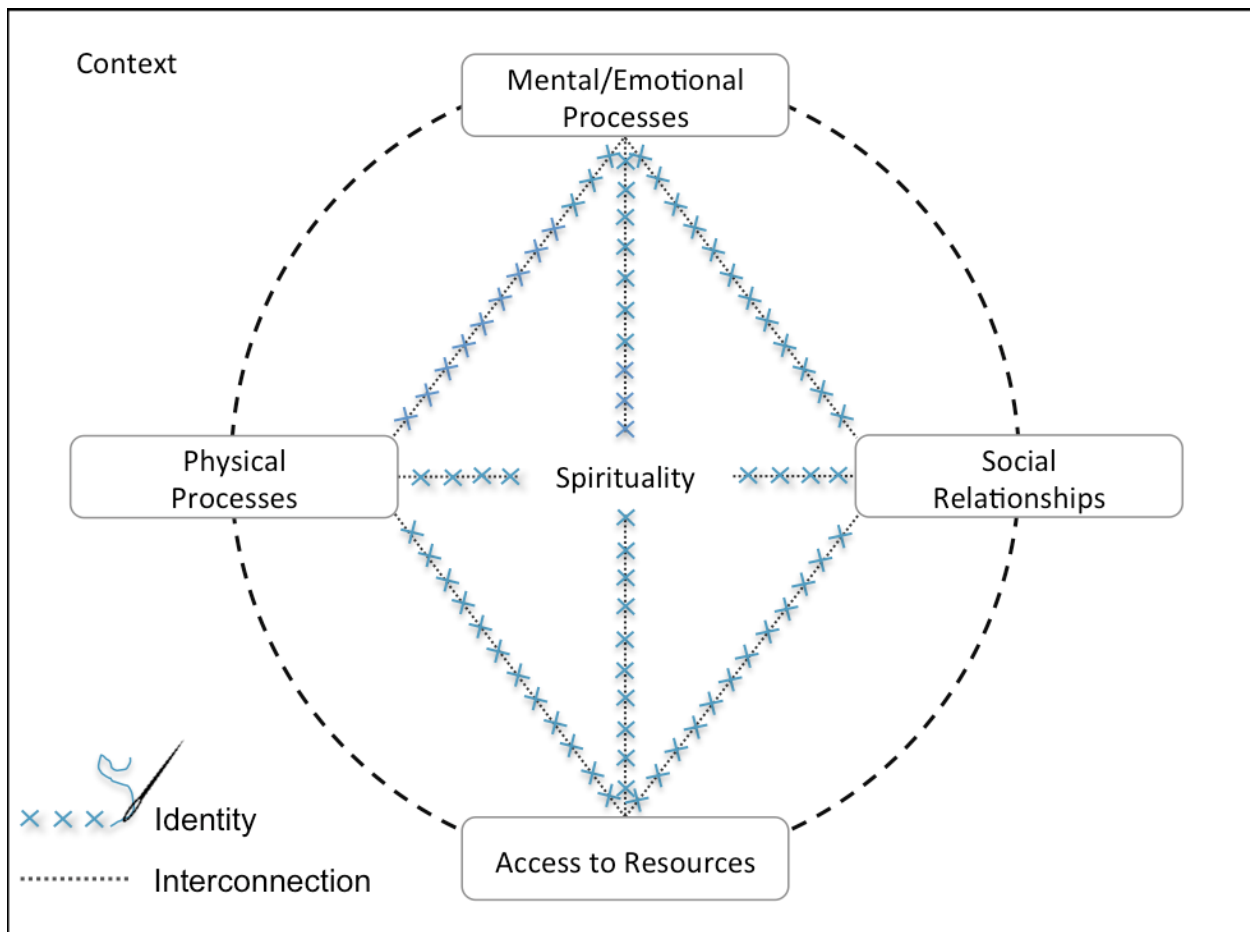
The narrative that emerged from participant stories concerning the meaning of responsive and responsible health and healing will be presented in two forms: a visual representation and a written narrative. A conceptual framework is a visual representation of an idea that highlights the components of the idea and relationship among the components. The written narrative provides a more in-depth look at each of the components represented in the conceptual framework, as well as a more in-depth look at the relationship among the dimensions. Both the conceptual framework and narrative are informed by the themes and sub-themes that emerged through an inductive thematic analysis of participant stories. First, we will take a look at the conceptual

framework that serves as a visual representation of the various dimensions of responsive and responsible health and healing. After presenting and describing the framework, we will then move on to the written narrative for a more in-depth look.

### Conceptual Framework

Seven dimensions comprise the conceptual framework: spirituality, physical, mental and emotional, social relationships, access to resources, context, and the interconnection among the dimensions. Refer to Figure 2.

Figure 2. Responsive and Responsible Health and Healing



Spirituality is at the core of participants' conceptualization of responsive and responsible health and healing. Spirituality governs every part of participants' personal being, as well as the



ways in which participants interact with the world. Surrounding spirituality, physical health has to do with the ways in which participants saw physical pain and disease as related to health and healing. Mental and emotional health refers to the ways in which participants saw thoughts and feelings are related to health and healing. Social relationships have to do with the various relationships in which participants have been engaged throughout life and the ways in which these relationships promote or act as barriers to health and healing. Access to resources refers to the ways in which their access to basic needs (e.g. housing, utilities, food) and health-related resources (or lack thereof) were related to health and healing. The dotted lines that cross-connect each of the four dimensions located on the circle represents the way participants envisioned the four dimensions as interconnected. The dotted lines that cross-connect each of the four dimensions located on the circle show that spirituality is not bound within the space of the diamond formed by the cross-connecting lines, but rather spirituality encompasses the whole space within the semi-permeable circle. The context encircling the five dimensions has to do with circumstances and events participants saw as related to health and healing. The dashed line that provides the structure of the circle represents participants' sense of permeability, symbolizing the interconnectedness of context with each of the four dimensions positioned on the circle, as well as the interconnection between the context and spirituality. While not a dimension in and of itself, personal and collective identity is a significant element woven through the seven dimensions. Identity is represented by the cross-stitch overlaid on the dotted lines to demonstrate the way identity is interwoven through the dimensions. The circle on which the four dimensions are positioned represents the way participants saw health and healing as a balance among the dimensions. The circle also represents the way they envisioned health and healing as cyclical, continually striving to maintain balance among the dimensions. Health for

participants referred to a balance among the dimensions, unhealthy occurred when there was an imbalance among the dimensions, and healing involved continual engagement in various interventions and activities that help to bring about balance among the dimensions.

### **The Narrative**

With the visual representation of the story of responsive and responsible health and healing to guide us, we will move on to the telling of the story. The inherent challenge in telling this story is how to present a narrative that is circular/cyclical in nature in a fashion that is linear. To begin, the narrative will introduce and discuss contextual elements addressed by participants. This discussion is meant to create a setting for participants' construction of health and healing, as conceptualized by participants, allowing for a deeper and richer understanding of the construction derived from participant stories based on the context that gives shape to the construction.

As contextual factors are external forces that influence participants' construction of health and healing, spirituality is the internal anchor that grounds the construction. After contextual factors are introduced and discussed, the narrative will address the dimension of spirituality that anchors the structure of responsive and responsible health and healing.

Following spirituality, the narrative will focus on each of the four dimensions that comprise the structure of responsive and responsible health and healing. The narrative will first address the physical processes dimension followed by the mental and emotional processes dimension, as it seems discussions in the other two structural dimensions often refer to physical and mental and emotional processes. Next, the narrative will address the social relationships dimension, highlighting the important role of social relationships in the lives of participants as related to the ways in which they thought about health and healing. Finally, but no less important

than the other three structural dimensions, the narrative will address the ways participants saw access to resources, both basic needs and health related resources, as related to health and healing.

With the six dimensions of the conceptual framework addressed, the interconnected nature of health and healing (i.e. seventh dimension) will be discussed. The narrative will conclude with a conversation about the way participants envisioned the role of balance and imbalance in their conceptualization of responsive and responsible health and healing.

Following the presentation of the narrative that is informed by the voices of participants, Chapter 4 will conclude with taking a look at *learnings*, which are take-away lessons that I derived from the narrative.

### **Context**

The contextual elements that will be addressed in this section include a collective introduction to the characters whose voices inform this narrative; historical factors identified by participants as important to the backdrop of the narrative, including the role of federal recognition; as well as a look at the complexities surrounding the cultural identity of participants.

#### **Participants: A Portrait**

This narrative is informed by the voices of seventeen participants. In any narrative, it's important to have a sense of who the characters are. This section will introduce the characters, addressing several characteristics that seem important to the narrative of the story: participant tribal affiliation, age, perception of health, and identity.

**Tribal affiliation.** Participants represent a variety of Virginia American Indian tribes including *Chickahominy*, *Chickahominy Indians Eastern Division*, *Mattaponi*, *Pamunkey*, and *Rappahannock*, as well as non-Virginia Indian tribes whose tribal names will not be identified

for purposes of confidentiality. All participants with non-Virginia Indian tribal affiliations are tightly woven into the Virginia Indian landscape as they have lived in Virginia Indian communities for decades.

**Age.** The collective age of participants is particularly relevant to this sample and their construction of responsive and responsible health and healing. For several participants, their age was an important consideration in their construction of health and healing. Several participants voiced that they had been giving considerable attention to their current living situation. Some participants living alone expressed concern about falling and not being able to access help. “It’s always in the back of [my] mind that here you are here by yourself and if something happens I might not have my cell phone on me or something like that” (Wewoka Adkins). Further, some participants living alone expressed concern about how long they would be able to live independently in their current place of residence:

I don’t want to leave home: I want to stay here. I know my children would let me come live with them but I don't want to do that. I want them to have their privacy. I would feel that I would be invading their privacy and I just don’t want to do that. I would rather be to myself. I mean it’s lonesome and all, but, I mean I would still rather be in my own home. And that’s some of the main things that are really bothering me at this point (Butterfly).

The natural aging process of the physical body was also on the minds of participants:

I told my daughter the other day, once you hit seventy, everything changes. Like a good example is I took a tumble down the stairs. It was not because I’m feeble. It’s just my foot slipped on the carpet and I took about three stairs in one fatal step and it took me about two weeks for the knee to heal with all the blood that was underneath the skin. If it

had been fifteen years ago, it would have been a day. You just remember that you are at a stage in life where you don't heal quite as fast (Dennis Hogge).

Similarly, given the natural aging process, participants also voiced concern about the increased difficulty in performing daily living activities. "When I was younger, you do lots of things you don't even realize it. You get older, it's harder to do those little things and if you're not well it makes it triple hard" (Lorraine Hedgeman).

In addition to the ways participants talked about their age as related to health and daily living, the age of participants also tells a lot about the historical hardships through which many of them walked and changes they have seen during their lifetimes. This will be evidenced throughout the narrative, as age is a thread that runs throughout several dimensions. Therefore, it is important to be mindful of the ways in which the age of participants shaped the perspectives shared in this narrative.

**Perception of health.** Participants held varying perspectives of their personal health. Some participants firmly believed they were not healthy. "I'm in *bad* health" (Elaine "Dancing Owl" Custalow). Others made light of their personal health by comparing it to the perceived health of others or to a perceived standard of health.

Sometimes I feel like I'm having poor health and then I'll look around me, at [my family], and I said I have nothing to complain about. My health is so much better than theirs. They have so much more things wrong with them than I do (Butterfly).

Some participants were learning how to manage a recent diagnosis/condition in order to maintain a certain level of healthiness. Others reported feeling healthy despite having a diagnosis.

I have good health, recently good health. Probably the one single factor now affecting my lifestyle more than any other is my diabetes because I have to be so careful about what I

eat, I've had to give up foods that I enjoy and love a different lifestyle as a result (Mac Custalow).

Some reminisced about the days when they were healthy. "I remember when I was healthy..." (Elaine "Dancing Owl" Custalow).

**Participant identity.** For the participants, identity was complex. In regard to identity, a common denominator among participants was their identity of being a Native person. While all participants shared a Native identity, however, what it meant to be a Native person varied among participants.

All over the United States, other Indian reservations, other Indian tribes and all, it's a survival thing. The survival is totally different. And that's what is with everyone as individuals are trying to survive in, in their own way. So thusly we are related and we are connected. But we're not totally one... Well, like here. I'm related to everybody here. But yet I'm still the individual of my own self because everybody has the desires to survive, and do the best they can, with what they've been dealt with. You know, whether it's you haven't been dealt with the wealth of someone else, you haven't been given the skills of someone else, and the knowledge of someone else. So it's all individual in that respect (Dorothy "Red Wing").

The personal and collective life experiences of participants seemed to influence the ways participants perceived their Native identity, and, often, the identity of their families. The perception of others concerning the degree to which they perceived one to "look Indian," and the degree to which one perceived one's self to "look Indian" seemed to be an influential factor in how participants experienced their Indian identity. For example, participants who grew up in an all Indian environment and perceived themselves to look different from the majority of the

Native people with whom they engaged on a day-to-day basis (i.e. having lighter skin color than those in their day-to-day environment) experienced their identity in a particular way that often presented certain challenges.

I remember asking, “Mama, why can’t I be dark like the other kids in school,” because they were beating the hell out of me...It was pretty tough sometimes being so light [referring to his skin color] being in an all Indian school. But it was the best memories I ever had, too” (Dennis Hogge).

Participants who “passed” as Native based on the color of their skin and strong tribal association talked about keeping quiet about a recent discovery of mixed race ancestry for fear of being hurt by what others may say.

I don’t talk about it. It isn't something we go around talking about because I know comments would be made and everything, and I just don’t want to get anything, you know, all stirred up and everything. Well, I don’t guess it would hurt their feelings, but it would hurt mine (Butterfly).

Some who identified their immediate family as mixed race talked about the ways in which love transcends the different skin colors represented among their family members.

Whether a person grew up in a Native environment also seemed to influence participants’ experience of their Indian identity. For example, one participant talked about his/her Indian heritage coming through his mother, but being raised in a non-Indian environment and not knowing much about his Indian heritage until later in his life when he married into an Indian family.

The first contact I had with a reservation was after I met [my spouse], came back here and met [spouse’s] folks and found out where [spouse] lived. In my readings, the Indian

culture kind of interested me, and I paid attention when I came back here (The Old Sailor).

One participant recounted the challenges and complexity around growing up in a Virginia Indian community but being unable to communicate with his family and how this lack of communication interrupted his ability to learn about his Native culture, as well as assume a Native identity.

Overall, however, participants talked about their pride in being a Native person broadly, and Virginia American Indian person more specifically. The conversation about their Native identity were closely aligned with conversations connected to federal recognition. Some participants described their Indian identity as something personal, “not needing to prove to the rest of the world who you are” (Dorothy “Red Wing”), while others desired federal acknowledgement of who they are as Native people. In addition to finding identity in their Indian identity, some participants also expressed pride in their tribal affiliation. “Eastern. We’re Eastern. Not Chickahominy. Chickahominy is Charles City. We’re Eastern Chickahominy. That’s why my [license] plates say ‘CIED.’ Chickahominy Eastern” (Dennis Hogge).

In addition, participants also told stories about how their identity extended beyond their Indian identity to include identity found in their faith, their role in their community, and their role in their family. Participants saw themselves as mothers, fathers, wives, husbands, daughters, sons, grandmothers, grandfathers, aunties, uncles, cousins, neighbors, friends, church members, and tribal members.

Having introduced the participants whose voices inform this narrative, various historical elements as identified by participants as relevant to their construction of health and healing will be explored.



## **Historical Context**

This section is an amalgamated story of the received and experienced histories of participants as related to the context of the narrative. The contextual elements were identified and informed by participants and are meant to add depth to an understanding of what responsive and responsible health and healing looks like to the group of Virginia American Indian people who participated in this study.

**Health of Native peoples pre-settler contact.** It's important to understand that prior to European contact, the Native people inhabiting this land were a strong and healthy people. Participants told of Native people who lived off the land, eating foods that grew in a natural environment, gathering nuts and berries, growing and harvesting vegetables and beans, hunting wildlife, and fishing in clean streams, rivers, and lakes. Participants told of Native people who did not suffer from illnesses and diseases that became present after European contact, largely because Native people did not have exposure to the disease and illnesses pre-contact. Participants describe Native people as a clean people, people who practiced cleansing. Participants describe the Native peoples inhabiting the lands prior to European contact as smart, very smart, living their lives "just fine" before the arrival of Europeans (Connie Laskowski).

History, well, as far as the Native Americans were concerned, we really had no health issues. Not, not, like you know, the illnesses and disease per se because we were never exposed to them. We believe in cleansing. We were a clean people, regardless of what it was thought, we were clean people. And we took care, and took the herbs and the care that they needed to take care of. Then when disease came along, well, wiped a lot of us out. And now, it's still wiping people out (Connie Laskowski).

**History, a euphemism.** In conversations with participants about the ways in which post-settler contact affected and continues to affect the health of American Indian peoples, the word *history* became a euphemism for the oppressive conditions that are a result of a history of colonization. Before we talk about the ways in which participants envisioned a relationship between health and history, it's first important to consider what history is a euphemism for, as informed by participants. We will begin with general references to the ways in which participants envisioned how Native peoples broadly were affected by European contact, particularly as related to health, and then jump to what history serves as a euphemism for in the past and current lives of participants.

As mentioned, “before the White man came here, all of the diseases that we have here today didn't exist” (The Old Sailor). Native peoples living on the land now known as the United States of America experienced good health. Europeans, however, brought with them a multitude of diseases that emanated from conditions of over-population, war, and famine in their home countries, soon wreaking havoc on Native peoples, wiping out large sections of Native populations. Europeans also brought with them food that was foreign to the bodies of Native peoples: white potatoes, white rice, white sugar. “We were eating what we were getting from the Europeans and our bodies were not created to eat some of that stuff, and so because of that, our bodies developed other diseases, diabetes” (Bonnie Sears). In addition to germs and foreign foods, Europeans also brought beliefs that differed from those held by Native peoples. One participant recounts,

The Native people were persecuted, uh, annihilated for their simple beliefs. They were not simple to the Native people but...to the incoming influx of influence, they weren't values, they were simple things...According to the White man, you came over here and

we weren't much above the animals that roamed in the forest and things like that. But they had to educate us and bring us to their thoughts and ways of life (The Old Sailor).

Participants also talked about specific references to history that have immediately impacted their lives and the lives of their families and communities. The collective age of participants is again important to keep in mind when considering the history which participants recall. Participants vaguely referenced, as well as explicitly told, of the oppressive conditions they have experienced throughout various times in their lives, as well as encounters with racism, discrimination and prejudice, both past and present. Participants told stories of being called a "red nigger"; not having been allowed to frequent certain establishments in nearby towns; having had to make purchases from local town establishments through the back door; having overheard a local establishment owner for which a participant worked told a visitor to the area, "There are no Indians in this area, only niggers" (Dennis Hogge); not having been allowed to ride the bus; having had to sit in the back of the bus; not having been allowed to attend public White schools; having been made to travel over a thousand miles to an Indian boarding school in order to receive an education past eighth grade; and having been denied health care; as well as stories of a spouse who as a child attended a Catholic boarding school where her long braids were cut off without parental permission; stories of growing up in poverty; and stories of long days of picking cotton as a youth to help provide for the family. "We were kind of like a close-knit group all the time, if you understand what I'm saying. At one time Indians just stuck with Indians because I guess the on-going feeling was that Whites didn't want you around" (Red Cloud).

Two particular events seemed to be on the collective memory of participants: state and local efforts to erase American Indians from the cultural landscape of Virginia, particularly by attempting to re-identify Virginia American Indian people as "Black," and the state's use of the

public school system as a vehicle to help achieve this agenda, particularly related to school desegregation. Prior to the early 1970s, Virginia Indian children attended local tribal schools. Although there were White teachers as well as Native teachers, and although the educational curriculum was largely Western/European influenced, children still received classes such as dancing, drumming, and regalia making, where they learned about their culture. Further, Indian children solely attended the tribal schools, so there was a sense of belonging as children shared a collective history and culture.

Until the early 1950s, tribal schools did not offer education past the eighth grade. Virginia Indian youth wanting an education past eighth grade had two options: attend a Black high school or leave their family and travel over a thousand miles to Muskogee, Oklahoma, to an Indian boarding school. “We didn’t want to go to [a Black school] because then you would have been considered Black” (Kind Heart), so most Virginia Indian youth who pursued an education past eighth grade left their families and communities to attend Bacone Indian College in Muskogee, Oklahoma.

I would say probably it was a mind-set of most of our tribal members as we grew up.

When you’re in school, you want to go to a Native school. You want to be amongst your own, so it was *years* that the only college [and high school] that our kids went to was Bacon [the Indian boarding school in Muskogee, Oklahoma] because it was an *Indian* college [and high school] (Red Cloud).

In the mid-1950s, two tribal schools united and began to accommodate Native youth past the eighth grade. This allowed Native youth the opportunity to stay in their communities. In the early 1970s, however, the state began integrating the Indian schools. A participant who was a teacher in one of the Indian schools at the time commented,

When they desegregated the schools, that took a lot out of teaching and learning for the children...and the [Native] children really had it rough going to school because they were picked on. They were called names, all different names. [Non-Native] children would make fun of [Native] children. And it was several years before the kids got where they really seemed to be comfortable with it (Glenda Chavis Adkins).

The experiences of participants related to education are clearly experiences in the collective minds of participants. A particular quote by a participant really captures the hardship of the times in which many participants grew up, related to both engagement with education, as well as engagement with non-Native communities in close geographical proximity to their Native communities. The quote is lengthy, but is important to understand the experiences of participants because these experiences are influential in shaping their conceptualization of responsive and responsible health and healing.

The people that think Native, grew up as Native. Now kids won't do that, going to an all-Indian school. Therefore all of us, and our mothers and fathers, all thought the same, pretty much the same way. The state did their best to beat that out of us and to stop thinking like Indians. Why aren't you like everybody else? Well three-hundred years we weren't allowed to go to any other schools. All of a sudden in '71, they wanted to take the school that had been an all-Indian school, forever, and they didn't put Whites in with us, they put Blacks in with us. That was kind of a slap in the face...I remember when I was back from Vietnam, my brother, they finally decided that if all they were going to do was put Blacks in the all Indian school, which is basically a way to say there are no Indians, they are all Blacks. I've heard people say that, "Oh there's no Indians." I remember working in a place in [nearby town] where guys came up and said, "There's

some signs back there saying Virginia Indians live around here somewhere, where do they live?" And I remember the man standing there said, "There are no Indians in this area, there's only niggers." There were two of us who were working for him. I said, "That's it." I turned my grease rag in and I said to my buddy, "Turn your grease rag in. We're gone." Never been back there since. It started in a way that you started to worry about what is so wrong about being an American Indian (Dennis Hogge).

Today, participants told of the ways in which they still experience racism, discrimination, and prejudice. Participants told about experiencing discrimination when accessing health care, with medical providers assuming certain things about them because they are Native. Participants told of feeling like they're the only group of people who are not supposed to be offended by racist or discriminatory acts.

We supposed to take it. You look how long the Redskins use that name. And they have been asked, they have, I mean all kinds of things have been done, and they don't change it, but it's a money thing, and they don't have to change it because of who they are. And that's wrong. I mean we have a right, too, you know? And I see all those little things, when you let them slide, just makes everything worse (Lorraine Hedgeman).

Participants recount the inclusion of Native people in certain spaces as mere tokenism.

Participants talk of the ways in which eastern Indians seem to fall in the shadows of "Western" Indians. Participants recount stories of still experiencing prejudice attitudes in local towns, but view the interactions as fairly "low key" given that "we're mostly assimilated" (Roth Summoth).

Participants talk about the ways in which treaty rights are still being threatened. Participants told about the sustained denial of their Indian identity by the U.S. federal government. Although the accounts of racism, discrimination, and prejudice manifest differently today than decades ago,

subtler in nature now than centuries and decades ago, participants talk about the ill intended acts being nonetheless painful. Overall, though, participants express that times are better for them as Native people today than they were centuries and decades ago.

### **Federal Recognition**

The topic of federal recognition brings the previous conversation about received and experienced histories related to oppression, discrimination, and prejudice into the present. Federal recognition also serves as a tangible example of the oppressive and discriminatory conditions faced by participants that largely shapes the current reality of participants. The issue of federal recognition, or lack thereof, is a thread that is woven through many aspects of this narrative.

Of the 11 Virginia Indians tribes, only one tribe, the Pamunkey Indian Tribe, has been extended federal recognition. Participants tell of how six Virginia Indian tribes have been engaged in a decades long battle to gain federal recognition. This study includes members of the Pamunkey Indian Tribe who have recently been extended federal recognition, members from tribes who are currently seeking federal recognition, and members of tribes who are not currently seeking recognition. So participants variously connected to the issue inform the narrative around federal recognition.

**Meaning of federal recognition.** Federal recognition holds various different meanings for participants. Some participants saw federal recognition as a means in which to access an assortment of social services perceived as needed to support the health of participants, as well as their communities. “And [when extended federal recognition] the federal government would somehow have to help take care of us better” (Dorothy “Red Wing”). Most of all, participants talked about how federal recognition would provide much needed health care for their people.

“The benefits like health care would help the Indian people” (Kind Heart). Specifically, health related resources referred to by participants in connection with federal recognition included access to affordable medications, medical practitioners, rehabilitation services, and health-related equipment. “So once we get help with the meds, then the healing will be a whole lot easier” (One Who Looks Out For Others). In addition to health care, participants also talked about the way federal recognition would help with providing educational benefits for youngsters, housing, and resources for the elderly and disabled. “I hope it’s going to mean more resources for those in need, the disabled especially, and the elderly, those who really can’t do for themselves” (One Who Looks Out For Others). However, participants from the one federally recognized tribe talked about the reality connected to accessing the social services identified by participants from non-federally recognized tribes. As one participant from the federally recognized tribe explains:

Well I haven’t seen much of what it’s going to do with health because the nearest health facilities to us is in North Carolina and Delaware, I believe, so either way it’s a five-hour drive if I have to go to the doctor, and most of us don’t have the appropriate funds for that, so, at this point, I see no health benefits to federal recognition with a five hour drive, one way. There is some talk Virginia *might* get a health clinic, so I’m not sure. The stories that I’ve heard are all hearsay...So I really can’t give you a clear answer on that because we have no Indian Health Services close by for us. They were talking about getting a bus and going out once a month, but that would still, that would be almost one-hundred dollars a person, just to go to the doctor, and gone all day...So I would be better able to answer that question if I had been able to get help, and so I’m not able to get help through them so, federal recognition has done nothing great in that aspect. But like I said,



if we get a health care facility in Richmond, it would be absolutely, it would be good, but we don't have it, so, I don't know how to answer you (Bonnie Sears).

Further:

I can get housing if I have *new* housing. The grants are all for newer housing. My housing is 1985, so I don't qualify at this point. Education, I haven't tried that. Maybe I'll use some of that and go back to school and finish up my degree. I don't know. I hope I don't sound bitter, because I'm not" (Bonnie Sears).

Even participants who identified the potential benefits connected to federal recognition and hoped their tribe would someday be federally recognized, there was still a recognition that federally funded benefits are at the discretion of the federal government. As one participant describes:

Look what's going on at Standing Rock right now...I mean, even if we got federal recognition, if it didn't suite the government to provide it, they'll take it away whenever it suites them. I mean, we're still the savages that have no right to own this country when it was discovered. That's how the government treats us. Any benefit that we got, or recognition that we get, it's only temporary and it's only good so long as it benefits the government (The Old Sailor).

In addition to access to social services, participants told of the ways in which federal recognition was connected to identity. For some participants federal recognition meant an acknowledgement of their Indian identity. "But I would *love* us to be federally recognized. I mean I am proud of being an Indian now, but I would be I'll say more so with the actual recognition" (Butterfly). Other participants talked about how their Indian identity was a personal thing, yet, still recognized the value in public acknowledgement of their identity.

Yes, [one's Indian identity] has to do with your self-esteem and your own pride in who you are, yes, yes it does. You don't have to prove to the rest of the world and all who you are. Yes. It's the acknowledgement, I guess, is what it would be called (Dorothy "Red Wing").

Yet, other participants directly challenged the whole system of federal recognition.

This will sound really bad and this is just how I feel, no other race of people in the United States needs the federal government to recognize them for who they are. Why should I as a Native have to have the federal government tell me who I am? That might sound embittered, it's really not, it's just the truth. When I was at a pow-wow, I had my booth up and I had somebody come up to me and ask me if I was a real Indian. And I said, "What's a real Indian?" And they say, "Oh one that has a federal card." Of course I have my federal card and I said, "Oh are you a real human being?" And they said, "What do you mean by that?" And I said, "Well if being a real Indian means I have to have a federal card, I guess being a human being you have to have cards for one of those, too, right?" And they got all upset and I took my federal card and I put it on the table and I said, "Yes, according to the government, I am counted and I am real." They said, "Well we've never thought of things that way." I said, "Well before you walk up and ask somebody if they're a real card carrying Indian, if they're federal, you need to understand how it feels."...This was a Native person. And they were all smiley when they were talking to me but when I made the comment, they got upset, and I can't help that they got upset, but that's how I feel. Federal recognition only means that the government now says that I am somebody...So any who, that's why I said, please don't think that I'm resentful, but, you know, like I said, why do I need the government to tell me who I am?...This is

our country. We are not foreigners here where we have to carry a visa to work and a green card and have a passport to live here...It's a big pain for a lot of people (Bonnie Sears).

In light of the history of oppression, discrimination, and prejudice endured by Virginia American Indian people (past and present), for some participants, federal recognition is an act of restitution.

I would love for us to be federally recognized because our tribe, not just our tribe, through the years, we have been through *so* much from years and years ago. I mean, even before I was born, but I mean things that I remember, you know, that we weren't allowed to do, places that we weren't allowed to go in, restaurants, you know, things like that, just like a lot of the African Americans weren't allowed to do. And a lot of times it just hurts (Butterfly).

Overall, participants talked about the extension of federal recognition being long over due. "I'd be glad for [my tribe] to get federal recognition. I'd really feel good. And I think about how *long* and how *hard* it's been for my people. Yep. Way over due" (Lorraine Hedgeman).

**Seeking federal recognition.** Participants of tribes who have been seeking federal recognition for decades talked about the process – describing the various avenues in which federal recognition can be pursued (i.e. Bureau of Indian Affairs and U.S. Congress), identifying the steps their respective tribes were taking toward federal recognition, and speculating perceived barriers to receiving federal recognition. Some participants identified internal barriers to federal recognition such as diminished collective interest among the tribe for federal recognition. Others talked about external barriers, primarily related to Congress. One participant saw the continual denial of recognition for her tribe as Congressmen who won't vote in support

of their tribe receiving federal recognition as “just feel[ing] good holding it over our heads” (Butterfly). Another participant attributed the continual denial of his tribe’s pursuit for federal recognition to “something else [always] tak[ing] priority over our bill and it get[ting] pushed back to the back burner” (Red Cloud). Yet another participant brought up the issue of casinos as a continual barrier to receiving federal recognition and speculated about how the concern over casinos may be smoke and mirrors for other unexpressed agendas.

You’ll hear [the Congressmen] bring up we might get a casino or something like that.

We’re not interested in casinos. We’re interested in the medical and the educational, the things of that nature... And the only thing that that means is they’re hiding behind the casino rather than com[ing] out and say[ing] what they really object to. They are saying the casinos but what the lawmakers are thinking about is the cost, the additional cost, and they have another agenda that they have promised [their] constituents. Getting the Virginia Indians federal recognition isn’t part of what they chose to support (Kind Heart).

Participants of the tribes seeking federal recognition also talked about the tasks in which they have been personally engaged in supporting their respective tribe in the process of seeking recognition, and feelings connected to the process of pursuing recognition. Participants talked about the emotional labor involved in the process. In researching and documenting her family lineage at her tribe’s request, one participant recalled the emotion involved in having to come face-to-face with some painful memories. Having recounted a particularly traumatic event that happened in her family, one participant commented, “People have no idea at all the things that some of the Native Americans have had to go through just with things that other people take for granted. But I guess that was having to do with the background for all of the ancestry line back. It brought a lot of those things back to memory” (Kind Heart).

Participants from tribes who have been engaged in a decades-long pursuit of federal recognition held various perspectives concerning whether they thought they would see federal recognition in their lifetime. Some participants expressed that their tribe would never get federal recognition. One participant felt as though his tribe probably won't receive federal recognition, and if his tribe does, probably not in his lifetime. "But see, I'm not really that anxious or got that much faith that we're going to get it, to tell you the truth, so, I mean if we do, I don't think I'll see it in my lifetime" (Wewoka Adkins). Others felt like their tribe would receive federal recognition at some point, but perhaps not during their lifetime. "So I feel that some day we will have federal recognition. I don't know if I'll be here to see it, but I feel like we will" (Butterfly). Some acknowledged that they might not see federal recognition personally, but hoped their children and grandchildren would see it. And others were hopeful that their tribe would receive federal recognition and hopefully during their lifetime. "We're hoping to see it in our lifetimes" (Kind Heart). Regardless of perspective concerning whether participants will see federal recognition in their lifetime, there seems to be consensus that extending Virginia Indian tribes federal recognition is way past due.

Like, federal recognition, now why is it taking so long when who saved their lives when they first came over here to stop some of them from dying? And what harm is it going to do them to give us federal recognition to our own land that they're immigrants in? It's just, it's way past time (Red Cloud)!

### **Cultural Identity**

Cultural identity seems to be an important contextual factor in participants' conceptualization of health and healing, as it shapes the ways in which they understand and engage with the world. A conversation about cultural identity is intimately tied to the previous

discussion about history and the role of oppression, discrimination, and prejudice in the lives of participants. One participant described culture in the following way: “Culture means a home” (Loyal Oak). This section discusses three particular historical events identified by participants that have threatened their cultural homes, and the ripple effects of these events on the cultural identity of participants and their respective communities. Perspectives on cultural identity vary considerably. While participants widely believed that traditional Native culture was/is threatened by the imposition of Western/European beliefs systems, the degree to which Virginia American Indian people still practice traditional American Indian culture varied considerably by participant, and in part by tribe. This section highlights the variability in perspectives.

There are three particular events that participants identified as being connected to the interruption of their people’s traditional beliefs and practices: original contact of Europeans, desegregation of tribal schools, and integration of tribal churches. One participant recounted how European contact interrupted the cultural beliefs and practices of his people.

I mean, you go back to the U.S. history, I mean, this tribe, this tribe right here and [name of tribe], [name of tribe], [name of tribe] and what have you, in the original contact with the White man, when [White man] came to settle the country, and [Native] way of life was impacted greatly by the White man...Downhill... I mean they started even back then. All this belonged to the Native people, and, the Native people withdrew back and gave the White man space, and the White man wanted more and more space, till [Native people] got corralled into reservations and they could no longer sustain themselves the way they used to. They were I guess forced in some ways to take on the not so good traits of the White man (The Old Sailor).

Participants also talked about the way in which desegregation of tribal schools deeply interrupted the continuation of traditional cultural beliefs and practices. Prior to desegregation, there appeared to be a cultural cohesion among Virginia American Indian people, "...The people that think Native grew up as Native, now kids won't do that, going to an all-Indian school. Therefore all of us, and our mothers and fathers, all thought the same, pretty much the same way" (Dennis Hogge). Following desegregation, however, the same participant went on to say, "The state did their best to beat [our cultural beliefs and practices] out of us and to stop thinking like Indians" (Dennis Hogge).

Similarly, participants talked about how the gradual integration of non-White people into tribal churches also interrupted the cultural identity of Virginia Indian people, however, it seems to a lesser extent than the desegregation of schools.

I remember when all the activities in this community, it was kind of centered around the church. You had socials, auxiliary organizations branching out from the church...and most of the church members were tribal members, way back. So it was one and all the same. I remember, and it hasn't been really that many years ago, that the church was [name of church] *Indian* Baptist Church. In the later years its been changed to [name of church] *Baptist* Church. And if you want me to be honest about it, some of the older heads still don't like it because the word *Indian* was taken out of it, but by having the word *Indian* in it, I realize *now* that kind of, it was sending that message that other races were excluded. And that is not what Church is supposed to be about (Kind Heart).

A participant from a different tribe similarly recalled, "I'd say over half the tribe went to church" (Dennis Hogge). As the churches became more integrated with non-Native people, however, it seems the central role of the church in each respective community has diminished, although not

disappeared. Participants also recalled how tribal churches still serve as venues in which to draw the respective Native communities together, but it seems to a lesser extent than years gone by.

In addition to generally referencing the ways in which European contact, desegregation of tribal schools, and integration of churches have impacted the cultural identity of their people, participants also recounted specific ways in which their personal cultural identity and the cultural identity of their people has been effected. Some participants talked about the way Virginia Indian people have mostly assimilated into mainstream society. "...most of our people have more assimilated into society" (Roth Summoth). Becoming assimilated was referred to by one participant as "falling into the White man's trap" (The Old Sailor) and another as "being White-ized". "I don't think anyone really practices much of the old ways anymore. My other brother used to say, 'We got White-ized'" (Dennis Hogge).

Participants seemed to really wrestle with the degree to which their communities still identified as "Indian," as well as to what degree traditional culture beliefs and practices were present in their communities. One participant recounted how his tribe had "stopped being tribal," and remarked about the strong cultural identity of a neighboring tribe. Some considered whether anyone among the tribes still speaks their native Algonquian language. Some participants recounted who in their tribes still practiced traditional ways. One participant talked about how marrying a fellow Native person seemed to be a protective factor for cultural preservation, and, similarly, marrying a non-Native person seemed to be a threat to maintaining one's Native identity. "Once we started losing our relationship as Native Americans and started marrying, and I mean this in a non-facetious way, marrying outside of the tribe and more Caucasian, a lot of things changed [negatively]" (Dennis Hogge).



Participants recounted how the White man's ways, which many Virginia Indian people adopted, are at odds with traditional Native beliefs. For example, some participants talked about the different perspectives on gender roles and responsibilities held by Western and Indigenous societies.

This tribe, the male part, were hunters and warriors, okay? The women owned the land; they owned everything physical. And they had the major right. They had the say-so.

There were female Chiefs. Our history don't say that. Our history wants to make it, "This is a male society and all the males..." This [name of tribe] had female Chiefs. Right now [in this tribe], a woman can be born into this tribe, but she has no rights. She can't own any property. She can't attend Council meetings or have anything. If she does, is allowed to attend a Council meeting, she has no *say* in anything that's talked about or derived there. And the women used to have the major say. They lost that respect they had there and [tribes] started leaning toward the outside influence where the man was all-powerful and he had all the control and what have you (The Old Sailor).

However, despite the interruption of their traditional ways, participants also talked about the ways in which traditional beliefs and practices are still present in their lives and in their communities. Some participants talked about giving their children Indian names, which was met by varying degrees of acceptance by their children. Some talked about the interest of their grandchildren wanting to know about their Indian heritage. "Well, my grandchildren, they want to know more and more and more about how much Indian they are and the culture, and they love to hear the stories of what I call the older people" (Dennis Hogge). Some participants told of the joy in watching younger relations dance at pow-wows. "Whenever [my daughter] started dancing [at pow-wows] was the highlight of the pow-wow for me. You know, to *see* her out there, and I

had *never* done that” (Glenda Chavis Adkins). Similarly, “I could sometimes watch my goddaughter dance [at pow-wows] and just cry” (Becky Adkins Branch). Participants also told of hosting Native healing ceremonies, as well as engaging in different cultural activities such as participating in pow-wows and creating various types of Native artwork.

As the participants told of the ways in which a complex received and experienced history was intricately connected with the cultural identity of their communities, participants also told of the complex ways in which these elements are intricately related to their personal identity and identity of their respective families. As contextual factors are external forces that influenced participants’ construction of health and healing, spirituality is the internal anchor the grounds the construction. The narrative will now shift from external contextual factors to the dimension of spirituality that anchors the structure of responsible and responsible health and healing.

### **Spirituality**

Spirituality was at the core of participants’ conceptualization of responsive and responsible health and healing. Spirituality governed every part of participants’ personal being, and shaped the ways in which participants saw, understood, and interacted with the world. Spirituality served as an anchor for participants as they weathered the storms that swirled around them. This section addresses the centrality of spirituality in the lives of participants, the function of spirituality in the lives of participants, the role of prayer in the practice of spirituality, and the relationship between spirituality and health and healing.

Participants held a wide array of spiritual and religious beliefs and practices. These beliefs and practices include various Christian denominations including Baptist, Protestant, Assembly of God, and Catholic, as well as Messianic Jewish, Quaker, Native Spirituality, Traditional, Medicine Woman, belief in Supreme Being, and belonging to no specific

denomination as the Spirit is within. Irrespective of the specific spiritual beliefs held by participants, spirituality was at the core of the lives of participants. "...You have to know there is a greater Being than yourself. You have to believe, have faith. Faith is a big part in all I do" (Connie Laskowski).

For participants who practiced traditional Native spirituality (in part or in whole), each step of the day and each relational engagement with people and nature is a sacred spiritual act.

[Native people] believed in a spirit world to where the earth had a spirit, the sun has a spirit, and the moon. Everything had a spirit and to survive and to make sure it was taken care of properly, you had to have respect for it and that developed people's morals" (The Old Sailor).

For them, in a world where everything is of spirit, equal, and interconnected, a deep sense of respect develops towards all things, which underpins their relationship with all things and the way one engages with all things. Life in its most basic essence is sacred and going about one's day is a spiritual act.

We are part of everything in the universe. We're not above it or below it, we're *part* of it and you can find that peacefulness and the healing through Spirit and I believe that our prayers help, you know. There's an old Lakota saying that you want to walk in a sacred manner on this earth, so each step that you take is a prayer, and when each step you take is a prayer, you're walking in a sacred manner, and so I believe that the spiritual is everyday... (Roth Summoth).

The centrality of spirituality in the lives of participants functions and manifests in a variety of other ways. Participants relied on God/Great Spirit to help them navigate through many challenging circumstances in life. After a troublesome event occurred in one participant's

work life, a co-worker asked the participant how she got through it so gracefully to which the participant responded, “God [is] on [my] side” (Becky Adkins Branch). God helped her through the circumstance. “If you don’t have God in your life and a spiritual life, you’re out. Having a spiritual relationship with God, you’re able to work through it” (Loyal Oak).

In addition to helping participants weather hardships in life, God/Great Spirit teaches participants what they need to know. Having recently walked through a particularly stressful time in her life, a participant shared, “The Lord has a way of teaching us and straightening us out. I had to learn to let go. I had to let go of the expectations I had of people. I could not do it without my faith” (One Who Looks Out For Others). For them, God/Great Spirit was a protector, protecting participants when they felt unsafe, and God/Great Spirit was a provider, providing resources (i.e. housing, food, medical care, etc.) when participants were in need. God/Great Spirit was always there to help participants with their various different needs. As one participant explained:

Oh my goodness, child. You do *nothing* but by the grace of God. Nothing...you don’t get up get in that car and go nowhere without by the grace of God. People just *think* they do this, *they* do that. They don’t do nothing. No, I know that [italics added to reflect emphasis in participant’s voice] (Lorraine Hedgeman).

### **Learning about the Centrality of Spirituality**

The importance of having a strong spirituality (inclusive of the various spiritual traditions represented among participants) has been passed down through the generations and continues to be passed down from participants to their children and grandchildren. “See the way we came up, we were more or less raised in the church, and in the tribe, so they kind of all worked together...that’s about all I been used to, that’s the way I was raised” (Wewoka Adkins).

Spirituality was often at the core of the identity of participants' families through the generations. "I came from a Christian family, and it was just, it's a part of us" (Red Cloud). Spirituality helped families weather the storms of hardship. "Even though my family, we were poor and we suffered through our poverty, I could see very positive aspects because they were spiritual and I learned from them to be spiritual" (Loyal Oak). Grandmothers seem to have played a particularly important role in the transmission of spirituality from one generation to the next, as participants recounted stories of learning about their respective faith tradition from their grandmas. Likewise, following in this tradition, participants who were grandmas told stories of teaching their children and grandchildren the ways of their respective spiritual traditions.

In addition to families playing a central role in fostering a strong sense of spirituality, participants also identified the communities in which they grew up also playing an important role in teaching participants about the centrality of spirituality. "I learned [a strong sense of spirituality] through my family having faith and through the community, because the community ever since I was young played a great part in my life, so I think you kind of spread it around" (Connie Laskowski). One participant also talked about the role of a college professor in developing his faith.

No one is without a spirit...A professor from Sweden who specialized in sociology really impressed that *no one* is without a spirit. *No one*. And I like that. Even though, being Swedish, which you think would be an anti-religious person, he says, "No one is without spirit." So that had a profound impact on me. Interesting. No one is without a spirit. And so, including religious people, so *all* the world has it, *all* religions have it. Therefore I believe it (Loyal Oak).

## Prayer

Prayer was the vehicle that allowed participants to connect with their Higher Being, and served several functions in the lives of participants. Participants engaged in prayer to give thanks to their Higher Being for providing for them and offering protection, as well as to give thanks for taking care of loved ones. “I thank God every morning when I get up for watching over me, keeping me safe throughout the night” (Butterfly). Prayer was also suggested as an anecdote for worrying. “I don’t really have a plan for never worrying again. Some people say why worry when you can pray. That’s one thing I don’t do enough of...I don’t do enough praying” (Wewoka Adkins). Participants engaged in prayer to seek counsel for themselves and others, as well as to ask their Higher Being to answer particular needs for themselves or another. “And knowing that when you’re trying to help someone, with that spiritual part and faith, it can happen. So prayers to me are very powerful. My house was built with prayers, literally” (Roth Summoth). Prayer was also an avenue through which participants cultivated a closer relationship with their Higher Being. “I have gotten closer to God because I’ve been praying more” (Butterfly). Prayer also created strong social bonds among groups of people with whom participants are connected, as prayer is sometimes practiced in a group, or prayer requests sent through a “prayer chain,” whereby a particular prayer request is passed around a network of people. Prayer was also important in connecting spirituality and healing. Prayer was the vehicle by which healing can occur. One participant recounts a story that speaks to the importance of prayer in the lives of participants, as well as reflects the role of prayer in healing.

I believe in prayer. I believe God answers prayers and I believe God can heal us, and He will heal us. I believe in that, firmly believe in that. Not only do I pray for myself, I pray for other people. I visited a lady today, this afternoon, who has cancer, and she’s

Catholic, but I remember some time ago, for whatever reason, just feeling like I needed to go and see her and to pray for her, pray with her, and I did that, and we stood and held hands and prayed. And I could feel the power of God, and I believe, and I went to see her today, and this has been over two years ago, around two years ago we did that, when she was really struggling with cancer, having a bad time. Today she still has, she's still taking some chemo, but she is *much* better than she was two years ago. How do explain that? I believe God did that [pause], I really do. So I believe it, I believe very, very deeply that, very strong, very deeply, at least that spirituality plays a major, a large part in healing. (Mac Custalow).

### **Spirituality and Health and Healing**

While spirituality was at the core of the lives of participants, spirituality was also connected to the ways in which participants thought about health and healing. “I don’t think that your spiritual part can be disconnected from your well-being. I think your spiritual part is a big portion of your well-being and how you see things and how you feel. I don’t think they’re separate” (Roth Summoth). In addition to physical, mental, and emotional elements, one’s heart and soul were identified as “the most important” aspects of being healthy (Loyal Oak).

Participants suggested peace and happiness are key characteristics of being healthy, and they identified spirituality as the root of peace and happiness. One participant explained:

If you have peace and happiness in your life, I think you’re healthier. [Peace and happiness] come from the spiritual part, your connection to the universe. We don’t feel that things are separate, feeling love from the Creator, having that love in your heart and sharing it with people (Roth Summoth).

There was a strong connection between spirituality and healing. Participants addressed this connection from various perspectives. One participant talked about the role of one's spirituality in the interconnected nature of healing, addressing the way in which spirituality interconnects with mental and physical dimensions in the healing process. "I think your spirituality has something to do with healing, too, your physical healing and spiritual healing. [Spirituality] can help you have a better attitude about life, and by having a better attitude, you have more life in you, or energy" (Wewoka Adkins). Participants also talked about the role of faith in healing. Stories were told about how people were healed through their respective faith in a Higher Being and faith in the Higher Being's ability to heal them. One participant talked about the strong faith of his mother and attributed her strong faith in God to her recovery from a particularly traumatic event from which medical doctors predicted she would not recover (Red Cloud).

Another perspective on the relationship between spirituality and healing has to do with spiritual healers. Several participants told stories of a relative (usually a generation or two older than the participant) who was a spiritual healer of one type or another. One participant told the story of her "Grandpap" who was a healer and how people came from far and wide to call upon his gift of healing. It poignantly captured a certain essence of life, particularly as related to healing, that occurred approximately five generations ago.

My grandfather, every Saturday, he would walk the railroad tracks from Pembroke to Fayetteville and that is about 40 miles, one way, and he walked it on Saturday and he preached Sunday morning, and walked the railroad back to Pembroke that Sunday evening...[There] was a lady, she wasn't much older than I am, and, um, she had been sick all week and wouldn't go to the doctor. So her husband finally got her to agree to go



somewhere and she wanted to go to my grandfather's because she wanted, she said if he just prayed for her, she'd be fine. And it happened, just like she said it would...Grandpap was a faith healer [Baptist and Native American]...He was a preacher and he was Native American. And people would go to his house all during the week...they'd come from South Carolina...for him to pray over them and heal them...he would walk that railroad track week in to go to Fayetteville to preach. And then he said, one of my uncles had a filling station built in front of Grandpap and Granny's house, and whenever people started to seeing what was going on at the house, this lady in South Carolina heard about Grandpap and she, her folks were trying to get her to do something about being so sick, and, um, she told them she knew what she was going to do, she was going up [Grandpap's] house and she'd get better. And she did. She couldn't walk when she got there but she walked the walk when she left...He just prayed. He didn't give them nothing to drink and all, but, um, my Grandpap could give you a prayer and that's what he would do. I remember my baby brother, he got sick, and, um, Mama wanted to take him to the doctor. Daddy told her, "No, I'm going to take him to Paw," says, "He'll, he'll be alright." And he went down to Granny and Grandpap's house and wasn't long before he came home. My brother was running and playing. It happens...I've seen it. But not a lot of people believe in it now. But I would. I've seen it with that one [referring to her daughter]. Those headaches. Daddy would take care of it, my Daddy, her granddaddy. After Grandpap passed away, my Daddy, he had been doing a lot of church work and all and he said there was a prayer that Grandpap left with him, and Daddy started praying for people who'd come to the house for having healing. And there's not many down in North Carolina where I grew up, there's not many of them that doesn't have somebody that they

go to for prayer...The only ones I know about are Native Americans...down there, down where I was brought up in North Carolina (Glenda Chavis Adkins).

While participants told stories of a strong connection between spirituality and healing, it is also important to acknowledge that participants identified times in which they experienced an “imbalance” in the relationship between spirituality and healing. During these times, participants recalled teachings about God being a healer and if one wasn’t healed, “...there was something wrong with you, because you didn’t have faith” (Bonnie Sears). In one instance, a participant was questioned by his congregation for having not been healed of a particular condition with which he had been born. Participants stressed that it was important to have a balance in perspective regarding the role of spirituality in healing. “Yes, God does heal, at the same time he uses doctors as well as miracles” (Bonnie Sears).

Spirituality was at the core of the lives of participants and was a key dimension in their conceptualization of health and healing. For them spirituality was not static, but, rather, changes through one’s lifetime, growing deeper and richer as participants faced challenges throughout their lives. Spirituality not only shares a unique relationship with health and healing, but it is also interconnected with other dimensions of health and healing. To understand a conversation about the ways in which participants saw spirituality as interconnected with other dimensions of health and healing, it is important to explore the other dimensions of health and healing identified by participants. The next section will include a discussion of the ways in which participants envisioned the physical process dimension related to health and healing because, surprisingly, it represents the most paradoxical or subtle of all the information provided by the participants and, yet, is probably the most measurable dimension of all.

## **Physical Processes**

Of the five dimensions of health referenced by participants, the physical processes dimension of health received the least amount of attention. When asked about what it means to be healthy, participants generally referred to the physical processes first. After the initial reference, however, the physical dimension received limited direct attention during the interviews. The meaning of “direct attention” is well illustrated by the following: While a particular physical ailment or condition may have been discussed several times during an interview, the focus was not always on the condition itself, but rather on areas such as accessing needed medications to help alleviate or control the health condition, the ways in which family or friends helped out when a participant was experiencing a particular hardship due to the health condition, or the way in which an ailment or condition may have interfered with a participant engaging in some sort of activity.

Accordingly, this section concerning the physical processes of health and healing is rather brief. The section addresses the ways in which participants identified health as physical, the physical health of participants, as well as the physical health of the families of participants. It is important to honor my commitment to confidentiality to the greatest extent possible for participants wanting to remain anonymous. Similarly, it is important to protect participants’ health information to the greatest extent possible. Therefore, this section is constructed so as to be general enough to reduce the possibility of identifying someone based on a known, or not previously known, physical health condition, but detailed enough so as to not sacrifice participants’ intended meaning.

On the surface, for participants, the physical dimension of health referred to being free from disease, as well as being free from bodily pain. “I have a lot of body pain. A day to wake up

healthy to me would just be a day not to hurt” (Connie Laskowski). When asked what it means to be healthy, participants often shared various diseases, or physical conditions, with which they have been diagnosed, followed by a general assessment of their overall health. “I’m not healthy. You name it and I got it” (Elaine “Dancing Owl” Custalow).

Collectively, participants experienced diabetes, heart disease, high blood pressure, kidney disease, lung disease, and physiological body pain emanating from various circumstances and conditions. After reflecting on their personal disease profile, some participants concluded they were not healthy. Some participants, however, reasoned that a disease profile doesn't necessarily make someone unhealthy; but, rather, health was contingent on the choices a person makes in taking care of one's self and the ability one has to practice healthy choices, despite the diseases one may experience. For some participants, the absence of disease was the presence of health, and the presence of disease was the absence of health. For others, it was possible to be healthy despite the presence of disease.

People can be healthy and have diabetes or have different other diseases. They can be as healthy as they *can* be with those particular diseases. That's what I mean by being healthy...That would be good blood sugars, good AC13 levels, really good, taking care of yourself, walking, exercising, doing the things that keep you healthy. With heart disease, making sure your cholesterol is down as far as it can be, and following your doctor's orders, striving to be as healthy as you can...[It's] [t]he *desire* to want to be healthy (Bonnie Sears).

In conversations related to personal health conditions, the conversation often shifted from self to family. In reflecting on family health, some participants identified relationships between personal health conditions and health conditions in their family, particularly as related to health

conditions experienced by parents and grandparents. For some participants, recognizing the presence of a particular disease or health condition through the generations seemed like a new realization, and, for others, it seemed like the link was something that had been considered before. Recognizing the presence of certain health conditions through the generations brought up conversations regarding the genetic nature of certain diseases, highlighting the physical genesis of disease. One participant told a story of how she was adamant that she and her husband undergo blood testing when they were married to assess for any health conditions that may be present within their genetics. Upon learning that she was borderline diabetic, the participant refused to have biological children for fear of passing on diabetes to her child. Instead, she and her husband decided to adopt a child.

Because physical health is probably the most measurable dimension of all, it follows that perhaps a discussion of physical processes as related to health and healing might be a straightforward conversation; however, participants spoke to the complexity involved in the role of physical processes as related health and healing. Woven throughout participant stories, physical processes were often addressed in light of mental and emotional processes, and, conversely, mental and emotional processes were often discussed in light of physical processes. While a conversation about this connection is reserved until later in the narrative, because of the relationship between physical processes and mental and emotional processes, the mental and emotional processes dimension will be discussed next.

### **Mental and Emotional Processes**

Mental and emotional health was important to participants' conceptualization of health and healing. What participants think and how they feel are distinctly related to health and healing. To them, one's mental and emotional health was not always solely assessed based on

one's thoughts and feelings. Mental and emotional health could also be assessed based on the ways in which mental and emotional health interconnect with various other dimensions of health in the formation of a holistic notion of health and healing. Some participants referred to the two processes distinctly, addressing thought processes as mental health and feeling processes as emotional health. Some participants seemed to use the term mental health or emotional health to synonymously, referring to both thought and feeling processes, sometimes with the terms being used interchangeably.

This section will address specific mental and emotional processes discussed by participants. Because of the distinction between mental and emotional made by many participants, the processes are grouped according to whether the process has its basis in thoughts (i.e. mental) or feelings (i.e. emotional).

### **Mental Health**

Mental health from the perspective of participants had to do with one's thought processes. Most participants talked about three types of mental processes that are important to health and healing: positive thinking/negative thinking, memory, and *remembering*.

**Positive thinking/Negative thinking.** Positive thinking was associated with good health. "There is definitely a relationship between positive thinking and health. When your thoughts are positive, your body is healthy" (One Who Looks Out For Others). Further, positive thinking was important to the healing process. "Positive thinking is *very* important in healing. And I don't think there's a good doctor around who will tell you anything different" (Mac Custalow). On the other hand, negative thinking, or as many participants said, "stinkin' thinkin'," was associated with poor health and inhibited the healing process. "Stinkin' thinkin' will make you unhealthy"

(One Who Looks Out For Others). While negative thinking was generally considered unhealthy, as one participant pointed out, sometimes it just felt good to get out some good ol' whining:

And then I will pray and ask God, I like that song 'God forgive me when I whine.' I try not to complain so much, that doesn't make anybody feel better hearing about my aches and pains. But sometimes I feel better once I get it out (Butterfly).

**Memory loss.** Participants also referred to mental health as having to do with the ability of one's mind to function in such a way that it can successfully store and remember information. Participants referred to Alzheimer's and dementia, both in relation to a personal connection to the conditions, as well as general assertions about the conditions. Some participants voiced concern about their mind not being as sharp as it used to be, and expressed trouble with remembering. "That's some of the main things that bother me. Like memory. Someone will say, 'Well, I told you this.' Sometimes I know that they did not and sometimes I'll just say, 'I don't remember you're telling me.' And it's things like that that really upset me" (Butterfly). Some participants shared stories of the challenges involved in taking care of someone suffering with dementia and/or Alzheimer's. "...having seen my [family member] go through [Alzheimer's], that terrible, ravaging disease, it's a heartbreaking situation" (One Who Looks Out For Others).

In relation to losing one's ability to store information and remember, participants viewed poor mental health as worse than poor physical health.

To me, if one had to go [mental or physical], I'd rather it be physical than mental. I've seen so much before the mental part is gone and the physical part is still good and I believe it takes more of a toll on the people around about you, the mental part gone than the physical part gone (Kind Heart).

It seems reasonable to suspect that because participants were of an age where dementia and Alzheimer's typically begin to present in people, participants' concerns about mental deterioration were an important aspect of good health for participants.

**Remembering.** Another aspect of mental and emotional health that has to do with memory, but in a quite different vein than the previous topic regarding loss of memory, is that of remembering. For participants, remembering had to do with the intentional act of remembering and narrating memories from their past. Without solicitation, participants often engaged in storytelling about years gone by. Stories included enjoyable recollections of past events and ways of living, memories of family, painful memories, and ways in which memories appear as dreams. For example:

Grandma was eighty-six or eighty-seven. I remember this story. Because grandma finally got to the stage where it was harder for her to get up the stairs, the steps, which there was a porch with steps on it. So [name of aunt] and [name of uncle] just said "Mama, why don't you come stay with us? We all took care of you." Back then you took care of your family, not send her home. So granny went over, she lived with them for about five years. But would get up everyday and walk. No joke, I think she walked about five miles a day because everybody on Indian Hill was her daughters, sons, nephews, grand-nephews, grand-nieces, and she would go visit. [Well before that Grandma ended up getting] a trailer at the bottom of the hill where our house was. You'd go out and play the devil one night and I remember her knocking on my door one morning, "I just wanted to know why you were coming in at 12:35 last night." And we said, "Sheriff, there's a billboard and she's behind it on her Harley and she's waiting on you." But [name of Aunt] said, "Grandma come in one day and said, '[name of Aunt], I'd like to have my favorite lunch



if you don't mind.' So [name of Aunt] said she made up a thing of greens, cress, a fried porkchop, and some small mashed up couple of potatoes for everybody for dinner and said Granny said, 'I miss [name of grandma's late husband].'" She said she walked in the room, laid down, crossed her arms, looked up, and said 'I think I'll just talk to the Lord for a minute,' took a breath, and that was it." Granny always said, "I want to talk to [name of late husband] before I go." Granddaddy, she missed granddaddy. That anybody should ever remember me that way (Dennis Hogge).

The telling of stories brought tears of joy and pain, both from the storyteller and me as the listener. It seemed these stories were waiting to be told as participants often released a deep sigh of relief after recounting a story. Sometimes participants said that they had never told that particular story before. Sometimes it seemed the story was just waiting for someone to listen. It seemed like the telling of these stories was cathartic for participants, making the intentional act of remembering an important element of mental and emotional health. As one participant who particularly enjoyed telling stories advised:

Well you and your family, you just remember all of the things that you are doing right now are the memories that you're going to have to share when yours gets to twenty-five, thirty-years-old...Because your children will think that you have the most special stories of anybody in the world...Don't ever discount the things you've done in your life as anything other than major. That will mean a lot to your children and grandchildren in the years to come...Well you don't have to *think* that far, just know that it's coming. It's like you don't always have to know where the train is, but you can hear it on the tracks (Dennis Hogge).

While types of processes were grouped based their source in either thought or feeling, it's important to note that for participants, the line between the two was often blurred. The act of remembering seems to encompass both thought and feeling. Moving on to emotional processes of health will further demonstrate the connection between the two.

## **Emotional Health**

Emotional health has to do with one's feelings. Participants identified several processes connected to emotional health: lack of emotional health that are important to health and healing: worry/stress, feeling depressed and overwhelmed; harboring ill feelings, and hopelessness. You'll notice that the negative side of these dimensions were presented (e.g., hopelessness instead of hope). Conversations about these dimensions largely occurred in the context of what it means to be unhealthy or as barriers to being healthy. This section begins with worry/stress because it is an example of a process that involves both thought and emotion.

**Worry/Stress.** Participants talked about worry and stress both from the perspective of general assertions about the ways in which worry and stress were related to health and healing, as well as shared personal stories about things which worried them and how stress affected their lives. Participants worried about a vast array of things: personal health, the health of family members, ability to maintain independent living, ability to pay the bills, ability to afford medications, ability to access quality medical care, and ability to make necessary repairs on the house. For most, when it comes to worry and stress, there is a strong relationship between thoughts and feelings because negative thinking leads to negative emotion, namely worry/stress.

Well, sometimes when I'm sitting around by myself, thoughts come into my head and I feel like I shouldn't be thinking thoughts like that. 'What if this happens? What if that happens? What are you going to do?' I've thought about that several times...It can lead

to worry, a situation like that can lead to worry. And it's not good to sit around and worry about what might happen. I guess when I start to think stuff like that I need to get into another gear, think about something else I guess. I know it don't help, sit around thinking about what, you know, could happen... When you get into another gear, think about better things (Wewoka Adkins).

Worry and stress manifests in various ways in the lives of participants from not being able to sleep at night to elevating one's blood pressure or "throwing off" sugar levels. Left unchecked, worry and stress can have devastating effects. "Stress will kill you. I'm serious. If you can't get a grip on it" (Lorraine Hedgeman).

**Feeling depressed.** Similar to worry/stress, feeling depressed is another type of process that encompasses both thoughts and feelings. The nature of conversations related to feeling depressed were mostly personal in nature, with participants telling stories about the ways in which they have felt depressed or were feeling depressed at the time of our conversation. These stories were largely connected to loss. Participants who had lost loved ones talked about the feelings of sadness that lingered in their spirits. Stories of feeling depressed were also related to traumatic events that had occurred in the lives of participants. Some participants described conflicting feelings of being incredibly lonely, wanting to be alone, yet at the same time enjoying being in the presence of family and friends.

Some days I don't even want to get out of bed, or don't want to go anywhere, or don't want to see anybody, but then again I want the house full of people. It comes and goes, but right now I'm doing good (Butterfly).

Some participants sought the services of a mental health professional to help work through their feelings of sadness; some relied on family and friends; some relied on their faith community for

support; and some carried the heaviness of feeling depressed on their own.

**Harboring ill feelings.** Equally important to participants discussion of emotional health, or a barrier to emotional health, was harboring ill feelings. Participants saw harboring ill feelings as having to do with holding negative feelings, such as anger, dislike, hate, and lack of forgiveness toward people (including one's self), things, and/or events. For them, holding ill feelings was connected to being unhealthy and was a barrier to healing. This negatively affected not only one's self, but also their relationship with the world. For participants, consistently harboring ill feelings without release threatens the longevity of one's life.

Well, when, when you're unhealthy, you harbor too many things. In other words, you're, you're loaded with too many crosses and you want to hold on to them. You don't want to let them go. In other words, you want to be controlled by the devil himself. And if you're being controlled by other demons, then you yourself are carrying too heavy of a load and that right there affects everything about yourself. Your health. Your general well-being. How you look at things and how you look at the world. It's all, it's all right there. Your faith. Your spiritual health. Everything (Dorothy "Red Wing").

**Hopelessness.** While the above-mentioned types of mental and emotional processes were expressed by participants in relation to themselves, hopelessness was mainly talked about in relation to "Western" American Indians. Participants recounted stories of incredible oppression and discrimination experienced by "Western" American Indian communities, both in the past and present. Participants expressed how the overt oppression and discrimination experienced in these communities has led to deep poverty and limited opportunities for these American Indians, leading to a pervasive hopelessness among them. Participants talked about hopelessness in light

of the dire living conditions and connected both with high rates of alcoholism, drug abuse, and suicide.

When it comes to the alcoholism, suicide, that goes back to a mental state. And that's more predominant in the Western Indians than the Eastern. But you'd have to know what they're living through, the conditions they're living under, to understand that. When those kids out there today, the drop out rate even in high school is just terrible. But for those who stay there and get a high school education, most of them don't have anything to look forward to after that. Those who rise above make up a very small number. Again, people who are oppressed, to say not accepted is putting it mildly, again, I guess you know what all of that leads to? Depression. The alcohol is an attempt to escape.

Depression, and when you live under that kind of conditions, situation, it leads to hopelessness. Where there's hopelessness, you'll find a very high suicide rate, because there's no hope, or they don't *see* hope. But yet we got all of those Native American people out there, to whom this Country belonged and was taken from them, cheated, lied to, and still living in squalor, a lot of them. And what's our government doing to help out them? Almost *nothing*. And that doesn't bode well with me, particularly being Native American...and my own people are here with the highest suicide rate in the nation, among those high school kids, and the older. They, alcohol, alcoholism, and now substance abuse other than alcohol, when they can get that. Because you got a people who are living an almost hopeless lifestyle (Mac Custalow).

Hopelessness affects not just one's emotional health, but also mental, physical, and spiritual health, as well as one's social relationships. "When there's that loss of hope, I mean, your spirit just dies and your will dies" (Bonnie Sears).

In discussing the dimensions of physical processes and mental and emotional processes, participants spoke about the significance of both to what it means to be healthy. These two dimensions mainly focused on self. The remaining two dimensions still to be discussed – social relationships and access to resources, focus more on self in relation. It was clear from participant stories that social relationships are key to their construction of responsive and responsible health and healing. Thus, the next dimension of responsive and responsible health and healing that will be addressed is that of social relationships.

### **Social Relationships**

Social relationships were an important element in participants' conceptualization of responsive and responsible health and healing. Social connections offered participants companionship, a shoulder to cry on, and someone to laugh with. Social connections offered participants a space to seek and provide counsel. Social relationships served as a source of strength and encouragement for participants during hardships, as well as the motivation to care for one another when needed. Social relationships provided a venue for participants to challenge their beliefs and broaden their perspectives. Social relationships provided spaces for participants to collectively reminisce about the past and collectively dream about the future.

Money is important and we have to have a certain amount of it, but it's not the most important thing in life, relationships are...as you get older, I think you too will find relationships become more, more important to you" (Mac Custalow).

However, as some participants acknowledged, social relationships can simultaneously be spaces of tension and hardship.

Participants identified various types of relationships in which they were involved: community, family, friendships, church, tribal, inter-tribal, and inter-generational. As will be

addressed, these various types of relationships are rarely discrete, but often overlapping. This section will address four types of social relationships in which participants are engaged and the role these relationships play in health and healing. The four types of relationships to be addressed seem to capture the sum of the types of relationships mentioned by participants, however, four types will be more directly addressed than the others. The four types of social relationships about to be addressed all seem to be significant to participants in their own right. The estimated extent to which participants talked about each type of social relationship will be used as a strategy for ordering the discussion that follows. This is not to suggest that one type of social relationship is more important than another. Ordering the discussion by the extent to which each type of social relationship is collectively addressed just serves as logic in how to proceed. Overall, participants talked about the role of community in their lives extensively; therefore, community will be addressed first, followed by family, then friendships, and, lastly, inter-tribal relationships. It's worth noting, again, that these types of relationships are rarely discrete, as boundaries are often blurred. Following this discussion of the four types of relationships will be a conversation about how participants saw social relationships as related to health. Perhaps as a natural extension of the high value placed on social relationships in the lives of participants, engaging in acts that help others was also a meaningful component of health and healing identified by participants. This section on the dimension of social relationships will wrap up with a look at the helping relationships in which participants are involved.

### **Types of Social Relationships**

**Community.** Community is the foundation of social life for many participants. “The community, ever since I was young, played a great part in my life, in different way” (Connie Laskowski). Participants report the close-knit nature of many of their communities. Some

participants told of the current closeness of their respective communities, and some talked about the closeness of their respective communities in the past tense. Participants of one tribe that is particularly known for its close-knit community use descriptors such as “one loving community” (Butterfly) and “one big family” (Wewoka Adkins) to describe their community.

While participants talked about the importance of community in their lives, when asked to define community, whom their community includes, things become less clear. This is where the boundaries around various types of social relationships become blurred. Tribe and church make up the core of communities described by participants, however, communities are not exclusively comprised of tribe or church. One participant explains the complexity in defining community:

[Defining community] Church. Friends. It's not just your friends at church either. It's...surrounding area...yeah, kind of just surrounding area... [It's] probably not as much [having to do with fellow tribal members] now as once was, okay, because at one time, I guess, well, I remember when all the activities in this community, it was kind of centered around the church. You had socials, auxiliary organizations branching out from the church, you know....and most of the church members were tribal members, way back...So it was one and all the same. I remember, and it hasn't been really that many years ago, that the church was [name of church] *Indian Baptist Church*. In the later years it's been changed to [name of church] *Baptist Church*...But we're still, even though the surrounding community and everything, but we're still the tribe...predominantly Indian...yeah. It gets hard to explain when you're talking about your tribe. It's still something different in there. It doesn't mean that I would think any less of you because you're not [part of the tribe to which participant identifies] than, um, I would think of my



neighbor because she's [part of the same tribe as participant]. But, it's just heritage, feeling, I don't know exactly how to describe it... (Kind Heart).

The words of the participant in the above quote speak to the closeness among Native people generally, and fellow tribal members specifically. Participants attribute the close-knit quality of their communities to a shared history that shaped the parameters around the ways in which communities related in the past and present. "Because we were not well accepted by some other groups of people outside of the Indian people may have encouraged us to bond even closer, and I think that can, it happens often...that may have even encouraged a closer bond" (Mac Custalow). Consequently, "we gr[ew] up together, kn[e]w each other, mingle[d] together, worship[ed] together, play[ed] together, [ate] together" (Wewoka Adkins).

Participants express strong social ties to their respective communities. Subsequently, "[When] something bad happens to someone, it affects more than just the immediate family, it affects the community..." (Kind Heart). Participants describe a multitude of ways in which their respective communities, in part or in whole, have come together to support a particular person or family in need. Participants prepare and deliver food, organize and host informal fundraisers, participate in fundraisers run by formal non-profits, provide transportation for neighbors, accompany neighbors to an appointment, visit a neighbor in the nursing home, stack wood for neighbors, help with household chores, and provide yard work. A strong sense of community is something that participants report was modeled for them since childhood. "...That's all I been used to, that's the way I was raised" (Wewoka Adkins). Community plays an integral role in the lives of participants and their health and healing.

Family comes next in relation to the extent to which it was collectively mentioned in regard to types of social relationships.

**Family.** In addition to community, family is integral to health and healing. Families and communities share several qualities and functions. Similar to attempting to define community, boundaries around family and previously mentioned types of social relationships are blurred. Family is often interwoven with community, tribe, church, and friendships. One participant described community as “several kin people right there together” (Wewoka Adkins). Participants identify family as consisting of blood relations, as well as adopted (formally and informally) relations. Similar to communities, participants describe their families as close-knit, laughing together, celebrating together, crying together, leaning on each other in times of hardship, helping each other when needed, and loving each other (even across differences).

Families are described as contributing to good health and productive healing. Family relationships that serve as a source of close relationship to participants are described as integral to promoting strong mental health among participants. “Family really, really helps your mental health because if you have that close relationship with your family, your mental health is going to be much better” (Red Cloud). When there are times of need, families step in and perform any number of day-to-day activities for each other including household chores, yard work, and providing transportation when needed. Families also step in to provide care when needed, accompanying family members to medical appointments, visiting family members who are ill, providing counsel, providing medical care at home, and sitting with a family member as they exit one world and enter another. Family provides companionship and motivation to keep going in times of hardship.

It really is hard. It is very hard. I’m a widow. My husband died suddenly four years ago. I’ve got my grandchildren here, thank the Lord, because if I was in this house by myself, I would have to buy me some kids. You [addressing grandchildren] keep me going and

everyday is just because, you know, I know I've got to keep a roof over our heads  
(Connie Laskowski).

This is not to suggest that all participants describe their family relationships in a positive light. Families are also described as contributing to poor health and inhibiting the healing process. Unhealthy family relationships are a source of tension for participants, often negatively impacting the body's ability to be healthy. Participants talked about the ways in which unhealthy family relationships during formative years of one's life, sometimes in the form of abuse or neglect, can have ripple effects later in one's life, sometimes resulting in devastating effects on health. Similarly, participants currently engaged in unhealthy family relationships told of the ways in which the unhealthy family relationship has negatively impacted their health, often first affecting their emotional health in the form of anxiety or depression and then manifesting physically in any number of ways, sometimes bringing the lives of participants to a halt. In addition, participants talked about the hurt involved in being limited to superficial communication with one's family and the ways in which a lack of family intimacy inhibits their ability to be healthy.

More broadly, participants also talked about the ways in which families are significant to healthy communities.

And really again, families, the foundation of the family is an issue. If it wasn't for the foundation of the family, then there would be greater loss [suicide]...I know you have a higher suicide rate, the higher alcoholism because the family relationship. I think that's the issue. That's the key. I think it's the families, it comes back to the families. Sorry I say that. Even though my family, you know, we were poor and we suffered through our

poverty, I could see very positive aspects because they were spiritual and I learned from them to be spiritual (Loyal Oak).

From the stories shared by participants, it is clear that families play an integral role in the health of participants, regardless of the nature of the relationship. Following community and family, friendships received the next amount of collective attention by participants.

**Friendships.** Similar to community and family, friendships are influential in the lives of participants, particularly as related to health. Different from community and family, the friendships in which participants engage are largely chosen by participants, rather than a relationship into which one is born. Participants told of friendships as positive social engagements, with friendships having a positive impact on the health and healing process of participants. The following is an example:

I have a friend, a Cuban friend, and I just talked about him today, who lost his next door neighbor, or man that lived two doors down, but they were really, really close, and before the other gentleman passed, he and I had become really good friends and did things together, and my Cuban friend, now, I have, in his life I have somewhat taken the place of his friend who lived two doors from him because he calls me, we see each other, we do things, because he has no one there now to do those things with. So now, we have formed a really good close relationship, and, and that makes me feel good that maybe I'm filling just a little bit of void in his life, by being a friend to him. But by the same token it's reciprocal because he, he's certain been a friend to me (Mac Custalow).

Similar to community and family, the boundaries around friendships and previously mentioned types of relationships were largely blurred, so friends were often members of one's respective community, family, tribe, and church, the only difference being that friends are select

persons from these various types of relationships. Accordingly, the positive qualities of community and family that have been previously described, and the positive roles and functions these types of social relationships played in supporting the health of participants are applicable in addressing the relationship between friendships and health and healing. Friendships offered companionship, emotional support, and a helping hand when needed, contributing to positive mental and physical health among participants.

Last, but certainly not least, participants identified inter-tribal relationships as an important type of relationship in their lives.

**Inter-tribal.** Talking about inter-tribal engagement brings a glow to the faces of participants. Mattaponi Healing Eagle Clinic (MHEC) operates on a first come, first served basis. Upon arrival, service-users add their name to a sign-in sheet and wait their turn to be seen by a medical provider. Service-users will wait in the main room of the community center where clinics are held anywhere from fifteen-minutes to a couple of hours to see a medical professional. During this time, the waiting room becomes a hub of activity, service-users representing various tribes visiting with one another, exchanging stories about one's self, family, tribe, cultural events, church activities, hobbies, hunting, fishing, vacations, various issues, the past, and things to happen in the future. The waiting room of MHEC serves as the sole opportunity for many Virginia American Indian people from various tribes to connect with one another. Participants talked about this space for inter-tribal engagement with palpable excitement.

Yeah, that is great. Because like I say, the different tribes, sometimes you don't see them unless it is at the Clinic. And it is good, good seeing people, and that does make you feel good seeing somebody you haven't seen, or you can talk to somebody and say 'Well, you know, how is so and so doing?' And to hear about other people. That's good

communication and that *does* do you good. That will put a smile on your face no matter how bad you feel, to see somebody you like, another friendly face (Connie Laskowski).

While access to medication free of cost to participants is often the primary motivation for attending MHEC clinics, some participants admit going to MHEC primarily for the opportunity to reacquaint with fellow Virginia American Indian people who they haven't seen in a while.

Actually, I enjoy going just to, you know, just to see some of the people that are, you know, wanting to see over there. I mean I wouldn't see them if I didn't go. I enjoy being reacquainted with people I don't see that often. And I don't get upset if I don't get the medicine I need. If they don't have it, they just don't have it (Wewoka Adkins).

In addition to enjoying inter-tribal engagement, participants also enjoy inter-generational interaction. In reference to the waiting room at MHEC, "We like to listen to the stories. We like to talked to the older people who told stories, stories of before our time. It's history" (One Who Looks Out For Others). Another participant shares, "So I would enjoy when I would walk in and [a particular elder] was there or if I'm there and she walks in, you know, it was a bright spot in my day, to see her and he able to socialize with her" (Mac Custalow). Inter-tribal and inter-generational engagement is a type of social relationship that is highly valued among participants. It is clear from participant stories that inter-tribal and inter-generational relationships are beneficial to participant health and healing.

### **Health and Social Relationships**

Participants envisioned several ways in which social relationships were related to health, many of which have already been addressed in the above sections pertaining to types of social relationships. To address the ways participants talked about social relationships as related to health calls upon the interconnected nature of the dimensions. For example, participants

acknowledged that, “[Social connections are] definitely good for your mental health, as well as your physical health” (Mac Custalow). Conversely, participants linked isolation to unhealthiness, mentally and physically. “And people today who ostracize themselves, they’re miserable, in many cases very unhealthy, particularly mentally, and often times physically, when they try to ostracize themselves, live alone” (Mac Custalow). In considering the various types of relationships in which participants engaged, participants identified certain types of relationships that contribute to the promotion of health and other types of relationships that inhibit good health, often even contributing to poor health conditions. Participants talked about the ways in which relationships can be a source of tension in their lives, serving as an obstacle that must be worked through to maintain (or recover) one’s health. Overall, however, having relationships in one’s life, irrespective of the type of relationship, was seen as important to participant health and healing.

As a natural extension of the high value placed on social relationships in the lives of participants, engaging in acts that help others is also a meaningful component of health and healing identified by participants. The next section will look at the meaning participants ascribe to helping others.

### **Helping Others**

Participants are engaged in a vast array of helping relationships including providing in-home care for ailing and/or ill family members; working as a home health aid for people with ill health; volunteering at a local food bank; offering support to caretakers; singing for residents of a nursing home; performing yard work and snow removal for elderly neighbors; visiting with elderly neighbors; collecting and delivering items for low-resourced communities; raising money for a local free clinic; advocating for people experiencing trouble accessing medical care and

needed resources, participating in a formal fund-raiser to raise money for a cause connected to someone special, accompanying a loved one to medical appointments, providing transportation, and providing childcare. Although most participants are retired, they stay busy helping others in various ways. Participants envision helping others as important to their personal health and healing process.

There's an old saying, people say, 'Well you're retired.' I said, 'No, I didn't. Because when the mind retires, the body expires.' And I meant that I was not going to mentally retire. That's why I [help out in various ways at the Clinic]. If you're going to be healthy, you need to serve other people (Dennis Hogge).

Participants described qualities that are important in helping relationships. First, participants talked about the reciprocal or cyclical nature of their helping relationships. Some participants were motivated to help others because they were helped at some point in their life and they wanted to pay forward the help that was extended to them. "I felt good about helping someone else because I had been helped so much" (Butterfly). Some participants talked about initiating a cycle of helping.

It's a cycle. You have that cycle. In order for something to stay good you have to create that cycle. It's *always* going to give back to you. *Always* going to give back to you. Yes, I truly believe that because I'm being looked out for, so it's up to me to look after someone else. And that's just my feelings, but that's a part of me paying it forward (Connie Laskowski).

Although participants talked about the importance of giving or helping, the urgency to give is not driven by a feeling of duty, but rather out of a strong desire to want to give to or help someone. A participant told a story about preparing a special meal for the medical professionals



at the Mattaponi Healing Eagle Clinic as a sign of his appreciation for their dedication to the Virginia Indian community. In addition, while participants talked about the cyclical nature of giving/helping and receiving, participants are not motivated to give or help with an expectation of receiving something in return.

This leads to the second quality of helping relationships described by participants: having no ulterior motives.

I think it basically goes down to it that you're touching someone else. Only you always have to be careful that the touching of someone else is on higher ground and there's no alternative reason for it. There's nothing to be gained your own self. You're giving it away for free, with no returns (Dorothy "Red Wing").

As another participant said, "...if you're doing it for praise or whatever, you're doing it for the wrong reasons" (Mac Custalow).

The third quality of helping relationships identified by participants was that helping relationships are relational. This has a few subsets to it. First, often the helping relationships in which participants are engaged, either as the giver or receiver, is an organic function of living in close community. Participants told stories of the ways in which they come to know about a need in their community and work independently or in a group to meet the need.

One participant described a fairly involved fundraiser she and her family organized to raise money for someone in their community who was having trouble providing for his family because of losing his job due to a medical condition. Many people from the community came together to organize and carry out the fundraiser for someone in the community, and the fundraiser drew participation from the community. The whole helping event, in all its dimensions, was an organic response to being in community.

Further, participants talked about other helping relationships in which they were engaged and how they shared themselves with the people which they were helping. "...if you do a kindness for anyone whether physically, mentally, of if you're speaking or if you even offered someone something to eat, you're giving back, and you're sharing yourself with someone" (Dorothy "Red Wing").

While participants told of giving or helping with no ulterior motives in mind, participants do describe benefits they experience from engaging in helping relationships. Participants describe a joy they experience in giving or helping. "There's a joy, you talked about giving, there's a joy in giving" (Mac Custalow). One participant tells of her love to give: "If I had two dollars and you needed it, I'd give it to you...Cause I just love to give. Yeah. I love to give" (Elaine "Dancing Owl" Custalow). Further, participants describe the personal healing they experience as a result of engaging in helping relationships. One participant explains, "The way I look at it spiritually is to help somebody else, the light of God has to go through you and it can't help but heal you too" (Roth Summoth).

When asked about where they learned to give so abundantly and sacrificially, participants shared of how the environments in which they were brought up modeled the importance and beauty in giving and helping. The stories of participants witnessing the various ways in which their families and communities "naturally" took care of each other are numerous. The following is an example:

Because up until recent years, there was no SSI, there was no aide, assistance, and people looked out for each other. You know, it was very typical to have either and/or both grandmother and grandfather living with their families in their later years. In some cases, uncles or aunts. You didn't just turn your back on somebody who needed help, I mean,

you made whatever adjustments necessary, and sometimes, you know, there were a number of people living in the same house, and living on limited resources, but you always, you made the stretch, whatever that required, to provide for someone who needed help, especially someone in your family or sometimes it wasn't immediate family. I remember many instances when my, when I was a little kid, and mom and dad would go to [nearby town] and go grocery shopping on Saturdays, and they'd come home and my great Uncle lived up the road from us and his second wife and he, now he did have some dementia but he was very old and he couldn't function, and they didn't have any money, so my mom and dad would go grocery shopping on Saturdays and they'd come back and on the back seat of the car they'd be some bags of groceries they had purchased for them and when they would come home they'd told us, "Children take this up the road, you know, to Uncle [...] and Miss [...]." And they would, I mean, and we didn't have much money, believe me, back then. I'm talking about back in the '50s when times were hard and, you know, but mom and dad would take a part of what they had to buy groceries and provisions for the family and take a part of that and buy groceries for them, to be sure that they had foods to eat, and whatever they needed (Mac Custalow).

While the above conversation highlight the various ways in which participants and their respective communities engage in generous, sacrificial helping relationships, both in the past and currently, it's important to recognize the hesitancy that sometimes goes along with asking for help. For them, at times it feels easier and safer to be at the giving end of the helping relationship than the receiving. The following story highlights the vulnerability and pride involved in being on the needing end of a helping relationship, as well as the strength involved in walking together

through a hardship. This story also highlights the reciprocal nature of helping relationships, all parties having something to contribute.

We need to have the strength to stand up and say, “I need help.” Sadly in Native culture we don't stand up and say, “We need help.” Because it, in our minds, it reduces us to being needy, and there's a pride thing with Natives. We don't want people to think that we are weak. And it's not about being weak, it's about I need somebody to help strengthen me as I walk, and to help guide me as I walk. As they're guiding me, I've got important things that I can leave in their life. It's all about walking together and not trying to walk alone and by yourself (Bonnie Sears).

Having addressed the role of spirituality, physical processes, mental and emotional processes, and social relationships in responsive and responsible health and healing, the role of particular contextual factors play in health and healing, the narrative has, yet, to address the last structural dimension of health: access to resources. Similar to social relationships that were about self in relation to people, access to resources is about self in relationship to social and economic resources.

### **Access to Resources**

Access to resources is the final dimension in participants' conceptualization of responsive and responsible health and healing that is yet to be addressed. Access to resources has to do with the ways in which access (or lack thereof) to social and economic resources such as food, housing, clothing, utilities, and health care is related to one's ability (or family's ability) to be healthy and heal. This section will address general assertions expressed by participants related to the relationship between access to resources and health and healing, particularly as related to two groups of resources: basic needs and health-related resources. In talking about personal access to

resources, participants also reference social and economic conditions present among “Western” Indian communities, drawing connections between “Eastern” Indians and “Western” Indians as related to social and economic conditions. This section will also address these conversations.

Participants talked about how access to social and economic resources is important to health and healing, and how lack of access to those same resources limits one’s ability to be healthy and heal. Poverty, or having limited economic resources, was seen as a barrier to accessing social resources that promote health such as food, housing, and utilities. Living in poverty, or with limited economic resources, was seen as a liability to the overall health of a person, family, and/or community.

People liv[ing] in poor circumstances, squalor, are I believe less healthy than people [that] sit here and live in a big, fancy house or have enough money...to go out and actually see a physician. [People living in poor conditions] have to sit and wait till somebody comes to help them” (The Old Sailor)

One participant described poverty, and all the subsequent ripple effects of poverty, as a disease in and of itself (Roth Summoth).

Participants identified two groups of social resources that in their presence are important to the promotion of health and healing, and in their absence, inhibit one’s ability to be healthy and heal: basic needs resources and health-related resources. Basic needs resources included access to adequate housing, running water, utilities, food, and ability to upkeep house. Most participants lived on a fixed income and feel the strain of trying to meet basic needs. Participants told about how the strain increases stress, which manifests in various ways including interrupted sleep and diminished physical health.

And [worrying how to pay for a needed house maintenance project] really gets to me because sometimes I can't sleep, thinking about it, and all...how I can afford it. That's the main thing that's worrying me. And also, I use a wood heater, we did ever since we've been in the house. We have a heat pump, but it doesn't warm the house enough, to me, you have to run the thermostat so high, and I can't afford to pay the light bill, it's so expensive running it hot enough to keep the whole house comfortable, so that's why we got the wood insert. Now, with my [health condition] I won't be able to handle the wood. And last winter I couldn't do that much, and I won't be able to do as much, you know, handle the wood as much this winter as I did last winter, so that's what's worrying me too. What am I going to do (Butterfly)?

Likewise, participants also talked about the challenges involved in accessing health-related resources needed to be healthy and heal. The health-related resource most referred to by participants is access (or lack thereof) to affordable medications, but also includes affording health insurance premiums and co-pays, as well as accessing quality medical care within reasonable distance from one's residence. The general age of participants is, again, important to keep in mind in discussions concerning access to health-related resources, particularly in discussions concerning access to affordable medications. Given the age of participants, most participants have Medicare as their primary health coverage plan. Participants told of their struggles with accessing needed medications, particularly during the time of year when they fall into the "donut hole," when the maximum Medicare payout per beneficiary has been met, leaving Medicare beneficiaries to incur the high cost of prescriptions, unless a secondary insurance is involved. Further, participants explain that Medicare does not cover all their needed

medications. One participant describes the exorbitant cost of his medications and the stress involved in trying to access his medications.

...medication for a three-months supply, that's not counting anything for [spouse], would be thirty-seven hundred and fifty dollars every three months. That's off the top of everything, before anything else. So that, when you're on a fixed income, that hits hard and sometimes you're trying to think, you know, what you could do, and not thinking about the other expenses that you have...it can stretch things pretty tight (Kind Heart).

Participants talked about knowing people who take half the dosage of medication that a doctor prescribed in efforts to stretch the length of time their medication will last. Participants told of spending long hours trying to piece together ways in which to access their medications, including pharmaceutical company assistance programs, as well as various community clinics.

Participants relied on the Mattaponi Healing Eagle Clinic (MHEC) to help defray the cost of their medications. MHEC has a limited pharmacy on premise and medications are offered free of cost to service-users. Access to free medications is one of the most sought after services available at MHEC. While supplies are limited, and not all medications needed by service-users are available, MHEC is instrumental in defraying the cost of medications for participants.

It's helped us a lot as far as medication...that's helped us financially because especially with [family member], we went into the donut hole being a senior citizen. And it's helped me a lot. Because I very rarely have to buy [a particular medication], very rarely. And I know some people down here are people that don't have health insurance or whatever, it helps them out a lot (Becky Adkins Branch).

The dramatically reduced availability of the breadth of medications offered at MHEC, as well as a reduction in the quantity of each medication available has really impacted participants who

have depended on MHEC for access to their medications. That being said, participants are forever grateful for whatever they can get. “Medicare doesn’t cover a lot of the medicine [spouse] needs. MHEC has been very helpful in giving him medicine. They don’t have all the medicine he needs, but anything is helpful” (One Who Looks Out For Others).

Further, participants talked about accessing quality health care, including dental care, that is affordable and within a reasonable commute from participant’s place of residence. Participants talked about challenges involved in securing stable, quality primary care.

...you have a doctor one day and the doctor could announce that they are retiring or moving on in so many months or something and be gone...There’s no stability...There’s no stability in the medical world out there...For those of us that are in a stationary position in our lives – retired, there’s no stability in the medical services provided. The situation is too fluid. When you’re retired, you more or less put your roots down and stay put in one place and you kind of like to have the same doctor and go to the same grocery store, and you know, so the same things, and can count on being able to do the same thing and see the same people, because every time you go to a new doctor, they got forty-thousand forms that you got to fill out, and, hell, I’m so old right now, I can’t remember my medical history back when I was twenty-years old (The Old Sailor).

Participants also talked about the lack of access to any dental care, affordable or otherwise, as most participants do not have dental insurance. It’s important to note, however, that while some participants talked about the challenges involved in accessing medical care, some participants told of being very pleased with the medical care they receive at various community medical providers around the area. Nonetheless, MHEC serves as a medical home for some participants,



as well as an important source of medical care in a network of health care providers for other participants.

Given the fixed income of many participants and considering the struggle expressed by participants to financially meet basic needs, as well as the struggle to financially afford health-related services, it makes sense that participants talked about juggling limited resources to make ends meet.

My family, my family and all who come to the Clinic. Everybody's doing the very best they can. There's quite a few who can't even afford to have any kind of insurance, you know, because jobs and everything and all. It's hard, you know. And when you have other reasons for your money to be taken from you, like electricity and everything else, it doesn't leave a lot for anything else...robbing Peter to pay Paul...no big Bahamas vacations in other words (Dorothy "Red Wing").

While participants talked about the struggles they faced in trying to make ends meet, participants considered their struggles in light of the struggles faced by "Western" Indians. "I'm sure we're much better off than people at Standing Rock...on other reservations. We're a million percent better. We actually have it wonderful, really, as compared to other reservations...In the whole picture, we're doing okay" (Dorothy "Red Wing"). Participants talked about the dire conditions faced by "Western" Indians including extreme poverty; limited employment opportunities; high rates of alcoholism, substance abuse, depression, hopelessness, and suicide; and poor quality medical care. These adverse conditions and circumstances were addressed in the context of past and present oppressive conditions and circumstances faced by "Western" Indians, and the ways in which the U.S. has consistently failed "Western" Indian peoples, now and in the past. These conversations were had in light of comparing their experiences and conditions with

the experiences and conditions faced by “Western” Indian peoples. Despite the hardships endured by Virginia Indian people, participants talked about the easier plight compared to “Western” Indian people.

Because there’s a *genuine* need out there, honey. But, our plight here has been much easier, much better, than those people out West. There’s an awful lot of prejudice, but they’re in a situation where they really can’t help themselves. Or they’re so down trodden that they can’t see that there’s a better way or there’s a way to get there. You understand what I’m saying? When you’re beatin’ down so long, and so hard, again, what we talked about, hopelessness takes over, and you’ll even quit trying because you think, “Why expend the energy? Why even try?” So you quit trying. You give up. That’s sad. That’s sad. But I’ve lived through some hard times. Thank God it’s much better, but there’s some of those people out there, it’s no better, it’s no better, and that’s wrong, that’s very wrong (Mac Custalow).

With all structural elements having now been addressed, a direct conversation about the interconnected nature of these dimensions can now take place.

### **Interconnection Among the Dimensions**

The dotted lines that cross-connect each of the four dimensions located on the circle – physical processes, mental and emotional processes, social relationships, and access to resources, represents the way participants envisioned the four dimensions as interconnected. The dashed line that provides the structure of the circle represents participants’ sense of permeability, folding the dimensions of spirituality and context into the interconnection. Because participants envisioned health and healing in such an interconnected way, the interconnection among dimensions has been alluded to in some of the quotes in previous discussions relevant to each of

the dimensions respectively. However, this section directly addresses the ways in which participants talked about the interconnection among the various dimensions as related to health and healing. It's important to note going into this section that not all participants made all the connections among all of the dimensions represented in the conceptual framework, but all of the connections represented were made by at least one participant.

This section will first address the ways participants envisioned the interconnection of the various dimensions as they relate to health. As participants conceptualized their personal health as an interconnection among dimensions, participants similarly envisioned the need for an interconnected approach to healing. This section will also address ways in which participants talked about an interconnected, holistic approach to healing, as well as specifically identify the various healing practices proposed by participants to support their holistic perception of health.

### **Interconnected Nature of Health**

While all four dimensions positioned on the circle in the conceptual framework are equally important to the way participants thought about health and healing, there seemed to be substantial focus on the strong interconnection between physical processes, mental and emotional processes, and spirituality:

[Being healthy includes] not only the physical, it also includes mental and emotional health. I think those are the three aspects, the most important of course, your heart and your soul, but the key is the emotional, the mental, and the physical (Loyal Oak).

In regard to the interconnection between physical processes and mental/emotional processes, participants talked about the relationship between the two dimensions in two different lights. One perspective told of the interconnected nature of mental processes (i.e. thoughts), emotional processes (i.e. feelings), and physical processes. In this relationship, participants'

thoughts affected their emotions, both of which then affected their physical health. “[Negative thinking] affects you emotionally, which everybody knows your emotional health will affect your physical health. i.e. me being stressed and getting [particular physical condition]” (Becky Adkins Branch). Some participants told stories about the ways in which anxiety manifested physically in their bodies. Participants recounted how they thought they were having a heart attack, but, in reality, they were experiencing a panic attack from high levels of anxiety due to various circumstances they were facing at the time. Likewise, some participants also told of the ways in which their physical health affected their mental and emotional health.

You gotta feel good, too, I mean all over...In your mind, mental health has to be good also. And I think for your mental health, you have to feel good physically in order for your mental health to be good. And you also have to have your mental health together for your physical part to be good (Connie Laskowski).

Another perspective held by participants concerning the relationship between mental, emotional, and physical processes viewed the dimensions as separate. “Cause I know of instances where people are physically able but have debilitating emotional issues” (Mac Custalow), and, vice versa, participants told of instances where people suffered with a particular physical condition but had strong mental and emotional health. Several participants voiced concern about people who think they’re physically sick when, in fact, they are physically healthy, and noted that a person can sometimes make one’s self physically sick through talking one’s self into being sick. In the end, the two perspectives related to the relationship between physical, mental, and emotional processes are not discrete camps, but rather situational in nature.

Participants talked about the way spirituality plays an important role in the interconnected nature of health. “[Spirituality] can help you have a better attitude about life and by having a

better attitude, you have more life in you, or energy” (Wewoka Adkins). While some participants envisioned the their spirituality was connected with their physical health and mental and emotional health, some also considered how spirituality was also connected to their social relationships:

[Referring to participation in Bible studies] Really the spiritual part, I enjoy being with the people and then we do [Bible studies] like in the home and just sitting around the table talking, and then sometime we get off the lesson and we’re telling how each one feels, you know, “I’m having a problem.” We pray for each other. And umm and everyone’s problems seem to be different. And we’ll share how we’re feeling, how we have felt and everything. And it’s, it’s really great. That helps a lot. I really enjoyed that (Butterfly).

The above quote highlights the interconnected relationship between spirituality and social relationships. Like the interconnection participants saw between spirituality and physical processes, and mental/emotional processes, participants also talked about the interconnected relationship between social relationships and mental health and physical health. “[Social connections are] definitely good for your mental health, as well as your physical health” (Mac Custalow).

For participants, the history that Native people have had to endure (past and present) has taken a toll on their bodies, minds, emotions, spirits, and social relationships. Discussion of the relationship between health and history provoked a lot of emotion among participants as they recounted the ways in which history manifests physically, mentally/emotionally, spiritually, and socially among their people. References to the relationship between history and health largely seemed to be references to Native peoples broadly, inclusive of, but not specifically in reference

to Virginia American Indian people. Some of the references are directed toward “Western” American Indians, and some are specific to Virginia American Indians. I am intentional to identify when the references are specific to “Western” American Indians and Virginia American Indians, respectively. It’s important to highlight the sensitive nature of this topic. Some participants chose to directly talk about the hurt and some participants chose to remain silent about the topic. I honor the decision of all participants to engage with the topic as they felt was right for them.

Native people were living their lives just fine prior to European contact, but then: Bam! [Our way of life] got destroyed. Like I said when history slams you back, you know, all your life, for hundreds of years your ancestors, then you’ve got that hundred years to catch back up... Yes [history affects our health] because more stress, more worry, more depression, so that brought on more illness, more mental problems, more alcohol, more drugs, more suicides. Yeah, I do. Because it’s still happening right now (Connie Laskowski).

Participants talked about how history was at the root of several mental and emotional conditions including depression, stress, anxiety, hopelessness, and lack of self-worth; social issues including alcoholism, substance abuse, and suicide; and physical conditions.

I think history plays about 75% of the causes of some of the diseases with the Native Americans. ‘Cause, again, we’re talking whole person – spirit, mind, and body. When you’re eating the incorrect foods and then when you feel oppressed and you feel the hopelessness and you see people being killed and you see yourself going nowhere, your body reacts chemically to all those (Bonnie Sears).

Participants told of how history had a negative impact on the health of Native peoples, but sometimes the effects of history were not immediately recognizable. “Whether you recognize it or not it has to affect you. I think sometimes some of those feelings bear deep” (Kind Heart). Sometimes the effects of history manifest physically, mentally, or emotionally decades after a particular encounter.

And does it affect your well-being? Imagine being in a society that fails to recognize who you are. You know who you are. And then you have to go out and prove who you are. And it’s just maybe you say, “No, it doesn’t affect my health or well-being,” but sometimes, what we have doctors and all this for, sometimes they have to dig and dig to find out what is causing things to happen to you that happens now. Because I didn’t know that I had blanked out so much stuff until I was having [a particular health problem], this is a lot of years ago, and I was sent to a Christian counselor, the doctor sent me, and that’s when I found out that I had blanked out so much, because I had come against something I couldn’t handle, and it just, so a lot of times it affects us and we don’t even realize that it is, and we just, we just keep going on (Kind Heart).

Participants also talked about the way history has impacted one’s perception of self-worth. A participant working with a Sioux grandmother raising her seven grandchildren told a story of how the participant raised money for the grandmother and her grandchildren to stay in a nice hotel while visiting a family member in a hospital located away from their home. The participant expressed being excited for the respite the hotel could offer the grandmother and her grandchildren as the hotel offered a complimentary hot breakfast, cable television, and a swimming pool. When asked about her difficulty enjoying the respite, the grandmother told the

participant, “But you know what? I feel like I don’t deserve it. It comes from my past in a boarding school. I feel like I don’t deserve it.”

In addition, participants told of the way in which history affects the healing process. One way participants envisioned history inhibiting the healing process was the diminished empowerment to advocate for one’s access to needed resources to be healthy. One participant told of advocating for a particular Virginia Indian woman trying to access a needed resource.

But you see if she went in there again, I’m pretty sure that she would just not say a word, it’s just accepting they’re in power and they know more than me. And she’s been so oppressed that, and, so it’s just, I really think a lot of the history of prejudice and everything does have something to do with it (Roth Summoth).

Another way in which history affected the healing process is how history has interfered with Virginia American Indian peoples’ ability to heal using traditional practices. Participants told of the ways in which the traditional healing practices of their ancestors, particularly related to the harvesting and use of natural medicines, has been lost.

The knowledge [of the Old Medicines] isn’t there anymore. That’s very true. The knowledge isn’t there anymore. It’s gotten lost as to what you...when my grandmother was alive, my grandma still knew what to go to the river and get. Knew all about sassafras roots and another little root she would get from there for upset stomachs and things like that, but unless my mama can recognize it I don’t know what it looks like. Lost. Lack of knowledge. Lack of knowledge. And then, too, we weren’t allowed to continue our practices. Umm, time, construction, destruction, construction, has taken a lot of the land away where all that was grown and found, trees, so it was really no longer available, unless now it’s still especially grown somewhere or where they can ship it in,



you know, these special herbs and what not, but they're still not like what they used to be. So time, history, lack of knowledge, progress, as they call it, has all played a role. It has weakened us as people (Connie Laskowski).

While participants identified a relationship between history and health, perspectives regarding the nature of the relationship varied. One perspective recognized that, indeed, history did have a negative impact on the health of Native peoples, but Native peoples of the past, not current.

...people back years ago it probably had an effect on their health, I would think. But I really don't think this day and time, you know, this time now, people aren't affected by it. I wouldn't think. I wouldn't want to be living back in the days when all that stuff was going on, loss of identity and all of that. I sure wouldn't want to have been living back then, in those days. Cause at one time, there wasn't but two races. There was Black and White (Wewoka Adkins).

Another perspective acknowledged that history negatively impacted the health of Native peoples of older generations, but not the younger generations. "Probably [history affects the health of local Native people], our age group more so than the younger ones. Yeah because the younger ones haven't had to face any of that" (Kind Heart). It seems participants identified direct exposure to an unjust experience, or perhaps a certain degree of unjust exposure, as a condition for history to negatively affect one's health, or the collective health of a group of people.

As the participants have shared, experiences of oppression, discrimination, and prejudice affected the physical, mental, emotional, and social health of Native people broadly, and participants specifically. This highlights the interconnected nature of the dimensions of responsive and responsible health and healing, particularly the way elements in the context affect

physical processes, mental and emotional processes, spirituality, social relationships and access to resources.

### **Interconnected Nature of Healing**

For participants, a multi-dimensional, interconnected perspective of health calls upon engagement in healing practices that are similarly multi-dimensional and interconnected. Some of the healing practices identified by participants may seem relevant to a particular dimension of health; thus, appropriate for discussion within the respective dimension to which it would first appear to fit. However, they often talked about the interconnected function of a particular healing practice. For example, it seems like exercise would be a healing practice specific to the physical dimension. However, in addition to addressing how exercise was good for their physical bodies, participants also talked about how exercising made them feel good mentally. Further, participants also expressed how exercise supported their social relationships as they told stories about the fun of exercising with friends. Given the multi-dimensional benefits participants associated with many of the healing practices they talked about, and to highlight the full scope of healing practices identified by participants, healing practices will be addressed together in this section. This discussion will focus on the ways in which the practices identified by participants support a multi-dimensional, interconnected perspective of healing. The section will address the various healing traditions practiced by participants, self-care activities practiced by participants, and healing strategies related to mental and emotional health practiced by participants.

**Healing interventions of various healing traditions.** In regard to health care, participants told of the ways in which they engage with both Western healing traditions and non-Western healing traditions of various types.

*Engagement with Western-informed health services.* Participants engaged with the Western medical health system for the purposes of primary care and specialized care, as well as emergency medical care. Some participants talked about how routine check-ins with their primary care doctor are important to their health and healing. “I go to [name of community health practice] and I can get my medicines through there and I have a general practitioner that monitors my health. And so I have that security because I like her and she’s a good doctor” (Roth Summoth). Others talked about how regular engagement with specialty medical care for management of a chronic condition such as diabetes is key to maintaining their care.

My endocrinologist, she is *dynamite*. She is something else. She’ll do this work on me. She’ll send you to the lab, three days later I gotta be in her office, she goes over all that stuff with you, tell you what’s happening, what she wants you to do, change up medicine...And she gives all the lab work, it’s about five or six pages, and then the coversheet is the time before, last three months ago when she saw you, and the time she’s talking to you...She’s extremely thorough. Yeah, I love her. She says, “[Name of participant], this is going to kill you. You can’t get rid of diabetes. It’s going to kill you. All we try and do is *buy* you some time. I mean she’s right up front. But then she really digs down deep to help you make those changes too (Lorraine Hedgeman).

In addition to medical care, some participants also engaged in mental health care. “[After a particular hardship], I did see a psychiatrist and she helped me tremendously. And she gave me her card, and she told me I could call her night or day if I wanted to, but so far I haven’t had to contact her” (Butterfly).

For other participants, though, they talked about feeling healthy enough to only engage in Western medical services annually for check-ups.

[My spouse and I], thank God that we are as healthy as we are for our age and all. We don't go to the, we don't require a full fledged doctor all the time. See we only go whenever we have a true necessity need...Most of ours is, like when I injure myself and have to go to the emergency room" (Dorothy "Red Wing").

Emergency medical care leads to the next type of engagement participants referred to in regard to their use of Western medicine. Several of the participants recounted various times they and/or their families had relied on Western emergency medical services throughout their lifetimes for traumatic events and/or acute illnesses needing emergency care. To protect the confidentiality of participants requesting to remain anonymous, direct citations will not be included here because of the potentially identifiable nature of the events. Suffice to say, participants *all* expressed being satisfied with the care they received at mainstream medical hospitals. One participant expressed a dissatisfaction with the care she and her family received from a particular physician, but reported being satisfied with the overall care (i.e. nurse practitioner and nurses) she and her family received. In other words, no participant expressed feeling like that had been met with any discrimination when accessing Western medical services. This is not to suggest that participants have not experienced discrimination when accessing Western medical services, but no one talked about such experiences during interviews.

Medication management is probably the area in which participants reported having the greatest degree of interface with Western medicine. Overall, participants reported what seems to be a complex relationship with medications. Collectively, participants took medications for the management of a plethora of chronic medical conditions: diabetes, blood pressure, allergies, anxiety, depression, sleeping, pain management, etc. While participants told of how medications

were an important part of managing their health, several participants also talked about how there is an over-reliance on medications in our society.

I believe you can over do it with the doctors, too. Because a lot of these doctors, all they want to do is fill you up with pills, and that can help, help with some healing, plus it can be a deterrent to healing, too. I believe a lot of people are on too much medicine (Wewoka Adkins).

One participant told of the way she believed medications were “building up in [her] system, unbeknownst to [her], and would cause like a poisoning or overdose” (Connie Laskowski). Several participants reported having decreased the number of medications they had been taking. “[Taking prescribed medicines] Not like I used to. I take eight [medications] in the morning...it used to be seventeen, used to be, but now I take eight” (Elaine “Dancing Owl” Custalow). Participants described judiciously weighing which medications to take, how often, and how much:

I take one pill at night to help me sleep. I lay in bed and I just cannot go to sleep so I take one pill at night and, well, I’m supposed to take a half pill in the morning, a half in the afternoon, I don’t take it in the afternoon, unless I absolutely need it, I do not take it, so I’m trying to do it without it. I know getting off some of the medications will help me feel better as well” (Butterfly).

One participant described working with her doctors to “wean off” of some of her medications. “I’ve lessened my medicine by more than half...and I’ve let my doctors know what I’m doing because I had to *wean* off of them. I couldn’t just go cold turkey with any of them” (Connie Laskowski). Another participant described feeling better after having decreased some of his medications. “Eight years ago I used to take six prescriptions, now, I have three. That’s because I

decided I didn't want to take them anymore, and it didn't change my health, or my feelings, or anything...I have never felt better" (Dennis Hogge).

Participants saw Mattaponi Healing Eagle Clinic as a key component in meeting their medical needs, both for access to medical care provided by Western-trained medical professions and medications. For example, one participant weaves a particular MHEC physician into a network of doctors she visits in the community to augment her care.

He's [particular MHEC physician] a good doctor. Yep, and he helped. Whatever he can help you do. Write you a prescription. Tell you how he thinks you should do certain things. You know. To me, I don't like to miss when he's going to be there. I like to go because I never know when he's going to tell me something different [from community specialist]. He looks at my labs at stuff and tells me what he think. You know, which helps *a lot*...and I give [medical report from specialist] to [the MHEC physician], and [he] looks at it and puts his little remarks on it, talks to me about it...Yeah. And that's one of the reasons I like coming to the reservation, to [the physician]. He's thorough (Lorraine Hedgeman).

Another participant told of the way she and her family rarely used mainstream medical care save for emergency care and yearly checkups, but rather relied on medical care at MHEC for regular check-ups. "We count on [MHEC] a lot for everything we receive, and we greatly appreciate it, you know, for the little booboo things" (Dorothy "Red Wing"). Despite their complex relationship with medication, participants overwhelmingly recounted the ways MHEC met their pharmaceutical medication needs that would otherwise have gone unmet, jeopardizing their ability to be healthy. "And the Clinic has definitely helped a lot, helped us a lot, financially as far as medication" (Becky Adkins Branch). Whether a medical home, an important source of

medical care in a network of health care providers for other participants, and/or a place to gain access to free medications, MHEC plays a significant role meeting the Western health needs of the Native community it serves.

***Engagement with non-Western informed health services.*** As some participants shared, there is an over-reliance today on the use doctors and pharmaceuticals in the healing process. In addition to engaging in Western-informed health care, participants also told of various types of non-Western health care in which they engaged. While a diverse array of non-Western health practices were identified by participants, the common denominator seemed to be that their preferred non-Western health practice was more holistic in nature than Western-in formed care that mostly addresses the physical dimension of health.

For participants, incorporating a spiritual component into their healing practices was important. One participant identified practicing “Eastern philosophy” healing practices

I would practice more Eastern philosophy than Western philosophy. Eastern philosophies, they have the medicine that is different than the Western philosophies. The Western use more chemicals, the Eastern philosophies, they deal with medication and yet it works differently than the way Western philosophy of medication is and medicine, so I could see the difference. The Eastern philosophy of medicine was again related to a spiritual aspect, overlooking the spirit, and trying to get the spirit built up better, and in American, they still practice some things related to Eastern philosophy. Now today you see that more and more (Loyal Oak).

The same participant talked about how spirituality is “definitely a big part of [Native American] medicine,” but noted that [Native American] medicine has “changed from the past” due to a lot of oppression experienced within Native communities (Loyal Oak). Nonetheless, this participant

shared how “[spirituality] has become, over time, a little more open [in Native communities] and [Native people] have started thinking about their spiritual health, connecting that with their work” (Loyal Oak).

Some participants talked about incorporating a healing tradition connected to a particular culture into their healing practices. For example, some told of practicing Asian medicine such as acupuncture. Another participant commented, “...*all* cultures have something to offer [regarding healing practices]. Everybody has something to offer. We have to keep an open mind to that too. And I think that that’s really interesting” (Connie Laskowski).

The use of vitamins and naturally derived substances also served as an alternative to Western-based health care. Several participants talked about taking herbs and vitamins to support their health. One participant talked about how taking herbs and vitamins has helped her wean off of some medications that were, “unbeknownst to [her], caus[ing] like a poisoning or overdose” in her body (P. 3). Another participant shared how Natives would “eat the cactus pads, prickly pear cactus pads [to] help bring blood sugar into alignment” (Bonnie Sears).

All-in –all, though, participants expressed a need for blending types of healing traditions. “Everything’s of spirit...you pray for your people and you pray for the Earth Mother because it’s never separate to us. It doesn't mean that all of the wonderful things that have come from medicine is not good, it is good” (Roth Summoth). A story shared by one participant highlights the way in which he personally blended two healing traditions.

It wasn’t a conflict [for me to receive Western medical care in the hospital when the spirit part and the Eastern part is important to me]. I’d say that I just gave it all to God. I gave my care to God. I trusted Him and that He led me to these doctors, these amazing wonderful doctors. I knew that God had a purpose for all of this. Whether you have the



Eastern type or the Western type of medicine, there is no wrong or right, the point is that God has provided all of it. So you know taking care of my health, I really appreciate the [doctor] who did that. The Bible says in Luke, Luke himself was a doctor, a physician, he wrote one of the gospels, so he had experience with the medical aspect and he was a healer and it was God's intent to use a doctor as a person who, you know, to me that shows that God doesn't have a conflict between medicine and the East and the West. God will make it happen regardless of which kind, by His supernatural power, through the doctors. God gives the doctors the ability to do what they do. Medicines come from all of nature anyway, they come from the trees and the plants and they provide healing, that's their purpose so God has a purpose for it all, so you use both (Loyal Oak).

Participants identified healing practices of various healing traditions as important to supporting their multi-dimensional, interconnected perspective of health and healing. In addition to engaging in an assorted array of practices from a variety of healing traditions, participants also identified a diverse array of self-care activities that they engaged that supported their ability to be healthy and to heal.

**Self-care activities.** This section addresses five major groups of self-care activities in which participants engage: empowerment, compliance with medical care, lifestyle choices, mental/emotional care, and activities of enjoyment.

**Empowerment.** Participants described *empowerment* as being confident and motivated to act in one's best interest regarding their health. Empowerment was about being knowledgeable about the decisions participants had to make pertaining to their health, "not just accept[ing] anything that anybody says to you" (Roth Summoth). Ask doctors questions in order to gather the information needed to make the best decisions pertaining to their health, as well as

“researching and looking to see what else you can do that’s best for yourself” (Bonnie Sears) were identified as important activities to gather the necessary information to make informed decisions about their health. “Sometimes we have to make decisions that are not popular or are not easy to make, but we have to choose those things in order for ourselves to be healthy” (Bonnie Sears). One participant told a story about advocating for herself in order to get the care that she felt she needed to be healthy, and, in her case, for her survival.

I had a situation that could have cost my life. And I was truly very, very close to it costing my life. And to find someone in the medical profession to help me with this problem, I had to go spiritually through God himself or otherwise I would have ceased to exist. I would be gone because I was very close to actually leaving this world. My condition was deteriorating...I had to go through God for the healing. And I had to go through God to find the person that would take me seriously and want to actually not diagnosis what they thought was wrong with me, let me tell you what is wrong with me. And then let’s fix the problem...And the medical professional that I went to, I completely turned her thinking around into a whole different way...It was a surgical situation. But I told her, I says, “You’re either going to save my life or you’re not. And to save my life, then you’re going to have to trust what *I* tell you and take it that that’s what’s wrong.” And she did. And she called me her miracle person, and that I was like no one else she had ever met in her life, and that I totally turned her way of thinking around...So, I said “Because you’ll have to believe what I tell you, not the medical or the book learning to save my life.” I said, “And if you’re not willing to do that, then I will have to search again to find someone that will.” And she said, “What?” I says, “It’s on that, it’s that way. There’s no other way” (Dorothy “Red Wing”).

Participants identified barriers to being empowered including a person's education level, with higher education helping to gain access to resources; a history of oppression; and having been in an abusive relationship.

***Compliance with medical care.*** Participants identified compliance with medical care as a self-care activity connected to health and healing. For participants, compliance includes preventive care activities and healing activities such as getting recommended blood work, regular mammograms for women and prostate screenings for men, taking medications as prescribed, achieving and maintaining "good blood sugars" (Bonnie Sears), keeping cholesterol levels down, and attending medical appointments.

***Lifestyle choices.*** For participants, exercise, diet, and alcohol, tobacco, and illicit drug use are lifestyle choices that are related to health and healing.

***Exercise.*** Participants talked about various physical activities in which they engaged to sustain or improve their health and fitness: walking, running, riding a bike, dancing, participating in exercise classes such as Zumba, and using cardio machines at the gym such as the elliptical machine. For participants, exercise seemed to function as an activity that supported a multi-dimensional, interconnected perspective of health. "...exercise will help you to control how you actually feel and your weight and your general health" (Dorothy "Red Wing"). Several participants talked about how exercise made them feel good and have more energy. "I felt so much better when I was dancing. I wasn't as tired. I had more energy. Movement feels good" (One Who Looks Out For Others). Some told stories about the way in which exercising reduced their need for certain medications. For example, "When I walk I feel better and don't need [my] [anxiety] medication. If I can get out there and walk, I feel so much better" (Butterfly). Overall,

exercise was seen as a protective measure to maintaining good health, as well as an important activity in recovering from ill health.

*Eating right.* Along with exercise, participants also saw eating in a healthy way as an important component in maintaining good health and recovering from ill health. “It all goes back to eating properly” (Wewoka Adkins). For participants, eating in a healthy way has to do with the food they eat, as well as the quantity and frequency with which they eat.

You have to find a way around the guilt if you’re overeating, or if you’re over indulgent. That in it’s self is a hard struggle for everyone. Am I eating the right amount? Am I eating good things? Is the quality of everything equally as good as it would be if I didn’t eat those certain things (Dorothy “Red Wing”)?

Further, the quality of food today and the preparation of food were also seen by participants as connected to health and healing. In reference to the quality of foods, some participants talked about the way “half of our food now a days is engineered; it’s not natural anymore” (The Old Sailor). Others lamented about the preservatives, food dyes, and steroids found in our foods today. For participants, many envisioned a link between the compromised quality of foods and the rise of certain diseases such as cancers and Alzheimer’s. “I think a whole lot of these diseases are diet related” (Wewoka Adkins). One participated elaborates:

I will go to my grave believing a lot of the cancer we receive today and people experiencing it is coming from what we eat and drink. All of the preservatives and colors and all the stuff they’re putting in it and things and we don’t even know they’re putting in. Plus, I firmly believe that steroids that we’re feeding the animals and the birds and stuff that we eat, I believe that is a major contributor to cancer. And I say all of that to say this, when we were young and lived a different lifestyle, out there on the Reservation, and

so forth, we ate primarily what we raised. We had none of that... We didn't use all of that spray, and all the insecticides that we use today. I believe we are killing ourselves, with that. But I believe [eating what we raised and lack of use of sprays and insecticides] made for a healthier life for use, while we worked, plus we worked awfully hard, so you got a lot of exercise doing that too (Mac Custalow).

In addition to the quality of foods, participants also linked the preparation of food with ill health. "Well I think diet plays a lot in health issues because of the fatty foods, the greasy foods, the loading down with sugar, I think that has a lot to do with the health issues" (Becky Adkins Branch).

Similar to exercise, eating right seemed to function as an activity that also supports a multi-dimensional, interconnected perspective of health. For example, one participant talked about how eating affects both how she feels physically as well as mentally and emotionally:

When I eat poorly, I feel poorly and I think poorly; when I eat well I feel better, my whole body processes better and I think better. And then when emotional struggles come or if I'm eating a good source of nutritious foods, the stress doesn't seem as bad as when I'm trying to dine up on potato chips and pretzels and things that I shouldn't be eating (Bonnie Sears).

For participants, diet was also connected with social relationships. Some recounted stories about the forethought that goes into planning a menu and preparing food for family and community gatherings to accommodate people with various health conditions such as diabetes, and how these food accommodations often became the topic of conversation at the gatherings.

It's a running thing here. Like the family comes and our son wants to know if anything is not sweetened with sugar. He says [artificial sweeteners] leave an after-taste. He says he

can't handle [artificial sweeteners]. He comes in, like when we have a family get-together, "Mama is the tea sweet or the lemonade?" I say, "Yes, they're sweet." And you taste them and they are sweet. And he tastes them, and he is satisfied. Everybody knows, the kids know, but him, I do not sweeten anything with sugar. I'll do it for any diabetic can drink it and they'll be fine (Helping Hands).

Diet was also connected to history. Participants talked about the ways changes in the diet of Native people through the generations is linked to poor health in Native communities. A quote by one participant beautifully illustrates the relationship between health and healing and the interconnection between historical context, diet, and exercise as related to participants and Native communities at-large:

...but it's the way we eat. And the reason I say that is before the Europeans came over, we were healthy. Then we started getting white potatoes, white rice, white sugar, our bodies were not accustom or acclimated to that and so we began to not only eat what we had, but we were eating what we were getting from the Europeans and our bodies were not created to eat some of that stuff, and so because of that, our bodies developed other diseases. Diabetes, most people and most families, I understand, with Natives, is it's passed down from generation to generation, as well as it is with Europeans, but the Europeans were accustomed to eating the flour, they were accustom to eating the sugar, that was something, the sweetest thing we ate was honey, and so we ate stuff that was natural, and now we have all those processed foods, and the processed foods are not good for us, and so the pancreas can't take just a certain amount of things. I also understand that in some cultures, because they've eaten different things, different types of cancers have formed. You know, I have been researching that. But, you know, that's in my

understanding. And so I think it's been the change in the acclimation of what we're eating and what we're doing. We're not doing the work we used to do, that's why I see an increase in heart disease over the years. People are used to being farmers, going at it, working hard, so if they ate pork chops and fried chicken in the morning, they worked it off, where now we're eating the same amount of food but we're not doing the work related. In other words, we're not working as hard. Some of us have desk jobs, some of us have various other types of jobs where our bodies don't need all of that harsh food (Bonnie Sears).

*Alcohol, tobacco, and illicit drug use.* For participants, alcohol, tobacco, and illicit drug use were connected to health and healing. Some participants talked about how "excessive" use of these substances are related to ill health.

Drinking excessively or smoking, especially, and doing all the other drugs, drugs not prescribed by a doctor. And even drugs that are prescribed by a doctor that aren't taken in the proper fashion, or in the way they were meant to, those people aren't healthy, part of its mental and part of its moral (The Old Sailor).

One participant talked about the importance of moderation and saw having a beer with pizza as acceptable, but personally chose to abstain from the use of alcohol in recognition of the devastating effects of alcohol in Native communities. Another participant talked about the significant role a cup of coffee and a cigarette played in her morning routine:

Coffee and a cigarette. Yep. Don't talk to me in the morning till I have my cup of coffee. Then we're able to talk. Now the second one, I'm fine. I just need that first one. I can be in there in the bed, and somebody, "Coffee ready. Coffee ready" [referring to the home

health aide yelling from the kitchen, “Coffee ready.”] I get up...I get up. Coffee and that cigarette. Do wonders for you (Elaine “Dancing Owl” Custalow).

*It's a choice and it's hard.* For participants, lifestyle activities were closely related to health and healing. Eating a healthy diet, exercising, and, for the most part, refraining from excessive use of alcohol, tobacco, and illicit drugs, were seen as activities that promote being healthy. However, participants acknowledged the important role of *choice* in living a healthy lifestyle, as well as lamented about how the choice to live a healthy lifestyle is *hard*. In regard to engaging in lifestyle activities that support being healthy, making “the right choices and the right decisions on what you want to be healthy about” (Dorothy “Red Wing”).

For participants, it seems there were things in life that cannot be changed that influence our health (i.e. genetics), but, regardless of what couldn't be changed, participants still had power to influence their health by the lifestyle choices that they make.

I mean my grandmother had diabetes, my mother has diabetes, I have diabetes, so it's a family, a family line. My father's people have diabetes, so, when they told me I had it, it was like, well it's all in the family. What I choose to do with it is a whole different thing. If I choose to take care of myself then I can live a healthy life, I can walk in a healthy way. If I choose to eat everything in sight, I can loose my fingers, my arms, my toes, my feet, it's all in the choices that I make (Bonnie Sears).

Participants seemed to suggest that there is an element of personal responsibility in taking care of themselves.

You choose in the morning what you're going to have for breakfast, you make a conscious decision. It's not like you just reach in and start grabbing stuff and putting it in



your mouth. You can't say the devil made you do it because he doesn't have a gun to your head (Bonnie Sears).

As participants recognized that engagement in lifestyle activities that promote health was a choice, participants also acknowledged that making healthy choices was hard. Choosing to eat the right foods is hard, as one participant joked: "And I don't know, it looks like as you age, a good rule of thumb is, the foods you like you can't have anymore...that is really the truth" (Red Cloud). While there's a personal challenge in no longer being able to eat the foods one enjoys, participants also told about the challenge involved in trying to prepare a family meal while accommodating the various food limitations of family members.

We don't eat healthy. We don't eat complete meals. Well, a lot of ours is because of limitations on diet. Yeah, because there's a lot of things I can't eat. There's a lot of things [my mother] can't eat. And we just try to eat what's appropriate for us to eat (Becky Adkins Branch).

One participant living with diabetes recounted the struggle in choosing to eat a healthy diet, which is incredibly important to the well-being of people living with diabetes.

And I consider myself rather *lucky* that I didn't get diabetes until I was older. But it's a dog. You be so hungry. You go get something, you *crave* something you know you're not supposed to have, and if you're tired enough, you go ahead and eat it (Lorraine Hedgeman).

Similar to the ongoing struggle involved in choosing to eat a healthy diet, participants also recounted the struggle involved in exercising.

But it's hard, it's hard to push yourself to try to stay healthy. Because no matter what age you are, you still need to get out and exercise on a regular basis. It's hard, it's hard to push yourself to do it (Wewoka Adkins).

Overall, participants recounted the significant role lifestyle choices played in promoting or inhibiting their ability to be healthy. Participants talked about the personal responsibility they had in choosing to make the right lifestyle decisions to be healthy, as well as lamented about the struggle involved in choosing to maintain a healthy lifestyle. Several of the lifestyle choices addressed by participants highlighted the multi-dimensional, interconnected nature of health and healing. Next, this section on self-care activities will consider activities identified by participants that support their mental and emotional health.

**Mental and emotional care.** Participants identified several self-care activities connected to supporting their mental and emotional health: feeling good about one's self, forgiveness, staying on the positive side, humor, remembering, and activities of enjoyment. While these activities may seem directly related to one's mental and emotional health, participants acknowledged the ways in which strong mental and emotional health are related to other dimensions of healing and healing.

***Staying on the positive side.*** Overwhelmingly, participants recalled how staying on the positive side was an essential component of healing. Staying on the positive side referred to positive thinking, having fortitude, being grateful, and having humor. Participants recounted endless stories about the relationship between staying on the positive side and healing, both in their personal lives as well as in the lives of loved ones.

For participants, positive thinking and having fortitude, or as one participant said, the "want to" (Connie Laskowski), to go on despite hardship was essential to healing. The

following quote captures the urgency expressed by participants when talking about the importance of positive thinking and having the “want to”:

You want to rise *above*. Just tell yourself you want to rise above. This is going to get better. This is going to get better. If you can't say anything else, that's one positive statement. This is going to get better. Because you sure don't want to let it get any worse. So it's going to get better. That is healing because it is a positive mental thought. That's healing right there. You've got to admit it. Then you have to have the *strength* to go and get it. And if you go and get it and seek, just keep thinking, it's going to get better, each step you make, it's going to get better. You can pull yourself out of it. And that, right in itself, that's good mental health, that's good physical health. Just keep saying “Yes I can” because you say “Yes I can” instead of “No I can't. No I can't.” And you're just going to end up nothing to nobody. And you're either just going to die depressed and lonely or die drunk or O.D. You're going to fade, you're going to go nowhere. You're just going to die as a person. So, yeah, it's gotta come from within. It's. Got. To. Come. From. Within. [each word stated succinctly] You still have to have some want-to. That in itself makes a big difference in your healing, whether it be your mind, your body, your soul, your spirit. It's you've got to have the want-to (Connie Laskowski).

Participants recounted stories of people in their lives, including themselves, who overcame seemingly insurmountable circumstances through the power of staying positive and having the determination to get through it. For example, one participant told a story about how he relied on positive thinking to help him through a particularly difficult situation in his life concerning his physical health.

When I was in the hospital and I was sick, I couldn't fight anymore, and the doctor talked about my [health condition] and he wrote out all the different things that was going on with my [health condition], a long list of stuff, and I read it, and the words and the vocabulary was kind of hard to understand, and the doctor was saying, you know, "What I've written is just a fact." So I had to give that all up. I can't fight with my own nature to try to find a way to be healthy. There was no way I could win in that way, so I just had to accept that I had that bad health and that the doctor needed to find some way to be able to help me, and I had to stay mentally positive throughout it all, and get through it. It did work. The doctor's plan worked, so I am grateful (Loyal Oak).

Participants acknowledged, however, that staying on the positive side was not always easy.

Well, sometimes it's hard not to feel down, but you can't let it keep you there. You have to have more of a positive outlook that things are going to get better, and that things might not be that good right now, but it's going to be a lot better by this evening, the sun's going to be back out (Kind Heart).

Gratefulness was another form of staying on the positive side that participants talked about. Participants often followed up a story about a particular hardship they were experiencing by recounting a way in which they were "so blessed" (Butterfly) or something for which they were so grateful. "Maybe it was worse than I realized. And so I'm grateful for that doctor" (Loyal Oak).

In addition, for participants, humor was also a form of staying on the positive side. The importance of humor in healing was both expressed by participants, as well as observed by me as the inquirer, as I picked up on the way participants would often insert a humorous statement in story about hardship, or in the way a character in their story would often do or say something

humorous during a particularly difficult situation. For example, in referencing his divorce, a participant recounted, “Somebody said to me, ‘Why didn’t you marry inside the tribe?’ I said, ‘Because I always wanted to be sued by a White woman...become part of the Sioux Tribe’” (Dennis Hogge).

**Remembering.** While participants stressed the important role of staying on the positive side to healing, one participant pointed out that there was value in reflection on the past, including reflecting on the hard times, in order to gain new perspective on the hardships. She expressed how there was value in mourning, as mourning was a way to release any negativity that may be connected to the hardship.

Well, take like the Harvest Festival that we just did on Saturday. It’s you know about getting together and being thankful for what we’ve had throughout the year and understanding that...you’re thankful for the bad things as well as the good things because the bad things that have happened have taught you a lesson, and hopefully it’s a lesson you won’t have to re-walk, unless it’s something, whether it’s been a health issue, or it’s been an issue that, you know, like a death of a friend, the death of a husband, the death of a mother, there’s no control in that, so therefore, you know, being thankful for their lives, being thankful for the good things, and understanding, yes, it is healthy to mourn, and it’s healthy to be sad, and at Harvest time we go back over the memories of what has happened over the year, so we have the good talks and the good things that we saw and we see the bad things that have happened, then we see the good that comes out of the bad...it helps us to release a lot of things. It helps us to release stress, release sadness, release mourning, and bring us back into a place of joy (Bonnie Sears).

Participants also stressed the importance of actively remembering stories from the past to remember the lessons learned from the stories, as well as to remember the connections participants have to people and to places. Further, for participants, remembering challenges them “to know where you came from [and] what you’re about” (Dennis Hogge). As one participant asserted, “Never forget where you come from” (Dennis Hogge).

Staying on the positive side and intentionally remembering the past and where they came from provided a solid foundation for participants to feel good about themselves.

***Feeling good about one’s self.*** For participants, how they felt about themselves influenced how they related to themselves, how they engaged with other people, as well as the decisions that they made. Some participants talked about the importance of being comfortable with who they are and the role spirituality played in the process of being comfortable with their personal self.

You’re spiritual which basically governs everything about you. It’s how you feel about yourself. And basically in a spiritual way, your walk with God and your own natural walk. That has a lot to do with how you feel about yourself. Because you must be comfortable within your own self and within your own skin. You don’t have to walk the path that anybody else walks. Your path and your walk is totally yours. And this was my grandmother’s way of thinking. And how you feel about yourself is what your conscience and you live with. So whatever I do I don’t feel I have to justify anything or have the guilt or the feelings or anything and all because I myself know what I have to do with which to stay balanced, for me. And I don’t have to please anybody else to do this...I am who I am and I don’t want to *be* anybody else and I don’t want to *do* what anybody else

does or *feel* the way that anybody else does and by being that way, I am comfortable with me (Dorothy “Red Wing”).

Participants also connected feeling good about themselves with the ability to have good social relationships. “If you can’t get along with yourself, you’re not going to get along with anyone else” (Connie Laskowski). Further, some participants related how they felt about themselves with decisions they have made in their lives concerning how they engaged in a social relationship or with the world around them. For example:

It’s always important that you feel good about yourself. And if you’re going to feel good about yourself, try to do what you believe is the right things to do. Because, you know, I could fool you, and I could fool a lot of people, but I can’t fool myself. I know who I am. I know what I have. I know how I feel about you, how I feel about myself, how I feel about other people. I can put on a façade, and maybe fool you, but I can’t fool myself. And if you know in your heart that you’re doing bad things and you’re not being good to people, and so forth, I don’t see how you can feel good about yourself. If you know right and wrong and you choose wrong, you can’t feel good about it, down deep (Dorothy “Red Wing”).

***Forgiveness.*** To feel good about one’s self, forgiveness of one’s self and others is key. Further, participants identified forgiveness as an act of cleansing one’s self and an important element in healing. For participants, a particularly difficult act was forgiving one’s self.

...you forgive yourself, which is the hardest thing to do. And you must forgive the decisions and the choices that you made and then you must ask the Lord to forgive you for all of it. And the hardest one you have to forgive is to forgive one’s self. But when you forgive yourself, and you ask for forgiveness for yourself, you are asking for healing

of your own mind, body, and soul. And when you do that, you're cleansed white as snow. You are cleansing yourself. The same as when you burn the sage, you're cleansing yourself and everything around you because you are sending it to the Lord, in a puff of smoke. You're purifying (Dorothy "Red Wing").

Forgiving others was also seen by participants as an important element to healing. However, although participants may have acknowledgement the importance of forgiveness, one particular participant brought light to the fact that forgiveness is not an easy road. Upon recounting a particularly emotionally charged grievance in his life, a grievance which is ongoing but not new, the participant said, "Understand that my feelings are still pretty strong. I guess the word is forgive, forget, and go on" (Dennis Hogge).

For participants, engaging in self-care activities was seen as necessary for promoting multi-dimensional health and healing, but engaging in self-care activities was also seen as hard work. Participants also talked about the importance of engaging in self-care activities that are pleasurable and related to feeling healthy.

**Activities of enjoyment.** Participants enjoyed a wide array of activities that brought enjoyment, strength, and peacefulness to their lives. "Healthy hobbies breed healthy people, or actually it helps people" (Bonnie Sears). Some participants enjoyed hunting and fishing, being around their animals, being in nature, and doing artwork. "That's where a lot of my strength comes from, being outside and doing my artwork and connecting, and having my animals with me" (Bonnie Sears). Another participant described her close relationships with her animals and the refuge they provided her during a particularly difficult time in her life.

But I would go down and catch my horses and put them in a stall and feed them. I don't know if you ever listened to a horse eat...Munchy. Munchy. Munchy. Very peaceful.



You know, it feels like wow he's eating me out of a house and home, but he relaxes you. I mean something about them horses and I just go and sit down there for awhile and listen to them eat, talk to them, turn them out, get my stuff and go back to the hospital. But I *had* to have it every once in awhile just to listen to those horses. It calm me right down. It let me *think* about what I had to do next (Lorraine Hedgeman).

Others enjoyed listening to music and dancing.

I like good music, too. [There's] a healing process in music... Well one reason I like bluegrass, I like string music. It's a feeling you get from it, perks you up a little bit seems like. And then, it does something to your spirit, or whatever, when you hear music, loud music performed, rather than a recoding, too, I think. I mean I like both of them but, I don't know, seem like there's something about, especially string music, a live performance, give you a real good feeling (Wewoka Adkins).

And others talked about reading and seeing a happy movie.

Stress is a killer. I don't like [it], I have to get away. Like this weekend I went to see Cinderella. When I was a little girl, my parents, they read it every night to me. I know the book by heart. I was so enchanted by it and I said you know what, I had like three suicides [in the community in which participant works], I think I'm going to see Cinderella, and it was a nice little fantasy, all little kids, girls were there, they had on their Cinderella outfits. It was cute. Yeah, the underdog makes it, you know, she becomes a princess and a queen (Roth Summoth).

Overall, participants engaged in a wide array of self-care activities that engaged their multi-dimensional, interconnected perspective of health and healing such as being empowered, being compliant with medical care, making healthy lifestyle choices, practicing mental and

emotional care, and engaging in activities of enjoyment. In addition to engaging in healing practices of various traditions (i.e. Western informed healing traditions and holistic healing traditions) and a vast number of self-care activities, there is still one vital healing practice in the lives of participants yet to be addressed, engagement in cultural traditions. While engaging in healing practices of various traditions and participating in self-care activities were important to supporting the multi-dimensional, interconnected perspective of health and healing held by participants, engagement in various cultural traditions served as the quintessential healing practice that exemplified healing in six of the seven dimensions of responsive and responsible health and healing: spirituality, physical health, mental and emotional health, social relationships, context, and interconnection (sans access to resources).

**Cultural engagement.** Participants reported engaging in several types of cultural activities including various levels of involvement in pow-wows, wearing regalia, creating assorted types of traditional art, communicating with the Great Spirit, and simply being outside in nature.

Participating in pow-wows seemed to serve as a central activity for participants to engage with their culture. Participants recounted various ways in which they were involved in pow-wows including setting up, dancing, listening to the music (i.e. drum and flute), wearing regalia, and socializing with fellow relations. For participants, dancing in pow-wows was connected to healing and cleansing.

I dance, dancing makes me feel good. It's like a cleansing. It's like you just open yourself up and feel the beat of the drum. It's a cleansing. It's a good feeling. It's a fulfilling feeling...And when you get in that Circle, you let it all go. And when you come out of the Circle, you're feeling good. Sometimes I get a little sore as far as physical, but the

mental part will take such control you don't worry about the soreness in your feet from the dancing. You don't worry, I might have a sore knee going on, but I *enjoyed* that dance. It's what that dance did for me (Connie Laskowski).

Dancing at pow-wows was described as a body and mind work-out that elicited feelings of peace and tranquility. "[Dancing in pow-wows is] an exercise. It's moving your whole body. It's satisfying your mind. It's satisfying other things. You're, you're mixing yourself with the elements. And you're satisfying yourself. And you yourself are at peace, and tranquility" (Dorothy "Red Wing"). One participant described dancing at pow-wows as a space in which to "suck up on energy" (Connie Laskowski). Another participant talked about the significance of wearing her late-mother's regalia when dancing at pow-wows. "I feel close to her. I feel that she's with me all the time. Her spirit and my spirit are kindled together at the particular time" (Dorothy "Red Wing").

Other participants talked about experiencing similar feelings from just listening to the drum and flute music. "Mama could go to a pow-wow and go right to sleep. It's soothing to us and it's relaxing. The music is soothing" (Becky Adkins Branch). Pow-wows also provided participants a space to socialize. "And it's good to get to see people you haven't seen, and a lot of times it's the only time you get to see people" (Glenda Chavis Adkins).

While dancing was the primary activity participants talked about in relation to pow-wows, not all participants danced at pow-wows. Some talked about being unable to dance because of certain health problems, but still enjoyed many of the same qualities in just attending the pow-wow as those dancing. Others talked about the enjoyment they experienced in helping to set up the pow-wows hosted by their respective tribes. One particular elder talked about the joy she experienced in just watching her daughter dance:

Whenever [daughter] started dancing was the highlight of [pow-wows] for me. To see her out there, I had *never* done that. I had *never* danced at pow-wows. No, we didn't use [pow-wows] because we weren't financially able to have pow-wows (Glenda Chavis Adkins).

In addition to being a cultural activity, participants also recounted the spiritual element of pow-wows, as well.

It's spiritual, too, especially some of the dances are spiritual, and have a spiritual meaning, like the Jingle Dance has a spiritual meaning, it's like a healing dance. And like when they bring in the Eagle Staff, it's to Native Americans like the Bible is to some people. It's spiritual" (Becky Adkins Branch).

In addition to dancing, participants also talked about engagement in traditional artwork as a way of connecting with their culture. Being engaged in the creation of traditional artwork seemed to elicit many of the same healing qualities for participants as participation in pow-wows. One participant talked about weaving baskets and how it "tied [him] back to some of the old, more simpler, purer ways of life. That's what it does for me. And it relaxes me and relieves stress" (The Old Sailor). Another talked about the cultural and spiritual dimension of doing her artwork.

Well, [doing my artwork is] a place that I go inside of me, that's peaceful, between myself and Creator, and it's a spiritual thing, where I say prayers and I like to, if it's not cold, sit on the ground or be right in nature to do it, it's my communication and I feel one with everything, it brings me peace (Roth Summoth).

Another person talked about the multi-dimensional healing nature of creating pottery, describing the cultural, spiritual, physical, historical, and mental and emotional healing elements involved in

her artwork. The section on the role of cultural engagement in healing will conclude with this quote:

It's, personally, for me, it's a joy and I'm happy when I'm doing the pottery. It's a cultural thing because it's something that my people did and because my people did it for thousands of years, I want to carry on the tradition, and I want to teach it to other people, and sometimes it's just a way to connect with your history. I tell people that...it's almost like history talks to you when you're, when you're doing it. I can hear the drums playing and I imagine in my head the kids playing and how things were then, you know, versus how it is now. So it becomes a joy. It becomes a great joy. And even it gets out a lot of anxiety because with clay, there's different processes you have to do, like, you know, if you're really frustrated, you know there's a pounding of the clay to get the air bubbles out, so you can pick out pieces of clay and slam it down to get the air bubbles out while you're getting your anxiety and anger out...And then, you know, when you're putting the pieces together, you know, you're physically handling it and you're making the coils and you're actually creating it, then the creative nature comes out and, you know, the joy of seeing what it was in the beginning versus what it's *gonna* be in the end (Bonnie Sears).

The narrative presented thus far concerning responsive and responsible health and healing began with a look at several contextual elements that participants saw as important to informing their story concerning health and healing. After having addressed these external, contextual factors participants saw as shaping their health and, the narrative drew attention to the core dimension of participants' conceptualization of health and healing, namely, spirituality. After having told of the ways spirituality is at the core of participants' conceptualization of health and healing, the narrative introduced and addressed each of the four dimensions of health

and healing positioned on the circle surrounding spirituality. First the role of physical processes in health was considered, followed by mental and emotional processes. Then the narrative addressed the relationships between social relationships and health, followed by a discussion about the role access to resources plays in participants' conceptualization of health and healing. With the primary dimensions established, the narrative then addressed the interconnected nature of health, followed by a discussion considering the multi-dimensional, interconnected healing practices participants identified. In light of the narrative that has been presented thus far, what does it look like to be healthy? I'd like to first begin with a metaphor presented by a participant.

### **Walking in Beauty**

The narrative presented thus far tells of a multi-dimensional, interconnected framework for considering responsive and responsible health and healing. The narrative tells of the ways six dimensions – spirituality, physical processes, mental and emotional processes, social relationships, access to resources, and contextual factors, interconnect (the seventh dimension) to inform health as conceptualized by participants. Further, the narrative tells of multi-dimensional healing practices, identified by participants, that interconnect to support a holistic conceptualization of health. However, this narrative is not complete. The multi-dimensional, interconnected nature of health and healing presented thus far does not sufficiently capture the full way in which participants talked about responsive and responsible health and healing. *Balance* is an important element missing from this narrative.

With Native culture, everything is about balance. It's balancing the three, the three aspects of your personality, and balancing what's going on in the community, and when there's peace and there's harmony, it's good. When peace and harmony are out of balance, then it isn't good (Bonnie Sears).

The circle on which the four dimensions – physical processes, mental and emotional processes, social relationships, and access to resources, are positioned represents the way participants see health and healing as a balance among the four dimensions. The dotted lines that cross-connect each of the four dimensions located on the circle, and the dashed line that provides the structure of the circle, represents participants’ sense of permeability, folding the dimensions of spirituality and context into the interconnection among the four dimensions positioned on the circle. In light of the current conversation, the permeable lines (dashed and dotted) also represent the way in which context and spirituality are folded into the pursuit of balance with the four dimensions on the circle.

While participants described the need for balance among the dimensions in order to be healthy, they also described the need for balance within each of the dimensions. An imbalance in any one of the five dimensions throws off the balance of the entire health system.

We’re a whole person, we’re soul, we’re mental health, we’re physical health, and we’re spiritual health, so all three of them come into play and if any one of them is out of alignment, then it affects the whole triad of our personality and our being (Bonnie Sears).

Participants agreed that no one is one-hundred-percent balanced. “I don’t think it’s possible. Not in this world today. We can be as balanced as we can be” (Bonnie Sears). As one participant stressed, “If you’re too perfect in every aspect, you know, you don’t even need to be here because it’s just normal to face the variations and fluctuations in all four” (Loyal Oak). The circle also represents the way they envision health and healing as cyclical, continually striving to maintain balance among the four dimensions.

Sometimes [striving for a balance between the physical, emotional, mental, and spiritual] doesn’t work. People have to kind of pick and choose if they are over-emotional then

they will lose and not pay attention to the other aspects, and lose the balance of the other aspects. You know, so sometimes they pick being over-focused in one aspect over the other. That gets them out of balance...So it's a job to keep all four on even keel (Loyal Oak).

From the stories told by participants, health seemed to be a continuum and healing seemed to be a cycle. With constant motion in each of the five dimensions, as well as in the context of one's life, health has to do with sustained engagement in a healing process that continually seeks to bring about functional balance in one's whole health system in response to constant change in the dimensions. Ill health, then, has to do with when a change in any one of the dimensions overtakes one's ability to bring about a functional balance in the whole health system. One participant used a pottery metaphor and the Algonquian word for beauty to describe this idea of health being a sustained engagement in a healing process that continually seeks to bring about functional balance in one's whole health system. With these words, the narrative of responsive and responsible health and healing will draw to a conclusion.

So when I make a piece [of pottery] and I see the finished end result, I can say this is a thing of beauty. You know, the Natives here specifically have a word that's called *miscowah*, which means beautiful. It doesn't mean beautiful as in a beautiful woman, it's beauty as it's revealed. And so when the pottery is complete, that's beauty as it's revealed...And then you put it in the kiln and it breaks, well, you might be sad that it broke but then you break the pieces up and you turn it into powder and you use it in your next pot as a medium for, um, retraction and expansion so that you can use it in something with a fire or that, so nothing goes to waste, on it. So even though it may be a new piece, it has pieces of the old in it, and so that kind of reflects our health, our health



as, you know, the past being brought into the present. ...still a process of beauty, still a process of beauty...Healing looks like repairing. I'm referring back to pottery again. Because you could be making a piece and it could sit out, and the air hits and it gets a crack in it, and so you take the water, and you add a little bit of water to soften it, and then you take your fingers and you begin to fill in those cracks and fill in those holes, and then when it re-dries, it re-dries like it's supposed to so that it can be kilned, so healing, healing looks like a process of, okay, okay I may be sick, I may have this, that, or the other, but I can I fill in these cracks with this, and/or I can fill it with that, and it causes me to be whole again (Bonnie Sears).

### **Learnings Concerning the Research Question in the Studied Context**

As Indigenous peoples and communities generally disproportionately shoulder the burden of high rates of disease, deep-seated adverse social conditions, and the subsequent ripple effects of both, research in Indigenous communities must focus not only on knowledge building for the sake of knowledge building, but knowledge building for the sake of benefiting the people and communities involved in the research. There is a strong call by Indigenous scholars and Indigenous communities for research with Indigenous peoples to be problem-based and solution-focused (Kovach, 2009; Smith, 1999). Accordingly, it is incumbent upon me as a researcher engaged in a research relationship with Virginia American Indian people to further the discussion from findings to implications, with the intention of more effectively supporting the health of participants and their respective families and communities, as well as the seven generations to come. Further, as a doctoral candidate of a profession that seeks to “enhance human well-being and help meet the basic needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty”

(NASW, 2008), it is incumbent upon me to connect findings to implications for social work practice, policy, education, and research in order to contribute to the advancement of the mission of social work.

Chapter 5 will address implications of study findings for the promotion of responsive and responsible health and healing among Virginia American Indian people in the context of a reservation-based, non-federally funded health clinic, as well as implications for social work practice, policy, education, and research. First, though, it's important to consider lessons learned from the narrative presented above. In emergent, interpretive research, lessons learned are an extension of the inductive analytic process whereby "a researcher interprets the research participants' constructions of their world" (Ashworth, 2008, p. 19). If the narrative presented above is an accurate representation of participants' conceptualization of the meaning of health and healing in their lives, then it seems the following assertions about the research question in the studied context are plausible:

1. Consideration of an individual's whole health system seems integral to responsive and responsible health and healing, whereby it is important to view a condition experienced in any one dimension (i.e. physical, mental and emotional, spiritual, social relationships, access to resources, context) in light of an individual's whole health system.
2. Health seems to be a continuum and healing seems to be a cycle. There is constant motion in each of the five dimensions, as well as in the context of one's life. Health has to do with sustained engagement in a healing process that continually seeks to bring about functional balance in the whole health system in response to constant change in the dimensions. Ill health has to do with when a change in any one of the dimensions overtakes one's ability to bring about a functional balance in the whole health system.

3. It seems experiences of oppression, discrimination, and prejudice are stored deep in the minds and bodies of participants and affect the health and healing of participants on many levels, whether consciously or otherwise. Based on participant stories, it seems experiences of oppression, discrimination, and prejudice are sometimes experienced negatively, such as contributing to feelings of hopelessness and lack of self-worth, as well as sometimes experienced positively, such as contributing to strong social bonds among social networks.
4. In a group of people who place high value on social relationships, it seems relationships are important to health and the healing process on multiple levels: identity is found in being in relationship; leaning on social relationships during hardship; the importance of restoring compromised relationship(s) (with self and others); and the importance of having strong relationships with health care providers.
5. The strength of informal social networks of which participants are a part seem to serve as an integral factor in supporting the health of individuals, families, and communities.
6. It seems personal and/or societal acknowledgement of participants as American Indian or Native American is important to the health and healing of participants. Participants who are not federally recognized seem to see themselves as no less Indian than American Indians who are federally recognized, and participants who are federally recognized seem to see themselves as no more Indian than before they were before being federally recognized. However, while recognizing the Native identity of participants, it also seems important to recognize how individual experiences shape the meaning a participant ascribes to his/her collective identity.
7. Places, events, services, and interventions that recognize, affirm, and support the Native

identity of participants and their respective communities appears to be important to supporting the health of participants and their communities.

8. There seems to be healing in sharing stories about the past, present, and future, whether painful, seemingly mundane, or celebratory in nature.
9. Having access to affordable and quality resources (basic needs and health-related) seem integral to supporting the health of participants

As a reminder to the reader, it is important to consider the lessons presented above through the lens of the inquiry paradigm and principles that underpin the methodology and research design. In light of an emergent research design informed by a constructivist inquiry paradigm and Indigenous research principles, two important aspects must be considered: (1) The lessons learned are an extension of my most informed interpretation of the stories shared with me. I cannot assert the ‘Truth’ of the assertions. (2) Given the context-dependent nature of a constructivist paradigm and Indigenous inquiry principles, the narrative and subsequent assertions presented above are only representative of the voices of participants who participated at the time of the study: Virginia American Indian people in the context of a reservation-based, non-federally funded health clinic located in the Commonwealth of Virginia during the period of time between 2015 and 2017. I can make no claims to the generalizability of the findings. It is up to you, the reader, to assess the context and decide to what degree the findings may be transferrable to the context in which you are located (Guba & Lincoln, 1989; Kovach, 2009; Rodwell, 1998; Wilson, 2008). Accordingly, the implications presented in Chapter 5 are based on my most informed interpretation of the stories shared with me by participants in the context in which they were shared at the time in which they were shared.

## Chapter 5: Implications

Considering my relational accountability to both the community in which the research was situated and the profession from which I hold my doctoral degree, it is incumbent upon me to further the discussion from findings to implications. Linking findings to implications is instrumental in more effectively supporting the health of participants and their respective communities, as well as advancing social work's mission to bring about social and economic justice for oppressed and vulnerable groups of people. If the narrative presented in Chapter 4 is an accurate representation of participants' conceptualization of the meaning of health and healing in their lives, and if my interpretation of the narrative presented as *learnings* is accurate, then it seems the following implications for social work education, practice, policy, and research are plausible. The following implications are also informed by the research process.

### **Implications for Social Work Education**

The following section will address four implications of this dissertation research for social work education: positioning Western social science theories and subsequent practice models as cultural constructions, incorporating Indigenous knowledges in social work curricula, re-conceptualizing the biopsychosocial approach, and developing the capacity of faculty to facilitate such activities.

**Position Western social science theories and subsequent practice models as cultural constructions.** Western knowledges, theories, and practice models need to be seen as social constructions and, with that, become on par with alternative ways of knowing and doing, which will lead to less oppression of those holding non-Western views of knowing, being, and doing. In the United States, and arguably other countries dominated by a Western/European-informed worldview, knowledges emanating from Western/European ways of knowing are often viewed, usually unknowingly, as neutral constructions, and the standard by which all non-Western knowledges are compared and assessed for merit and legitimacy. There seems to be an assumption held by Western practitioners that non-Western knowledges are based in and informed by a particular cultural and socio-historical context; however, there is generally limited, if any, recognition of the cultural and social-historical context in which Western/European knowledges are positioned. Non-Western knowledges are seen as cultural knowledges, but Western-informed knowledges are considered science. Because Western/European derived knowledges are viewed as neutral, as science, the assumption is that they are appropriately transferrable to non-Western contexts. Recognizing and understanding the belief systems, values, and worldview inherent in models and theories used in social science-based helping professions in the United States, such as social work, largely shape the way a situation/condition is perceived, named, understood, and addressed.

Relevant to this study, participants talked extensively about the significance of various types of social relationships in their lives, as well as the long heritage of families and communities taking care of one another. Theories and subsequent practice models that focus solely on the individual may negate the ethos of cooperation that largely seems to underpin participants' way of life, at best rendering theories rooted in a spirit of competition only mildly

effective, and, at worst, continuing the advancement of a colonialist agenda. To meet the demands of an increasingly diverse United States, and to be relevant and effective in a progressively globalized world, there is a push within the helping professions, including social work, for practitioners to be “culturally competent” (NASW, 2015). I contend, however, that before a social worker can be “culturally competent,” it is first imperative for the Western social work profession to turn an eye inward and examine the cultural and socio-historical context that underpins the theories and models that guide its practice.

**Inclusion of Indigenous knowledges in social work curricula.** To more responsively and responsibly serve Indigenous peoples, it is important for social work students, soon to become social work practitioners and researchers, to become knowledgeable about the philosophical orientation and practice capacity that respects and actively integrates Indigenous points of view. Culturally relevant practice with Indigenous peoples extends beyond simple replication of a particular practice technique informed by Indigenous ways of knowing. As Duran (2006) asserts, “[Indigenous-informed] [m]ethods are part of a holistic approach to being in the life-world. If therapists who do not have a profound spiritual practice of their own attempt to mimic these strategies, they will be disingenuous and offensive to Native patients” (p. 2). Practicing in a culturally responsive way involves being familiar with the localized ways Indigenous groups of people understand and engage with the world around them. Practicing in a culturally responsive way also includes being aware of the socio-historical context of the particular group of people with which one is practicing. Understanding Indigenous ways of knowing and being was particularly relevant to this study, as being familiar with Indigenous ways of knowing and being in the world helped to inform decisions concerning methodology, study design, and implementation of the study.

It is important that social work curricula incorporate Indigenous ways of knowing and being in the world in a way that recognizes and honors Indigenous ways of knowing on equal footing with curricula that is Western-informed. Linking Indigenous ways of knowing and being in the world with Indigenous practice and research models, approaches, and techniques can provide students with an understanding of the ways in which models, approaches, and techniques are culturally informed, and highlights the importance of congruence between a peoples' worldview and interventions used by social workers. Inclusion of Indigenous ways of knowing and being in social work curricula may not only promote effective cross-cultural practice, but may also validate the ways of knowing and being of Native social work students, perhaps even leading to greater retention of Native social work students.

**Re-conceptualize a biopsychosocial approach.** Re-conceptualizing the biopsychosocial approach oft used in social work practice to include the dimensions of history, spirituality, and balance, would increase its responsiveness to the way in which participants thought about health and healing, opening a space for more responsible care. Social work has historically sought to understand human behavior from a multi-dimensional approach that recognizes human behavior as an interaction between person and environment over time (Hutchison, 2008). Specifically, a biopsychosocial approach seeks to understand human behavior as a “result of interactions of integrated biological, psychological, and social systems” (p. 11). It is beyond the scope of this section to review the various ways in which the biopsychosocial approach has been critiqued and adapted, particularly by scholars and practitioners in light of various localized Indigenous belief systems, however, it is the intention of this section to address how participants' conceptualization of responsive and responsible health and healing can inform the reconceptualization of the biopsychosocial approach.



The biopsychosocial approach and participants' construction of health and healing share several similarities, namely the way in which both conceptualizations view human behavior/health and healing as multi-dimensional and interconnected. Three elements that would enhance the responsiveness of the biopsychosocial approach to the particular group of Native people who were participants in this study are the inclusion of history, spirituality, and balance. While person in environment perspectives often take into consideration various elements of time, consideration of received history, in addition to experienced history, is important to understanding a person's behavior/health and healing. For participants, received and experienced histories seemed to play a significant role in their conceptualization of health and healing. Spirituality also played a central role in participants' conceptualization of health and healing and inclusion of spirituality would enhance the relevance of a biopsychosocial approach for participants. It seems social work is increasingly mindful of the role of spirituality in the lives of clients, and, thus, some biopsychosocial approaches have included spirituality as an additional dimension to consider. However, for the inclusion of spirituality in a biopsychosocial approach to be responsive to participants, its inclusion must address the dynamic way in which participants thought about spirituality. Lastly, folding the element of balance into a biopsychosocial approach would increase the responsiveness and utility for participants, and perhaps for Native people at-large. Participants talked about health as a continuum and healing as a cycle. With continual motion and change in each of the dimensions, being healthy had to do with striving to bring about a functional balance in a person's whole health system; and ill health had to do with when change in any one dimension overtook a participant's ability to bring about a functional balance in his/her whole health system. Therefore, rather than just assessing how elements in a biopsychosocial spiritual approach interact to influence a person's behavior, or health, it's

important to also consider how the person is seeking, or not, to bring about a functional balance among all of the dimensions. In teaching a biopsychosocial approach, introducing variations to the ways in which a biopsychosocial approach can be conceptualized to more accurately represent the belief systems of a group of people could help emerging social work practitioners be more responsive to Native clients, particularly Virginia American Indian people.

**Develop capacity of faculty.** To position Western social science theories and subsequent practice models as cultural constructions, and to develop social work curricula that incorporates Indigenous ways of knowing and being, requires faculty to have the knowledge and skills necessary to engage in such activities. While incorporating faculty who identify as Indigenous can certainly be an asset to any social work program, it is inaccurate to expect that an Indigenous faculty person will be knowledgeable in Indigenous ways of knowing and being simply because of their Indigenous identity. Eduardo Duran (2006) states:

Hiring practices will become increasingly interesting as more Natives go through graduate training. I have attended meetings that specialize in the recruitment and training of Native students [for clinical practice]. Many of the students do not identify with any aspect of Native culture and are basically Western in their cultural orientation and clinical practice. Therefore, just having a Native provider does not ensure cultural competence” (p. 37).

As Duran asserts, being a Native provider doesn't necessarily mean that one is knowledgeable in Indigenous ways of knowing and being. Similarly, it seems the assertion is transferrable to Native faculty, as well. Being a Native social work scholar does not necessarily mean that one is knowledgeable in Indigenous ways of knowing and being. Also, given that Indigenous knowledges are local and specific to a group of Indigenous peoples, it is inaccurate to

assume that an Indigenous scholar will be knowledgeable about ways of knowing and being of all Indigenous peoples, even if he/she is knowledgeable about the ways of knowing and being of his/her particular people. Therefore, developing the capacity of faculty, Native and non-Native alike, to be knowledgeable about Indigenous ways of knowing and being, Indigenous pedagogy, and Indigenous-informed practice, policy, and research, is critical to providing responsive care to Indigenous peoples holding an array of various beliefs, as well as how to effectively mentor and support Indigenous students.

### **Implications for Social Work Practice**

The following section will address four implications of this dissertation research for social work practice: be knowledgeable about the historical context of “clients,” use cultural interpreters in practice, account for the time it takes to build relationships, and expand practice to acknowledge historical trauma and unresolved grief.

**Be knowledgeable about the historical context of “clients.”** In order for social work practitioners to be effective in their helping relationships with Indigenous peoples, it is imperative for practitioners to be knowledgeable about the localized history of Indigenous peoples, as history informs present-day conditions and possibilities for practice. While it is important to be knowledgeable about the general history of American Indian and Alaska Native peoples, it is equally important to be knowledgeable about the local histories of Indigenous peoples.

As the research findings from this study demonstrate, the role of history in the lives of Virginia American Indian people is pervasive and ever-present. The received and experienced histories of participants are prevalent in countless areas of their lives including access to resources, individual and cultural identity, social relationships, and physical and mental health.

To holistically understand the health and well-being of a group of Native people, it is imperative to be knowledgeable about their localized histories, both received and experienced, and to consider the ways these histories are present in their current day health and well-being. Similarly, it's also important to consider the unique histories of a Native person, and how their individual experiences may differ or compare with group histories.

In addition, it is also important to be knowledgeable about individual and collective histories in determining courses of action. For example, Virginia American Indian people are largely ineligible to participate in Indian Health Services, as well as various other federally funded services available to federally recognized tribes. Being ineligible for federally funded services typically available to federally recognized peoples constrains the types of services and resources available for treatment. Being aware of received and experienced histories might also be important in understanding why some Virginia American Indian people may not frequent certain health care establishments. Realistically, for an outsider, knowing all aspects of a localized history and/or culture of a group of people is probably not a feasible endeavor, particularly at the commencement of a working engagement, therefore, having access to a cultural interpreter to help navigate potential uncertainties is important.

**Use of cultural interpreters in practice.** Access to and use of cultural interpreters when working across boundaries of difference is important to knowing how best to serve “clients.” While there is increasing attention to the benefit of using cultural interpreters in a research capacity, it seems literature concerning the benefit of cultural interpreters in practice contexts is lagging. Even though I enjoyed an insider/outsider position in the Virginia Indian community connected to the context of the study because of my involvement with the community for approximately five years before any engagement in a research capacity, having a cultural

interpreter was still essential to developing and implementing research that was contextually responsive. As my cultural interpreter became less available during the duration of the study because of personal health reasons, the situation was such that I had to make decisions that were less informed than I would have preferred. Whenever possible, I sought out guidance elsewhere; however, I missed the steady guidance of someone with whom I had a long-standing relationship, someone who I trusted. Working with a cultural interpreter in a practice capacity could help a practitioner build relationships in the community of practice and the trust needed to engage in meaningful work; help a practitioner navigate the politics present in any community or group; help a practitioner understand why things are the way they are as related to the work in which the practitioner will be engaged; and guide a practitioner in considering the appropriateness and responsiveness of potential types of engagement. While engagement with a cultural interpreter in a practice capacity may be resource-intensive and a strain on already tight schedules and budgets, it seems worth the investment for practice to be relevant and responsive to “client” needs. This leads to the next practice implication: account for the time it takes to build relationships.

**Account for the time it takes to build relationships.** In a group of people who place high value on relationships, to implement responsive and responsible care with Native people, time must be invested in building relationships with the multiple relations involved in a helping relationship. These multiple relations may include the people directly and indirectly involved in the helping relationship; the belief system of those involved; activities important to those involved; the history relevant to the particular helping relationship; the physical landscape that may be important to those involved in the helping relationship; and perhaps the spiritual world. Building these relationships takes time, and is often outside of the purview of any type of billable

practice.

Prior to volunteering at the Mattaponi Healing Eagle Clinic, I had read historical and cultural accounts of Virginia American Indian people to begin to develop an understanding of the people with whom and context in which I would be working. While volunteering at MHEC, I sat and listened to stories that were told in the community room while service-users waited their turn to see a medical professional. When invited, I visited MHEC service-users in their homes, attended family gatherings, cultural events, religious/spiritual events, and helped plant vegetable gardens. These engagements helped MHEC service-users (and their families) and me get to know each other and for trust to build between us. I continued to read historical and cultural accounts to better understand the stories I was hearing from MHEC service-users and their families. The former MHEC Administrative Director said that it was these relationships that had been established over the years of my volunteering at the Clinic that opened the door for me to engage in my dissertation research, both in receiving approval from Mattaponi Chief Emeritus to engage in a research capacity with MHEC service-users, as well as willingness of several MHEC service-users to not only participate in an interview, but also to participate in an authentic way. Building the knowledge and relationships needed to do meaningful work takes time, and time that has significant return in helping relationships. It is imperative for social work practitioners to account for the time it takes to build the necessary knowledge and relationships to do effective work in Native communities.

**Expand practice to acknowledge historical trauma and unresolved grief.** To work effectively with Indigenous peoples, social work practitioners must not only be knowledgeable about the general and local received and experienced histories of the Indigenous people with whom they are engaged, but social work practitioners must also be cognizant of the role the

histories may play in the individual and collective health of the people with whom they are engaged. For participants in this study, it seems experiences of oppression, discrimination, and prejudice are stored deep in their minds and bodies, and affects their health and healing on many levels, whether consciously or otherwise. *Historical trauma* is a term being used in Indigenous communities to refer to the cumulative emotional and psychological wounding over the lifespan and across generations emanating from massive group trauma (Brave Heart, 2003). *Historical unresolved grief* is “the profound unsettled bereavement resulting from cumulative devastating losses, compounded by the prohibition and interruption of Indigenous burial practices and ceremonies (Brave Heart, Chase, Elkins, & Altschul, 2011, p. 283). Duran (2006) asserts, “...these [soul woundings] are sensitive areas that have remained as the last sacred cows in our communities, but the time has arrived to face the reality of history and of the present moment” (p. 23).

Depending upon the community context, it may not be appropriate for non-Native social work practitioners to facilitate healing in this area; however, it is incumbent upon Native and non-Native social work practitioners alike to be aware of the ways historical trauma and unresolved grief may impact the individual and collective health of the Indigenous peoples with which they are engaged. Duran (2006) states, “Initially, what is required is awareness of the problem. Interventions can then be developed” (p. 23). Perhaps an appropriate role for a non-Native social work practitioner may be to support elders and community members as they consider how to implement healing processes in their communities, as well as offer support, as needed, during the implementation process. From the literature (Brave Heart, 2003; Brave Heart, Chase, Elkins, & Altschul, 2011; Duran, 2006; Duran & Duran, 1995; Weaver, 1999; Weaver, 1998), it seems processing through the historical trauma and unresolved grief in Indigenous

communities is essential for restoring the health and longevity of Indigenous people and communities. It is critical for social work practitioners working with Indigenous peoples and communities to be aware of the concepts and the role they play in the health and healing process.

### **Implications for Social Work Policy**

The following section will address three implications of this dissertation research for social work policy: hold governments accountable for upholding treaty agreements; advocate for federal, state, and local policies that support informal helping networks; and advocate for federal, state, and local policies that support integrated health care systems.

**Hold governments accountable for upholding treaty agreements.** Holding the U.S. federal government accountable to upholding treaty agreements with Native people is an important element in supporting the health and well-being of Native communities. From 1778 to 1871, the U.S. federal government entered into more than 500 treaties with Indian nations (Toensing, 2013); every one of them has been “broken, changed, or nullified when it served the government’s interests,” wrote Helen Pliff (as cited in Toensing, 2013). These treaties affect the lives of Indigenous peoples in many ways including displacement from ancestral lands, defacement of Mother Earth, restricting access to sacred lands, threatening the right to self-governance, and limiting access to social and economic resources, to name only a few. Participants in this study talked about the decades-long struggle in which several of the their respective tribes have been engaged to gain federal recognition, hoping that federal recognition will bring access to much needed social and economic resources for their people. Participants from the one federally-recognized tribe in Virginia told of how members from the tribe, while technically eligible to receive federally funded resources, still did not have access to those resources. It is incumbent upon social workers working with Indigenous people to not only be



knowledgeable about the treaties that impact the people with which they are engaged, but also to actively advocate for U.S. and local governments to honor the treaties.

**Advocate for federal, state, and local policies that support informal helping networks.** For Native people who do not have access to social and economic resources through membership in a federally recognized tribe, federal, state, and local policies greatly affect their access to resources needed to be healthy and heal. Social workers often turn to formal/professional services to help their clients, which are certainly an important component of helping networks, but findings from this study demonstrate the strong informal helping networks that are present in Virginia American Indian communities. Participants seemed to rely on these informal networks to support their health and healing, as well as to support the health and healing of their community, family, and friends. While it is necessary for social workers to be informed about, and perhaps advocate for, federal, state, and local policies that affect formal/professional services, it is similarly important for social workers to be informed about, and advocate for, federal, state, and local policies that affect the ability of informal networks to care for one another. For example, some participants talked about the hardship involved in providing home-based care for ailing family members. Supporting policies that could provide resources for families to care for their family in their home environment (e.g., education/training, monetary support, family-friendly work laws) would help support the informal helping networks present in Virginia Indian communities, and perhaps Native communities broadly.

**Advocate for federal, state, and local policies that support integrated health care systems.** Similar to the policy implication identified previously, for Native people who do not have access to health-related care through tribal membership in a federally recognized tribe, federal, state, and local policies greatly affect their access to health-related care. For participants,

access to affordable medical care was a challenge. However, in light of recent legislative advances that seek to repeal the *Affordable Care Act* (Kaplan & Pear, 2017), participants may find themselves further burdened when trying to acquire or maintain access to quality, affordable health-related services. In response to these recent efforts to repeal the *Affordable Care Act*, the National Association of Social Workers (2017) has issued a public statement “strongly oppos[ing] legislation to repeal the Affordable Care Act because it would have a devastating impact on the health of our nation’s most vulnerable citizens and make it more difficult to provide affordable health care for poor and low-income Americans.” It is critical that social workers advocate for health care legislation that meets the needs of all Americans, including poor and low-income Americans.

Based on findings from this study, however, it is not enough for social workers to solely advocate for legislation that provides health care for all Americans, inclusive of Native Americans, it is also important for social workers to advocate for access to health care that is integrated in nature. The multidimensional and interconnected nature of health and healing described by participants demonstrates the need for health care that is integrated, at the very least integrating medical care with mental and emotional care. Indian Health Services (IHS) offers some direction for mainstream health services in this area, as IHS seeks to offer services that “raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level” (IHS, 2017), by offering medical care, mental and emotional care, and public health services to eligible American Indian and Alaska Native people. Further, efforts are in place by the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Health Resources and Services Administration (HRSA) to promote the development of integrated systems of health care, integrating primary and behavioral health services (SAMHSA-

HRSA Center for Integrated Health Solutions, 2017). To more responsively support the health of Native peoples, social workers must advocate for policies that support integrated systems of care.

### **Implications for Social Work Research**

Cochran et al. (2008) assert, “How we go about acquiring knowledge in Indigenous communities is just as critical for the elimination of health disparities—if not more so—as the actual knowledge that is gained about a particular health problem” (p. 23). As the cultural landscape of the United States becomes increasingly more diverse, it is incumbent upon the social work profession to expand and diversify the scope of its research toolbox. This section addresses three implications for social work research: incorporate community-based participatory research principles when working across boundaries of difference; realistically assess the “hidden costs” involved in authentically engaging community in research processes that are relevant and responsive; and push boundaries around historically held notions of what constitutes science and acceptable data.

**Incorporate community-based participatory research (CBPR) principles when working across boundaries of difference.** Research approaches that are truly participatory and collaborative in nature; acknowledge and incorporate localized knowledges, skills, and resources; and are action-oriented toward change are needed to address the inequitable burden of disease and unjust conditions in Indigenous communities. *Community-based participatory research (CBPR)* offers such an approach. CBPR is a partner approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process, a process where all partners contribute expertise and share decision-making responsibilities (Israel, Schulz, Parker, & Becker, 1998). Israel, Parker, Rowe, Salvatore, Minkler, Lopez, et al. (2005) describe the aim of CBPR as “to increase knowledge and

understanding of a given phenomenon and integrate the knowledge gained with interventions and policy change to improve the health and quality of life of community members” (p. 1464).

The aim of CBPR is congruent with the mission of the social work profession and social work’s core values (NASW, 2008). While attention must be given to contextualizing CBPR principles when working in Indigenous communities (LaVeaux & Christopher, 2009), overall, the aim of CBPR also seems to be congruent with several Indigenous research principles that coalesce around the values of respect, reciprocity, and responsibility (Weber-Pillwax, 2001). While not a research method, but rather a set of principles that can guide a research process informed by either Western and/or non-Western knowledge systems, a CBPR approach to research can offer social workers a valuable research tool when working to enhance the human well-being of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty (NASW, 2008).

**Realistically assess the “hidden costs” involved in authentically engaging community in research processes that are relevant and responsive.** To engage in a research relationship with a community that is authentically participatory and collaborative in nature, and equitably acknowledges all parties in the decision-making process, takes an immense investment of time and energy, as well as the relinquishing of power that is typically held by a researcher in more conventional approaches to research. Trust-building that is necessary to do meaningful work with communities must begin prior to the commencement of any research study, and often occurs prior to the availability of any funding. Getting to know a community of interest calls for participation in community events and activities that may not seem directly related to the research one seeks to do in/with a community. Assessing a community’s capacity to engage in research, and building a community’s capacity for research, if needed, takes time. Seeking and

acquiring permission (informally and formally) to engage in a research relationship with a community takes time. Gaining community consensus on decisions related to the design and implementation of a research study takes time. Training a community to implement the research design takes time. Being trained by a community in how to responsively and responsibly engage with the community takes time. It's important to be clear that authentic community engaged research may not coordinate well with an academic calendar or fit neatly into the timetable set forth in research grants. However, while acknowledging the complexity a researcher involved in community-engaged research may experience, it is imperative to also recognize, and take into consideration, the investment of time and resources contributed by a community to build a research relationship. Community members similarly extend themselves, hoping their investment of time and resources, often scarce, will benefit their community. Communities take risks just the same as academic researchers. This must be acknowledged.

I hesitate to discuss the “hidden costs” involved in authentically engaging in community research in light of my work with the Virginia American Indian community for fear of my relational intentions being misinterpreted. The commencement of my relationship with the Virginia American Indian community began, and has continued, with a heart to serve the community. When I began volunteering at the Clinic seven years ago, a doctoral journey was not even a thought in my mind, at least not a conscious thought. My decision to pursue a doctoral degree emerged from the relationships I developed with people in the Virginia American Indian community and a desire to want to learn how to better support the health and well-being of Virginia American Indian people specifically, and Indigenous people more broadly. So the time invested in activities such as volunteering at the Clinic, listening to stories, attending cultural events, planting gardens, and grieving the loss of community members was never motivated by a

research relationship, but rather friendship. However, while my intention in building relationships with people in the Virginia American Indian community was not rooted in a research capacity, when an opportunity to engage with the community in a research capacity emerged, the relational foundation had already been developed. To my surprise though, engaging in a research relationship with participants created a more intimate relationship, as interviews opened the door for more in-depth conversations than I had previously had with some people. It is my hope that I have engaged in this dissertation research in a way that has been relationally accountable to the community, preserving relationships that had been established prior to engagement in a research capacity.

While I'm hesitant to discuss the "hidden costs" involved in doing community engaged research in light of my dissertation research for fear of my relational interests being misinterpreted, it is important to note the tension involved in doing community engaged research while operating within an academic calendar. It's first important to note that I was not engaged in community-based participatory research, so I cannot be held accountable to upholding CBPR principles; however, this dissertation research was community engaged in that community input was involved in several aspects of the study, including identification of the research question and certain design elements. That being said, while I would be pleased to relate that all methodological decisions were informed by community consensus, or based on an assessment of what would be most responsive to the community context, the reality is that I was also accountable to an academic calendar. Making decisions in light of both realities caused tension for me. Engagement in authentic community engaged research is critical to being responsive to the needs of communities, particularly marginalized communities; however, it is important for

social work researchers to honestly reflect on their availability and ability to engage in such a capacity and be transparent with themselves and the community.

**Push boundaries around historically held notions of what constitutes science and acceptable data.** This chapter has addressed the need for social work education and practice to position Western social science theories and subsequent practice models as cultural constructions and the importance of incorporating Indigenous knowledges in social work education and practice in ways that address Indigenous knowledge systems on equal footing with Western knowledge systems. It is similarly important to assess the notion of science through a contextual lens, acknowledging the ways history, politics, and religion have intricately shaped science through the centuries and decades. Recognizing science as a product of historical, political, and religious negotiation, rather than as a neutral, objective activity, opens the door for discussions about pushing boundaries around historically held notions of what constitutes science and acceptable data. This is an important discussion for social workers engaging in knowledge building/knowledge testing activities with people whose worldview differs from that of a Western worldview, which has dominated science for centuries. For research to be relevant and responsive to the various communities with which social workers engage, social workers must consider the relevancy of non-Western forms of knowledge building and knowledge testing. For example, dreams and visions are foundational ways of coming to know about the world in many Native cultures. The question for social workers should not be whether dreams and visions are legitimate ways of coming to know about the world, but rather how we can learn to embrace these “alternative” ways of knowing about the world in ways that push the profession to be more responsive and relevant in an increasingly globalized world. This is not to suggest that Western-informed ways of knowing are irrelevant when working in non-Western contexts; however, it is

important be critically aware of the philosophical foundations underpinning Western science, as well as its limitations, similar to operating from any worldview.

### **Future Research Directions**

Having addressed implications of this dissertation research for social work education, practice, policy, and research, this section will consider future research directions in light of this study. This section will begin with a research study idea that builds on the design and findings of this dissertation research, but extends the conversation about the meaning of health and healing in Virginia American Indian communities beyond the Clinic to the Virginia American Indian community more broadly. Next, this section will identify two capacity building approaches that seek to bolster the capacity of Virginia American Indian communities to engage in ongoing research.

This dissertation research sought to explore the question of what the meaning of health and healing is among Virginia American Indian people in the context of a reservation-based, non-federally funded health clinic. The conceptual framework of responsive and responsible health and healing that was derived from analysis of participant stories is context dependent, a construction of health and healing that is representative of the people who participated in the study at the time of the study. While this study provides important information pertaining to the ways Virginia American Indian people connected to the reservation-based, non-federally funded health clinic think about health and healing, it is limited in what it can tell us about the ways Virginia American Indian people broadly think about health and healing. I propose re-structuring this dissertation research to more broadly explore the meaning of health and healing among Virginia American Indian people outside of the reservation-based, non-federally funded health clinic that serves as the context of this dissertation research.



The proposed study seeks to answer the same research question – what is the meaning of health and healing among Virginia American Indian people – and similarly proposes to use in-depth, semi-structured interviews to gather the data; however, rather than sample from within the Clinic context, the sampling frame would extend to include all members (formally and informally identified) of a particular tribe, or all Virginia American Indian people, depending on community input. Extending the sampling frame beyond the Clinic addresses a limitation of this dissertation research – limited variation. It will be important to bring in the voices of youth in the proposed study, as well as various other dimensions of diversity. This proposed study would draw on CBPR principles, inviting the community to play a greater role in the design and implementation of the study. A construction of health and healing that is representative of a broader community could perhaps inform a subsequent quantitative study that would assess the collective health and healing of Virginia American Indian people using indicators of health and healing informed by the qualitative study.

In addition to the proposed study that would build on and extend this dissertation research, it seems building the capacity of Virginia American Indian communities to engage in ongoing research would be important to both the quality of the research and its responsiveness to supporting the health and healing of Virginia American Indian communities for today, as well as generations to come. I see two potential processes as important to developing the research capacity of Virginia American Indian communities: (1) use of a community readiness model to assess the readiness of Virginia American Indian communities to engage in future research, and (2) establish a tribal institutional review board.

Developed by the Tri-Ethnic Center for Prevention Research at Colorado State University, the community readiness model is a research-based method for assessing the level of

readiness of a community to develop and implement prevention programming (Edwards, Jumper-Thurman, Plested, Oerring, Swanson, 2000). The degree to which a program can be effectively implemented and supported by a community has been linked to the community's readiness to engage in the implementation of such a program (Edwards et al., 2000). The community readiness model provides a tool for assessing the level of community readiness to engage in a particular intervention, as well as proposes strategies for moving the community from its current level of readiness to the next higher level, if needed. The model has been proven useful in addressing a wide array of matters, ranging from health and nutritional issues to environmental and social issues (Jumper-Thurman, Plested, Edwards, Foley, & Burnside, 2003). The model has been used successfully in Native communities. I propose the use of the community readiness model to assess the readiness of the Virginia American Indian community to engage in research, and, if needed, to engage the community in strategies necessary to bring the community to a place of readiness to engage in research.

In addition to assessing the readiness of Virginia American Indian communities to engage in research, developing the capacity of the communities to make informed decisions about the types of research done in their communities, and having control over how the research is done and how it is used, seems important to ensuring that research in Virginia American Indian communities is beneficial to the community. I propose the development of an inter-tribal institutional review board. This is not a new idea, but rather draws from tribally based institutional review boards that have been established in other American Indian and Alaska Native communities. Establishing an inter-tribal institutional review board to monitor research engagements in Virginia American Indian communities would provide tribes with control over research that is done in their communities, allow them the opportunity to set their own research

agenda, and protect their people in the process. While tribally based institutional review boards are not a panacea against unethical research, they do offer opportunities for tribal communities to be informed about and have control over the research endeavors that occur in their communities.

### **Conclusion**

This study sought to explore the question: What is the meaning of health and healing among Virginia American Indian people in the context of a reservation-based, non-federally funded health clinic? Using an emergent approach to qualitative research grounded in a constructivist inquiry paradigm and guided by Indigenous research principles, a total of 24 in-depth, semi-structured interviews (15 interviews during Wave I and nine interviews during Wave II of data collection) were conducted with 17 American Indian service-users of a reservation-based, non-federally funded health clinic. Through an inductive thematic analysis of participant stories, a framework for understanding responsive and responsible health and healing was derived. The framework includes seven dimensions: spirituality, physical processes, mental and emotional processes, social relationships, access to resources, contextual factors, and the interconnection among the dimensions. Personal and collective identity was a significant element woven through the dimensions. From the stories told by participants, health seems to be a continuum and healing seems to be a cycle. With constant motion in each of the dimensions, health has to do with sustained engagement in a healing process that continually seeks to bring about functional balance in one's whole health system. Ill health has to do with when a change in any one of the dimensions overtakes one's ability to bring about a functional balance in the whole health system. The framework is context-dependent, true for the people who participated in the study at the time of the study.

## Epilogue

“All stories reflect the storyteller and where they are in their lives. A problem with writing down stories is that it makes it very difficult to change them as we gain new learning and insights” (Wilson, 2008, p. 22).

*Nearly four years have passed since the commencement of this research journey. I am not the same person at the end of this journey as I was at its commencement. I've moved across state lines. I've welcomed new life into this world, becoming a mother, and I've grieved the loss of life that has passed on from this earth. I've climbed new mountains and I've visited new valleys. I've welcomed countless sunrises, as well as watched the moon wax and wane across the nighttime sky. Seasons came, and seasons went, yet one thing remained constant, this dissertation journey.*

*During this journey, my understanding of Indigenous knowledges has deepened, broadened, and grown more mature. I've had the privilege of being invited into the hearts and homes of participants as we explored the meaning of health and healing in their lives. We laughed and we cried together. I'm still sometimes brought to laughter when I recount certain stories that were shared, and I'm still provoked to tears when I recall the painful ones. Participant stories seeped deep into my being and continually challenge me to feel more deeply, think more critically and creatively, and act more compassionately. Seasons came, and seasons went, yet one thing remained constant, this dissertation journey.*

*During the lifespan of this dissertation research, I've stood in solidarity with the Standing Rock Sioux Tribe and Indigenous peoples from around the world seeking to protect*

*Mother Earth and hold the United States government accountable to honoring the treaties. Through this journey, I've learned from Indigenous youth and elders alike about their localized beliefs and traditions. I've witnessed a story of strength and resilience born out of hardship. I've witnessed a story of struggle rooted in love and forgiveness, to a degree that I've never witnessed before. I watched Indigenous peoples walk proudly and humbly as they have selflessly fought to protect their Mother Earth; to honor their ancestors; to create a better today for their relations; and to ensure a bright future for the seven generations to come. Seasons came, and seasons went, yet one thing remained constant, this dissertation journey*

*During this dissertation journey, I've also listened to voices of Indigenous scholars working to Indigenize knowledge gathering processes. I've learned of ways in which Indigenous scholars have brought their localized knowledges, customs, and traditions into formal knowledge gathering spaces. I've witnessed challenges they have encountered in calling for the legitimacy of their ways of being and coming to know in Western dominated institutions of learning. I've also watched their fire to engage in research for the betterment of their communities burn bright. Seasons came, and seasons went, yet one thing remained constant, this dissertation journey.*

*I am not the same person today, toward the end of this dissertation journey, as I was when I began this journey, yet one thing remained constant, this dissertation journey. In some respects the continuity of this journey has been a comfort, a home, a place always to return as the world swirled around me. Sometime the journey itself became the storm, requiring me to momentarily retreat to safety, but always calling me home. In other respects, the constancy and continuity of this journey presented many challenges as I was continually faced with negotiating the degree to which my emerging self could (or could not) be brought into this research engagement. For example, while my understanding of Indigenous ways of knowing and being*

*broadened, deepened, and matured during the dissertation process, I continually wrestled with the degree to which it was acceptable to bring these knowledges into a research plan that had been developed, defended, and approved by a committee. While the design was emergent in nature, there still seemed to be parameters around how much a design could emerge to account for my growing knowledge base, rather than in response to ongoing engagement with participants. Seasons came, and seasons went, yet one thing remained constant, this dissertation journey.*

*While I've been faced with negotiating how to bring my emerging self into this dissertation journey, I know the journey will continue as this dissertation process draws to a formal close. In the beginning of this journey, I saw my identity as a White woman who was born, raised, and educated in a worldview informed by European/Western philosophy, values, and customs. I saw myself as a first-generation college student, born into a blue-collar family and raised in a blue-collar community. Four years later, I'm still all of these things; however, it seems my identity has become more complex. Today, I hold stories of Virginia American Indian people deep in my mind, and in my heart, and in my body, but the experiences of oppression, discrimination, and prejudice told by participants will never pulse through my veins in the same way it pulses through theirs. While I may have stood shoulder to shoulder with Indigenous peoples in their fight to protect Mother Earth and demand that treaties be honored, my ancestors never endured the persecution suffered by the ancestors of the Indigenous peoples I stood next to. While my understanding of Indigenous knowledges may have broadened, deepened, and matured over the last four years, either directly related to the dissertation process or otherwise, I was never raised with the teachings of Indigenous elders. So what does this mean for me as an*

*emerging scholar and social work practitioner desiring to continue working and building relationships in Indigenous spaces?*

*The same questions I wrestled with at the beginning of the dissertation journey are still questions with which I wrestle today. Despite continuing to learn about Indigenous knowledges and building relationships with Indigenous peoples, will there ever be a time when I could respectfully and responsively operate from an Indigenous way of knowing and being in the world? Will operating from an Indigenous paradigm always feel like an act of appropriation? As I go forward, how can I use my emerging knowledge of Indigenous ways of knowing and being in the world to support Indigenous peoples in a way that is relationally accountable? Perhaps the more appropriate question may be how do I use my privilege as a White, educated woman to support Indigenous peoples with whom I cross paths along my life journey? I suspect that these are questions that will continue to reverberate through my life journey.*

*Seasons came and seasons went, and this dissertation journey is drawing to a close. I am not the same person I was at the commencement of this journey, but my commitment to further support the health and well-being of Indigenous peoples is unwavering. While I have grown and changed during this dissertation process, my hope is that my actions through this journey have been respectful, responsible, and rooted in reciprocity to all my relations. Thank you for walking this road with me.*

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## Appendix A. Recruitment Script

Title: The Meaning of Health and Healing Among Virginia Indian People in the Context of a Reservation-based, Non-federally Funded Health Clinic  
IRB Study: HM20003553

### **Recruitment Script**

While I have been a volunteer at the Mattaponi Healing Eagle Clinic, I have also been a student at VCU. I am not a medical student like most of the volunteers at the Clinic. I am a social worker. Meeting and working with Virginia Indian people, like yourself, at the Clinic has motivated and inspired me to learn about ways to work with American Indian people to help create healthy American Indian families and communities for today and generations to come.

As part of my education, I am required to do a research project. The research project gives me a chance to practice the skills that I have learned in school, just like the medical student volunteers use the Clinic to practice what they learn at school.

The research project I came up with (with input from people in your community) has to do with learning how to better support the health and well-being of Virginia Indian people. The purpose of my project is to learn about what health and healing means to you and to other people in your community. Hopefully by learning about how you and others in your community think about health and healing, we can come up with ways to better help people in your community be healthy.

I would like to ask you to be part of this research project. By asking you to be a part of the project, I am asking if we can do an interview together. If you agree to be part of the project, we will have a conversation about what health and healing means to you. I am asking you to be part of the project because you are connected to the Mattaponi Healing Eagle Clinic and I think you have an important story to tell about health and healing.

I want to be very clear with you. Whether you decide, “Yes, I want to be part of the project,” or whether you decide, “No, I do not want to be part of the project,” your decision will not affect your medical care at Mattaponi Healing Eagle Clinic. If you decide to participate, you will still

receive the same kind of care you have been receiving at the Clinic. If you decide not to participate, you will still receive the same kind of care you have been receiving at the Clinic. I will not treat you or your family any differently at the Clinic. I will care about you and your family just the same whether you decide to be part of the project or whether you decide not to be part of the project. I respect your decision. No one other than me will know whether you decided to be part of the project. I will not tell Margie, the doctors, or any of the medical student workers. The stories that you tell will never be connected with your name, unless you ask specifically for your name to be used, but we can talk about that later.

If you agree to be part of the project, I would like to set up a time to meet with you at a place and time that is convenient for you. When we get together, I will tell you more about the project and answer any questions you may have about the project. If you would like to be part of the project, I will ask you to sign a form saying that you agree to be a part of the project. Then we can move along with the interview. I imagine the interview might take about one to two hours, depending upon how much you would like to share. When we get together, you can always change your mind and decide that you do not want to participate.

## Appendix B. 3<sup>rd</sup> Party Recruitment Script

Title: The Meaning of Health and Healing Among Virginia Indian People in the Context of a Reservation-based, Non-federally Funded Health Clinic  
IRB Study: HM20003553

### **Recruitment Script** (to be used by third party)

Amy Prorock-Ernest, from the Mattaponi Healing Eagle Clinic, is doing a student research project. Amy is interested in learning about how to work with Virginia Indian people to help create healthy Virginia Indian families and communities for today and generations to come. The purpose of her project is to understand what health and healing mean to Virginia Indian people who are connected to the Mattaponi Healing Eagle Clinic. She would like to interview people connected to the Clinic. The project is totally separate from your medical care at Mattaponi Healing Eagle Clinic. It will take about 10 minutes of your time to hear more about the project.

#### **[Are you in the same room as the eligible person of interest?]**

[If YES, say...]

If you would like to hear more about the project, please sign the Release of Information Form and I will give your name and contact information to Amy who will contact you.

[If NO, say...]

If you would like to hear more about the project, is it okay for me to give your name and contact information to Amy who will contact you?



Appendix C. Permission to Release Information

Title: The Meaning of Health and Healing Among Virginia Indian People in the Context of a  
Reservation-based, Non-federally Funded Health Clinic  
IRB Study: HM20003553

**Permission to Release Information**

I, \_\_\_\_\_, give permission to  
(print the name of Eligible Person of Interest)

\_\_\_\_\_ to release my name  
(print the name of the Person Asking for Permission)

and contact information to student researcher Amy Prorock-Ernest.

**[Are you in the same room as the Interested Person?]**

- If YES, ask Eligible Person of Interest to sign below.
- If NO, leave 'Eligible Person of Interest' line below empty.

Sign \_\_\_\_\_ Date \_\_\_\_\_  
(Eligible Person of Interest)

Sign \_\_\_\_\_ Date \_\_\_\_\_  
(Person Asking for Permission)

**Contact Information of Eligible Person of Interest**

Name \_\_\_\_\_

Phone Number \_\_\_\_\_

Best time for Amy to call \_\_\_\_\_



## Appendix D. Recruitment Flyer

# Your story is important...

What does health and healing mean to you?

**WHAT:** Amy Prorock-Ernest, a long-time volunteer with the Mattaponi Healing Eagle Clinic, is doing a student research project. Amy wants to learn about how to create healthy Virginia Indian families and communities for today and generations to come.

**WHO:** YOU! Amy would like to interview people connected to the Mattaponi Healing Eagle Clinic. Amy will ask you questions about what health and healing mean to you. There are no right and wrong answers. Your story is important.

**WHERE:** You name the time and place for the interview! Amy will meet you at a place that works best for you.

WANT TO LEARN MORE?

INTERESTED?

WANT TO TELL YOUR STORY?

Call Amy at 800

551-2108



## Appendix E. Participant Information

Title: The Meaning of Health and Healing Among Virginia Indian People in the Context of a  
Reservation-based, Non-federally Funded Health Clinic  
IRB Study: HM20003553

### Participant Information

1. *Participant Pseudonym* \_\_\_\_\_

*Participant Unique Identifier* \_\_\_\_\_

2. *Tribal affiliation* \_\_\_\_\_

3. *Age*

18 – 24

25 – 29

30 – 39

40 – 51

52 – 61

62 – 69

70 – 79

80 – 89

90 – 99

>=100

4. *Sex*

Male

Female

Prefer not to answer

Other \_\_\_\_\_

5. *Religion/Spiritual Practice* \_\_\_\_\_

6. *Health Insurance*

Private

Uninsured

Medicare

Other \_\_\_\_\_

Medicaid



## Appendix F. Questions to Guide Interviews

Title: The Meaning of Health and Healing Among Virginia Indian People in the Context of a Reservation-based, Non-federally Funded Health Clinic  
IRB Study: HM20003553

### Questions to Guide Interviews

Question 1: Talk to me about what it's like to be healthy.

Probe 1: Look?

Probe 2: Feel?

Question 2: Talk to me about healing.

Probe 1: Practices?

Probe 2: Promotes?

Probe 3: Gets in the way?

Probe 4: Relationship between health and healing?

Question 3: Talk to me about what it's like to be unhealthy.

Probe 1: Look?

Probe 2: Feel?

Question 4: Tell me about your experience with the Mattaponi Healing Eagle Clinic.

Probe 1: What led you to come (or not come) to MHEC?

Probe 2: Support you health?

Probe 3: Challenges?

## Appendix G. Informed Consent

### **RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM**

**TITLE: The Meaning of Health and Healing Among Virginia Indian People in the Context of a Reservation-based, Non-federally Funded Health Clinic**

**VCU IRB NO.: HM20003553**

**STUDENT RESEARCHER: Amy Prorock-Ernest**

- If any information contained in this consent form is not clear, please ask Amy Prorock-Ernest (the student researcher) to explain any information that you do not fully understand.
- You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

#### **PURPOSE OF THE STUDY**

- Meeting and working with Virginia Indian people at the Mattaponi Healing Eagle Clinic has motivated and inspired me (Amy) to learn how better to work with American Indian people to help create healthy families and communities for today and generations to come.
- The purpose of this project is to learn about what health and healing mean to Virginia Indian people connected to the Mattaponi Healing Eagle Clinic.
- Hopefully by learning about how you and others in your community think about health and healing, we can come up with ways to better help people in your community be healthy.
- You are being asked to be part of the project because you are connected to the Mattaponi Healing Eagle Clinic and because you have an important story to tell about health and healing.
- This research project is part of my (Amy's) education. This research project gives me a chance to practice the skills that I have learned in school.

#### **DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT**

- For this project, you will be asked to do *at least* one interview with me (Amy).
- During the first interview I will ask you questions like: What is it like to be healthy? What is it like to be unhealthy? What promotes healing? What gets in the way of healing?

- There are no right or wrong answers. I (Amy) am interested in *your* experiences, ideas, and feelings.
- The interview may last one to two hours, depending on how much you would like to say.
- If it is okay with you, the interview will be tape recorded so I (Amy) am sure to get your stories and ideas. I will not tape record the interview if you do not want your interview recorded. I will take notes during the interview.
- I (Amy) will interview about 30 people connected to the Mattaponi Healing Eagle Clinic.
- If you give me permission to contact you after the first interview, you may be contacted if I have any follow-up questions. You may also be asked to review and comment on ideas and stories that come from other interviews.
- You may choose not to be part of the follow-up questions if you do not want to be. You may choose not to review and comment on the ideas and stories emerging from the interviews if you do not want to.
- Your decision to be part of each step of the project makes the project richer, but you can always choose which part you want to be a part of.
- If you decide to be in this research project, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

### **RISKS AND DISCOMFORTS**

- Sometimes talking about our health, and the health of our families, can make us upset.
- During the interview, you do not have to talk about any topic that may make you upset if you do not want to. You do not have to answer any question you do not want to answer. You may end the interview at any time.
- If you become upset and would like to talk with someone who can support you, I will help connect you with someone who can help.

### **BENEFITS TO YOU AND OTHERS**

- You may not get any direct benefit from being a part of this study.
- Some say that sharing stories about our lives and the lives of our families helps us feel better and stronger. You may feel better emotionally after sharing stories about health and healing during the interview.
- Your ideas, feelings, and stories will hopefully help us come up with ways to better help people in your community be healthy.

### **COSTS**

- It will not cost you any money to be part of the project.
- I (Amy) know that your time is valuable and important. I am thankful for any time you give to be part of this project.

## CONFIDENTIALITY

- What is confidentiality? Confidentiality is about the way private information about you is kept in a safe way.
- All information that you share will be kept in a locked cabinet or on a computer that is protected by a password, so I (Amy) will be the only one who knows that you are/were part of the project (unless you want your real name connected to your interview stories).
- You can choose whether you want your name to be connected to your interview and the stories that you tell. You will have many chances to decide and many chances to change your mind. I (Amy) will first ask you whether you want your name to be connected to your interview and the stories that you tell during the informed consent process. I will ask, again, after the interview whether you want your name to be connected with your interview and the stories that you told. I will also ask you during any follow-up talks whether you want your name to be connected to your interview and stories. Until the end of the project, you can always change your mind. All you have to do is contact me and let me know that you want to change your decision.
- In all cases (whether you do want your name connected to your interview and stories or whether you do not want your name connected to your interview and stories), I (Amy) will ask you to come up with a “fake” or “pretend” name. Your fake or pretend name will be used to label your taped interview and any interview notes.
- *If you **do want** your real (legal) name to be connected to your interview* and the stories that you tell, your real (legal) name will only be used during the final write up of the project. Your real (legal) name will not be shared with other people who are part of the project. Your ideas, feelings, and stories will be connected to your real (legal) name only at the end of the project. This keeps your ideas, feelings, and stories safe (private) until the end of the project.
- *If you **do not want** your real (legal) name to be connected to your interview* and the stories that you tell, only the fake or pretend name you choose will be used at all times.
- The list (key) connecting your real (legal) name and the fake or pretend name that you choose will be kept in a locked cabinet. I (Amy) will be the only one who can see the list (key). No one else will be able to see the list.
- While I (Amy) will do my best to keep the ideas, feelings, and stories you share with me confidential (unless you want your real name linked to your interview stories), sometimes others may be able to guess who you are based upon what they may know about you before the project begins.
- Tape recordings and any documents with your real (legal) name on it will be destroyed one year after the end of the project. All other materials that are not connected with your real (legal) name will not be destroyed and will be kept by the student researcher (Amy).
- Given that I am a student researcher, I may share some of your ideas, feelings, and stories with a team of my professors who are helping me with the project. Your name *will not be linked* to your ideas, feelings, and stories.
- What we find from this project may be presented at meetings or published in papers, but your name will not ever be used in these presentations or papers (unless you want your real (legal) name linked to your interview stories).



- If you share something with me during the project that suggests you may harm yourself or others, I am required to report the information to the appropriate authorities.

## **VOLUNTARY PARTICIPATION AND WITHDRAWAL**

- You do not have to be part of this project.
- You do not have to answer any questions that you do not want to answer. You do not have to talk about any topics that you do not want to talk about.
- You can stop being part of this project at any time. If you do not want to be part of this project, please let me (Amy) know if I can use the ideas, feelings, and stories you already shared with me OR if you want all of the ideas, feelings, and stories you shared with me to be returned to you.
- VERY IMPORTANT – Your decision to be part of this project IS NOT CONNECTED to your medical care at the Mattaponi Healing Eagle Clinic.
- VERY IMPORTANT – If you decide to be part of the project, you will still receive the same kind of care you have been receiving at the Clinic. If you decide not to be part of the project, you will still receive the same kind of care you have been receiving at the Clinic.
- VERY IMPORTANT – I will care about you and your family *just the same* whether you decide to be part of the project or whether you decide not to be part of the project. I will not treat you or your family any differently at the Clinic.
- VERY IMPORTANT – *I respect your decision.*
- VERY IMPORTANT – No one other than me will know whether you decide to be part of the project. I will not tell Margie, the doctors, or any of the medical student workers.

## **QUESTIONS**

If you have any questions, complaints, or concerns about your participation in this research project, contact:

### **Student Researcher**

AMY PROROCK-ERNEST, MSW, MPH

Doctoral Candidate

School of Social Work

Virginia Commonwealth University

(804) 551-2108

ernestaj@vcu.edu

### **Professor Principal Investigator**

ALEX WAGAMAN, PhD, MSW

Principal Investigator

School of Social Work

Virginia Commonwealth University

(804) 828-2873

mawagaman@vcu.edu

*The student researcher and professor named above are the best person(s) to call for questions about being part of the project.*

If you have any general questions about your rights as a participant in this or any other research, you may contact:

Office of Research  
Virginia Commonwealth University  
800 East Leigh Street, Suite 3000  
P.O. Box 980568  
Richmond, VA 23298  
Telephone: (804) 827-2157

Contact this number to ask general questions, to obtain information or offer input, and to express concerns or complaints about research. You may also call this number if you cannot reach the research team or if you wish to talk with someone else. General information about participation in research studies can also be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

**CONSENT**

*I have been given the chance to read this consent form. I understand the information about this project. Questions that I wanted to ask about the project have been answered. My signature says that I am willing to be part of this project. I will receive a copy of the consent form once I have agreed to be part of the project.*

\_\_\_\_\_  
Participant (signature) \_\_\_\_\_  
Date

\_\_\_\_\_  
Participant (print name)

\_\_\_\_\_  
Signature of Person Conducting Informed Consent \_\_\_\_\_  
Date  
Discussion /Witness

I give permission for my interview to be tape-recorded.

YES  NO

\_\_\_\_\_  
Participant (signature) \_\_\_\_\_  
Date

I give permission for the student researcher to contact me with any follow-up questions and/or future opportunities related to the project.

YES  NO

\_\_\_\_\_  
Participant (signature) \_\_\_\_\_  
Date

I give permission for my real (legal) name to be connected to my ideas, feelings, and stories in the final report.

YES                       NO

\_\_\_\_\_  
Participant (signature)

\_\_\_\_\_  
Date

I give permission for my real (legal) name to be connected to my ideas, feelings, and stories in the final report.

YES                       NO

\_\_\_\_\_  
Participant (signature)

\_\_\_\_\_  
Date

I give permission for my real (legal) name to be connected to my ideas, feelings, and stories in the final report.

YES                       NO

\_\_\_\_\_  
Participant (signature)

\_\_\_\_\_  
Date

I give permission for my real (legal) name to be connected to my ideas, feelings, and stories in the final report.

YES                       NO

\_\_\_\_\_  
Participant (signature)

\_\_\_\_\_  
Date

Appendix H. Excerpts from the Four Electronic Files Used During Analysis

Step 1: Framework from Interview Protocol with Identifier

Unique identifier:

Date analyzed:

Question 1: Healthy – feelings, beliefs, experiences, stories having to do with the biological, psychological, spiritual, and social factors of wellness		
	Text	Note
Probe 1: Look like (measurable, observable)	-----	Q1.P1
<i>Individual</i>		
	-----	Q1.P1.1
Physical health		Q1.P1.1-1
Mental/Emotional health		Q1.P1.1-2
Self-care activities (self-discipline)		Q1.P1.1-3
Independence		Q1.P1.1-4
Positive thinking		Q1.P1.1-5
Empowerment		Q1.P1.1-6
Spirituality		Q1.P1.1-7
Origin of spirituality		Q1.P1.1-7b
Humor		Q1.P1.1-8
Identity		Q1.P1.1-9
Forgiveness		Q1.P1.1-10
<i>Relational</i>		
	-----	Q1.P1.2
Social relationships		Q1.P1.2-1
Family		Q1.P1.2-2
Individual and collective health		Q1.P1.2-3
Respect		Q1.P1.2-4
Reciprocity		Q1.P1.2-5
Spirituality		Q1.P1.2-6
Helping others		Q1.P1.2-7
Origin of helping others		Q1.P1.2-7b
Cultural engagement		Q1.P1.2-8
Origin of cultural engage		Q1.P1.2-8b
Animals		Q1.P1.2-9
Sense of place/ connection to the land		Q1.P1.2-10
Probe 2: Feel like (descriptive	---	Q1.P2

<b>Question 1: Healthy – feelings, beliefs, experiences, stories having to do with the biological, psychological, spiritual, and social factors of wellness</b>		
	<b>Text</b>	<b>Note</b>
affect description)		
	“Doing good,” “feeling better,” “not well”	Q1.P2.1
	Feeling good about one’s self	Q1.P2.2
	Probe 3: Shaped perspective about being healthy?	Q1.P3
	Probe 4: Health and wellness/wellbeing	Q1.P4
	Probe 5: Inter-relationship between physical, mental, emotional, and spiritual health	Q1.P5
	Balance	Q1.P5.1
	Probe 6: Other	Q1.P6

## Step 2: List of Codes (collapsed) with Identifier

[I am using the word 'code' to describe the groupings of corralled data segments according to the name of the probes from my question/probe framework. Probes have been combined across questions. For example the 'Spirituality' probe under Questions 1, 2, and 3, have all been combined into Code 22: Spirituality.]

- Self-care activities (self-discipline)/Lack of self-care activities (\*\*1)
  - Q1.P1.1-3
  - Q2.P1.1-1
  - Q3.P1.6
  
- Humor (\*\*2)
  - Q1.P1.1-8
  - Q2.P2.2-5
  
- Animals (\*\*3)
  - Q1.P1.2-9
  - Q2.P1.2-3
  
- Forgiveness (self and others) (\*\*4)
  - Q1.P1.1-10
  - Q2.P1.1-2
  
- Remembering/Memories (\*\*5)
  - A.2
  
- Empowerment/Lack of empowerment (\*\*6)
  - Q1.P1.1-6
  - Q2.P2.1-3
  
- Mental/Emotional health (\*\*7)
  - Q1.P1.1-2
  - Q3.P1.7
  
- Positive/Negative thinking (\*\*8)
  - Q1.P1.1-5
  - Q2.P2.1-1
  - Q2.P3.1
  - Q3.P1.2
  
- "Doing good," Feeling better," "Not well" (\*\*9)
  - Q1.P2.1
  
- Feeling good about one's self (\*\*10)
  - Q1.P2.2



- Hopelessness (\*\*11)
  - Q3.P2.1

...

### Step 3: "Codes" Analyzed

[The bulleted names in quotation marks under the code number and name refer to patterns in the data segments within each code. The data segments have been collated under each group name (in a separate document). For codes that do not have bullet names associated with them either (1) data segments associated with that code are few, or 2) there are not distinct patterns in the data segments collated with the code (although there may be loosely connected ideas grouped together.)

**Code 1. SELF-CARE ACTIVITIES** – having to do with daily activities in which a person can engage that

are connected to being healthy and promoting healing, or, when not practiced, can lead to poor health

**A. "Eating Right"** –having to do with the quality of foods eaten and the quantity eaten and/or the relationship between eating/diet and health

**B. "It's Hard"** –having to do with the struggle in making the right decisions to engage in personal actions that support being healthy and carrying out the personal actions that support health

**C. "Exercise"** –having to do with engaging in physical activity meant to sustain or improve health and fitness

**D. "Activities of Enjoyment"** –having to do with engaging in activities that are pleasurable and are related to feeling healthy

**E. "Compliance with Medical Care"** –having to do with maintaining activities related to medical care

**F. "Choice"** - having to do with the power humans have to choose whether to engage in or reject lifestyle behaviors related to health

**G. "Does Not Promote Health"** - having to do with lifestyle choices that do not help a person to be healthy

**H. "Additional Variation – Self-care Activities"** – having to do with self-care activities that add additional variation to the perspectives that fall within identified groups

**2. HUMOR** – having to do with the ability to be funny or to be amused by things that are perceived as

funny, particularly during times of hardship

**3. ANIMALS** - having to do with the nature of animals and/or the relationship between the interaction

between animals and humans particularly as related to health and/or healing

**4. FORGIVENESS (SELF AND OTHERS)** - having to do with ceasing to feel resentment toward self

and others

5. **REMEMBER WHERE YOU CAME FROM** – having to do with actively remembering stories of various dynamics of where you came from (i.e. family, culture, faith, etc.) and what you're about

6. **EMPOWERMENT** – having to do with having the power and confidence to control one's life and

claiming one's right, particularly as related to one's health, as well as having the power and confidence to act on behalf of (or in stride with) another person, particularly as related to another person's health

**A. "Empowered to Act in One's Best Interest Regarding Health Care"** – having to do with

acting in one's personal best interest in situations regarding one's personal health care

**B. "Barriers to Empowerment"** – having to do with obstacles (imagined or tangible) that inhibit a...

Step 4: Organization List of Themes and Sub-themes

**THEME 1: PHYSICAL**

**[Theme 1 has to do with assertions, thoughts, feelings, and experiences concerning how our physical state and processes are related to being healthy and unhealthy, as well as the ways in which our physical state and processes promote healing and/or serve as barriers to healing.]**

**1. HEALTH IS PHYSICAL** - having to do with the absence of disease or bodily pain (12)

**2. PERSONAL AND FAMILY PHYSICAL HEALTH STORY** – having to do with the physical health of participants, as well as the reported physical health of family members, often asserting a relationship between the two

**2A. Personal physical health** – having to do with the physical health of participants

**2A(i). Personal physical health conditions** – having to do with physical health conditions personally experienced by participants (13)

**2B. Family physical health conditions** – having to do with the reported physical health, and, in some cases death, of family members, often asserting a relationship between personal and family health (14)