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DISSERTATION

ART-BASED NARRATIVE INQUIRY WITH NATIVE AMERICAN BREAST CANCER SURVIVORS

Submitted by

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WE HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER OUR SUPERVISION BY ELIZABETH A. WARSON ENTITLED ART-BASED NARRATIVE INQUIRY WITH AMERICAN INDIAN BREAST CANCER SURVIVORS BE ACCEPTED AS FULFILLING IN PART REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY.

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ABSTRACT OF DISSERTATION

ART-BASED NARRATIVE INQUIRY WITH NATIVE AMERICAN

BREAST CANCER SURVIVORS

Background and Aims

Breast cancer rates for American Indian and Alaska Native women are lower than any ethnic or racial group. This fact alone has contributed to the perception that breast cancer is not an "Indian" problem among health officials. Cancer statistics in general for American Indian and Alaska Natives are unreliable because of the frequency of racial misclassification, underreporting, and clustering data under the "other" category. Inclusive data from The Intercultural Cancer Council suggests that rates of breast cancer for American Indians and Alaska Natives, who experience the poorest 5-year survivorship, have been increasing over the past 20 years. The majority of the cancer research among Native people has concentrated on eliminating social, cultural, and structure barriers to healthcare. What has not been included in the literature are culturally-relevant psychosocial interventions incorporating the expressive arts. Behavioral research in cancer care for Native American women is needed to address quality of life factors. The purpose of this post modern narrative inquiry is to explore, through artmaking and storytelling, the belief systems surrounding wellness and physical illness from the perspective of Native women diagnosed with breast cancer. This narrative inquiry would provide the ground work for culturally-competent psychosocial interventions utilizing the expressive arts.

Method

The participants were 2 American Indian women diagnosed with breast cancer from the Coharie tribe in Clinton, North Carolina, ages 74 and 66. These women were co-collaborators in an emergent narrative inquiry, incorporating a demographic interview, 3 main art task, and 8 open-ended interview questions. Their stories were analyzed discursively using the zoom model. To supplement the emergent themes from the analysis, 3 additional data sources, comprising interviews from a traditional healer and two tribal representatives, were included in the situational analysis.

Results

Two positional "maps" were created from the layers of narrative and visual discourse analysis. The maps charted different positions along a four different continuums: cancer related medical treatment, traditional American Indian healing practices, wellness, and breast cancer and breast cancer treatment. The maps showed that wellness and spirituality were inseparable and a core belief to undergoing breast cancer treatment and survivorship. Traditional healing practices were viewed as a complementary approach to Western medicine; however, this approach was not a shared position with providers. The positional maps suggested that a more culturally-relevant, holistic, approach to cancer care was needed in this community.

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DEDICATION

This is dedicated to my son Garrison Sky Davenport and my husband Walter Ross Davenport. Thank you for being there through it all.

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INTRODUCTION

Background of the Study

> Modern scientific medicine has deep roots into the traditional civilizations of American continents. Not only are contemporary students of natural health and exercise, and fitness finding answers in traditional Native ways, but we are beginning to acknowledge that the patterns of treatment of many modern physicians are mirrored in the ways of the earliest healers.
>
> (Pfefferbaum, Pfefferbaum, Rhoades, & Strickland, 1997, p. 212-213)

Modern medicine has benefited from, and continues to rely on, traditional American Indian medicine. By contrast, the Native people of today are the most medically-underserved racial group in the Western world. This seems to be an unfortunate juxtaposition when one considers the advancements and progress in Western medicine and the poor survival rates for medically ill Native Americans (Pfefferbaum, Pfefferbaum, Rhoades, & Strickland, 1997). Reports of acute and chronic illness among Native Americans continue to rise, with diseases of the heart and stroke as the leading cause of death (American Heart Association, 2007, Statistical Fact Sheet, para. 1) and cancer as the second leading cause of death for American Indians and Alaska Natives (AI/AN) 45 years and older (Association of American Indian Physicians, [AAIP], n. d., cancer, para. 1). With respect to cancer survival rates, AI/AN have the highest mortality rates for "all cancers combined" (Intercultural Cancer Council [ICC], n. d., iccnetwork.org/cancerfacts, para. 4). These mortality rates reflect the current disparities in the health status for American Indians and Alaska Natives, including access and quality of healthcare (Roubideaux & Dixon, 2001).

Although American Indians and Alaska Natives constitute the smallest racial group in the U.S., they are the fastest growing because of high birth rates (Roubideaux & Dixon, 2001). By 2050, the population of AI/AN is expected to double to 4.3 million with 1/3 of this growing population under the age of 15. In spite of the high rates of unemployment, drop-out rates, mental health issues, and health-related concerns, this growing population is a reality, providing a promising future for healthcare reformation. At the forefront of this reformation is the Indian Health Service (I.H.S.), a unique healthcare delivery system, a major provider of the healthcare services for the 35-federally recognized reservations and surrounding areas (Pfefferbaum, Pfefferbaum, Rhoades, & Strickland, 1997). Although, AI/AN have voiced a preference for this service--more so than federal programs such as Medicaid and Medicare--the I.H.S. has been criticized with respect to their allocation of funding, eligibility requirements, and limited accessibility. To further complicate matters, the I.H.S. is considered a discretionary source and the payer of last resort.

Native healthcare is a complex system and because of this, cancer initiatives for AI/ANs have been a focus of National Cancer Institute's Special Populations Networks for Cancer Awareness, Research, and Training programs (SPN) (Clanton, 2006). In 1999, a SPN specific to AI/AN population was developed: The Spirit of E.A.G.L.E.S. became known as the American Indian/Alaska Native Leadership on Cancer (Kaur, 2005). The Spirit of E.A.G.L.E.S. serves as a culturally-sensitive acronym to represent "...the strong cultural association of the eagle with power, healing, and spirituality... (and) to emphasize the components of (their) multifaceted outreach: Education, Advocacy,

Leadership, Elders, Scholarship and Survivors" (p. 2). Housed in the Mayo Clinic's Comprehensive Cancer Center, The Spirit of E.A.G.L.E.S. is one of several Native American program providing culturally-responsive care, education, and outreach, comprising Native Women Enjoying the Benefit of screening (Native Web) and Native Cancer Information Center and Learning Exchange (C.I.R.C.L.E.). The Spirit of E.A.G.L.E.S. has also been instrumental in tracking cancer patterns from multiple data sources.

Although research studies on cancer incidence among Native Americans have reported lower rates among AI/AN than White Americans (Centers for Disease Control [CDC], (2003); Espey et al., 2007), this discrepancy is partly attributed to racial misclassification (Frost, Taylor, & Fries, 1992; ICC, American Indian/Alaska Natives & Cancer, n. d.). For the vast majority of Americans, cancer rates are declining for the first time in 70 years (American Cancer Society, 2007), and according to the National Cancer Institute, the number of survivors from 1971 to 2002 has more than doubled to 10 million survivors (National Cancer Institute [NCI], 2007). These gains have seemingly clouded higher rates of cancer for the medically underserved including People of Color, lower socio-economic status, and non-English speaking (ICC, 2006). The Intercultural Cancer Council (ICC) was charged with the task to oversee racial and ethnic disparities in healthcare delivery, identifying five different criteria for cancer care: Available, Accessible, Acceptable, Affordable, and Accountable (p. 2). The ICC's mission is "to promote policies, programs, partnerships, and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations" (p. 1).

Their 2006 Survivorship Report details the impact of poverty and lack of insurance as a primary reason for poor survival rates for the medically underserved populations.

The statistics on cancer incidence and mortality rates are not reliable nor are they representative of the overall AI/AN population because there is no one database for tracking incidence and survivor rates. In addition to racial misclassification, occurrences of underreporting are widespread due to barriers in data collection efforts (ICC, 2006). American Indian and Alaska Native cancer data are often clustered with other racial/ethnic minority groups under the "other" data category. The appearance of cancer occurring less in AI/AN communities is partially attributed to the younger median age reported for AI/AN in 2000 US Census (2001), when in fact cancer is more prevalent in the elder population (ICC, 2006). Cancer rates overall continue to be reported as being lower for AI/AN by database sources from Surveillance, Epidemiology and End Results [SEER] (Clegg, Frederick, Hankey, Chu, & Edwards); American Cancer Society (2007); Center for Disease Control (2003); and U.S. Department of Health and Human Service's Office of Minority Health (American Indian/Alaska Native profile, n. d.). Conversely, available cancer data through organizations such as the ICC (American Indian/Alaska Natives & Cancer, n. d.), indicated that cancer has been increasing within the past twenty years for AI/ANs. Moreover, cancer is the second leading cause of death for AI/ANs over the age of 45. American Indian and Alaska Natives also have the poorest survival rate from all cancers combined than any other racial/ethnic minority group.

These discrepancies become even more apparent when looking at data sources for individual cancer sites. For instance, breast cancer among AI/AN women appear to be decreasing annually and have the lowest among all racial and ethnic groups; however, the

survival rates are the poorest than any other racial or ethnic group (Society for Women's Health Research, n. d., What do Native American women suffer from?, para 3). Although the mortality rates for breast cancer is 17 per 100,000 women, lower than that of Whites or Blacks (NCI, n. d., SEER stat facts sheet, para 1), according to the Intercultural Cancer Council (n. d., American Indian/Alaska Natives & Cancer), breast cancer rates have been increasing over the past 20 years. With the median age for diagnosis for breast cancer at 61 (NCI, n. d., SEER stat facts sheet, para 1), these statistics suggest that breast cancer is not a major health concern in Indian country. This discrepancy is partially attributed to lower cancer rates being reported, a 40-50% misclassification error, and clustering American Indian cancer data into "other" category (ICC, n. d., American Indian/Alaska Natives & Cancer)

American Indians and Alaska Natives have experienced tremendous health disparities, ranging from social and cultural to structural (U.S. Commission on Civil Rights, 2004). This ongoing problem has been a source of controversy for geneticists, policymakers, and advocates for socio-economic reform (Jones, 2006). Inequality resulting from factors such as power and wealth, contribute to disparities in healthcare status. However, for AI/AN this disparity is also attributed to traditional and bicultural belief systems related to Indigenous and Eurocentric cultural characteristics (Hodge, 1999).

> To many American Indians healthcare means more than dealing with illness and pain; it reflects the basic worldview and cultural values of the group, which in turn influences health and illness behavior. It is believed that healing takes place not only in the body but also spiritually and that it includes the family and community. These cultural characteristics also affect the acceptance of preventative medicine particularly with respect to breast cancer screening, and are important factors in designing an intervention that is acceptable to the American Indian Population. (pp. 209-210)

Holistic in nature, AI/AN differ in terms of their beliefs about illness and wellness from non-Natives. More specifically, Western medicine centers on the interrelationship between symptoms and physical illness in terms of diagnosing and treating the individual (Murillo, 2004) Native medicine consists of a mind-body or holistic approach that considers "individual health dimensions: the physical, mental, spiritual, and environmental context of the person" (p. 113). This difference in worldviews, is one of the primary reasons why a more culturally-responsive approach is needed in Native healthcare. Research into the bridging of traditional Native practices, such as storytelling and talking circles, with Western medicine has provided a more culturally-competent approach to disseminating information about health-related issues (Murillo, 2004). For instance, web-based programs such as the Native American Cancer Research (NACR) have included streaming videos of AI/AN storytellers as a means to share their cancer stories with AI/AN cancer survivors (Burhansstipanov, 2006b).

To be culturally responsive in healthcare requires an understanding of the notion of worldview. A person's worldview is defined by aspects such as cultural upbringing, values systems, and life experiences, which have a profound influence on how we think, interact with one another, and make decisions (Sue & Sue, 2008). Self-assessment is the first step in being able to experience divergent worldviews (Hayes, 2001). Without this awareness, "cultural oppression" (p. 293) may result unknowingly because of a lack of understanding.

> It has become increasing clear that many diverse groups hold worldviews that differ from members of the dominant culture and their practicing therapists. In a broader sense, worldviews determine how people perceive their relationship to the world (nature, institutions, other people, etc.).... (Sue & Sue, 2008, p. 293-294)

Although it is well known that divergent worldviews exist between Western and Native American thought, especially in relation to illness and wellness, Duran (2006) underscored the need for culturally-relevant approaches that extend beyond the *application* of Native practices to that of an *understanding* of Native concepts of healing and illness. Duran refers to this understanding as the "Native epistemological root metaphor" (p. 10) or *knowing* Native ways of existing in the world as they relate to multiple worlds (e.g., spiritual, physical, and psychological). This concept of Native epistemology is especially salient in working with AI/AN as holistic approaches in Western medicine, comprising alternative and complementary therapies, are gaining recognition (Office of Cancer Complementary and Alternative Medicine [OCCAM], n. d.). In spite of this holistic awareness, what is needed in Native healthcare is a culturally-relevant approach, to address Native concepts of wellness and illness.

Grounded in Native epistemology, complementary therapies such as expressive therapies could provide a more culturally responsive, holistic approach for addressing psychosocial factors in healthcare for Native Americans. The creative arts, including art therapy, have been beneficial in attending to concepts related to Native wellness (Herring, 1997), "The expressive arts represent avenues of emotional, religious, and artistic expression that remain an essential part of the life of most Native people" (p. 106). To Native people, the creative arts provide a nonverbal outlet of expression of feeling, allowing for disclosure to occur without the need for verbalization; this nonverbal outlet is significant when one considers that Native People use silence as a form of respect, especially toward authority figures and elders. From a Native

perspective, art is a form of life and ritual and one that is rich in metaphor, symbolism, and meaning; this is reflective of a Native way of being in the world (Herring, 1997).

The field of art therapy has experienced a paradigm shift in the direction of attending to one's belief regarding spirituality and wellness and away from the tendency to pathologize imagery (Farrelly-Hansen, 2001). Artmaking, in this context, is viewed as an inherent spiritual practice and a means to achieve wholeness. As a result of this growing awareness, wellness-based approaches such as mindfulness-based art therapy (MBAT) have emerged, incorporating stress reduction and visual forms of self-expression for cancer patients (Monti et al., in press).

> MBAT integrates mindfulness meditation skills and aspects of art therapy into an eight-week, gender segregated, supportive group therapy format. The multi-modal design is intended to provide opportunities for both verbal and non-verbal expression, enhanced support, and expanded coping strategies. (in press)

The integration of mindfulness practices in art therapy has enhanced psychosocial care for cancer patients. However, studies such as the MBAT, have developed primarily from an Eastern practice (e.g., mindfulness meditation) for use in the dominant society. Much of the literature on art therapy and cancer survivorship has not considered a cultural perspective, perpetuating the mindset that artmaking is a "universal" form of language (McNiff, 1992) and a form of "metaverbal therapy," (beyond words) (Moon, 1994, p. 29) and therefore applicable to all.

Paramount to working with Native people, is an understanding of the ontological (being, existence) and epistemological (knowledge) considerations specific to Native Americans. This awareness is vital to developing culturally-responsive approaches in healthcare. Postmodern qualitative research considers a similar perspective in addressing ontological and epistemological concerns. Narrative inquiry in particular involves

subjective ways of knowing in a collaborative approach to research. In this paradigm, the storying process elicits the "real" data. Narrative researcher Clinchy (2001) describes the ontological relationship as such, "The source of knowledge is located in the self. Listening to one's inner voice becomes primary as knowledge is seen as being based on one's personal experience and intuition" (p. 37). This "self-knowledge" is similar to defining one's worldview. Epistemology is the "knowing" part, and in the context of narrative research, accessing stories requires a collaborative effort between the research and participant who are more co-collaborators in a "connected mode" (Clinchy, 2001, p. 37) than neutral parties. This collaborative relationship is central to constructing meaning in the "storying" process with the intent "to understand and be understood" (p. 37). This process of meaning making from narratives also lends itself to "constructed knowing" (p. 37) through active discourse. Narrative researchers essentially co-construct stories with the participant or "expert" as an active form of interviewing. To the outside observer, these active interviews can resemble a therapy session in which the participant is encouraged to dialogue from a more subjective perspective. In this paradigm, the interview becomes a meaning making experience, not a "fact-finding" event. Every time a story is told, new meaning surfaces and the role of the narrative researcher is to access different levels of the storying process.

The narrative perspective in art therapy has filled a gap in terms of accessing personal stories through artmaking, primarily in holistic health care. Kate Collie's (2006) dissertation study is one of the few that has utilized narrative research in the field of art therapy to collaboratively "examine how women with breast cancer used art therapy and/or independent art making to address psychosocial needs that arose for them after

their diagnoses" (p. 3). Through the narrative perspective, this study was instrumental in transcending gross generalizations about how artmaking serves as an outlet or a nonverbal form of expression and instead, focused on the importance of the meaning-making experiences derived from each of these relationships. Although her study provided the groundwork for a holistically-based, psychosocial support for women with breast cancer; what made her study unique was her collaborative stance. Her co-collaboration offered her the opportunity to explore and subsequently *know* the culture of breast cancer, reflecting the fundamental relationship between ontology and epistemology and importance of worldview.

Statement of the Problem

Rates of breast cancer have increased over the past 20 years among Native American women in urban and rural communities (ICC, n. d., American Indians/Alaska Natives & cancer). Because of this increase, Native American breast cancer survivors have been a priority in community-based participatory studies, supporting a need for more culturally-sensitive healthcare (Burhanisstipanov, 2005). However, translational studies in cancer research with American Indians and Alaska Natives have focused primarily on social, cultural, and structural barriers to healthcare with minimal attention to quality of life factors (U.S. Commission on Civil Rights, 2004). To address this disparity, what is needed in the research are more culturally-appropriate psychosocial interventions incorporating expressive art forms.

Purpose of the Study

The purpose of this narrative inquiry is to explore, through artmaking and storytelling, the belief systems surrounding wellness and physical illness from the

perspective of Native American women diagnosed with breast cancer. This narrative inquiry would provide the ground work for culturally-competent psychosocial interventions utilizing the expressive arts.

Focus of Inquiry

How do Native American women, diagnosed with breast cancer, experience their treatment in medical institutions? What are their beliefs surrounding wellness and physical illness? How does this belief system affect their view of treatment? How are these beliefs expressed through artmaking and storytelling?

Definition of Terms

Native American: This identifier is being used interchangeable with American Indian, Indigenous people, Native people, Native, AI/AN (American Indian and Alaska Native) to reflect the varying preferences among Native people, researchers, and academicians.

Indian country: This is a term used within Native communities to represent the overall Native population.

Delimitations

This study was delimited to American Indian women from state-recognized tribes in North Carolina who are breast cancer survivors.

Limitations

Accessing participants for this study was a major limitation in spite of the support from Coharie tribe and the North Carolina Commission of Indian Affairs.

Theoretical Stance

As a narrative-based art therapist, this form of inquiry was especially appealing to me because this approach to research incorporated familiar concepts and terminology. Because of this, I struggled with separating my therapist self from my researcher stance, primarily because I realized there was a degree of interplay between the two. As a narrative therapist, my focus was centered on meaning-making experiences, such as, "unpacking" stories or deconstructing myths to co-construct different narratives. As my understanding of the narrative perspective broadened, I gained a better appreciation for how multifaceted this approach can be.

The multiple layers of meaning are evident even in terms of how one defines narrative inquiry. For example, Kathy Weingarten (1991) maintains a narrative perspective but from a social constructionist viewpoint, "...the self continually creates itself through narratives that include other people who are reciprocally woven into these narratives" (p. 89). This viewpoint is one that I resonated with because of its connection with narrative forms of therapies, in that, the co-construction process lends itself to meaning making through storying. This process makes sense when one considers that Self is not a fixed representation, it is co-constructed from the lenses of others including society (Freedman & Combs, 1996). The storying process is also the means by which one can re-author one's life (White & Epston, 1990). However, it is the interaction or co-construction process that is primary in narrative approaches and has the potential to transform stories; this is the basis of social epistemology within the social constructivist framework in narrative inquiry.

In narrative research, the storying process is a form of discourse that "consists of ideas and practices that share common values" (Weingarten, 1991, p. 286). Dominant and subjugated discourses are understood through phenomena related to the co-construction of worldviews as well as shared experiences. These phenomena have further implications for ontological and epistemological considerations: from the narrative perspective, relativism is viewed from an experiential framework (ontology), a transactional/subjectivist stance, and co-created findings (epistemology). This stance was consonant with Duran's (1996) notion of "Native epistemology" (p. 10) and the importance of knowing a culture through collaboration.

Through the lens of Native epistemology, critical race theory had particular relevance in terms of my research focus and identification as a Native American. Critical race theory (CRT) considers ethnic epistemologies and racialized discourses as an extension of earlier critical legal studies (Ladson-Billings, 2004). The underlying concept of this theory "...depends on the Gramscian notion of hegemony to describe the continued legitimacy of oppressive structures in American society." (p. 264). Antonio Gramscian was a Marxist philosopher who coined the term "cultural hegemony" to infer the presence of an oppressive dominant society (Joll, 1977). Critical race theory seeks to give voice to underrepresented minorities to shift the power differential in racial hegemony (Ladson-Billings, 2004).

> Critical Race Theory's challenge to racial oppression and the status quo sometimes takes the form of storytelling in which writers analyze the myths, presuppositions, and received wisdoms that make up the common culture about race and that invariably render blacks and other minorities one-down. Starting from the premise that a culture constructs its own social reality in ways that promote its own self-interest, these scholars set out to construct a different reality. (Delgado & Stefancic, 2000, p. xvii)

As a result, our belief systems, especially in relation to "assignments of prestige and power" (p. xvii) are social constructions that can be altered through "words, stories, and silence" (p. xvii). Through the process of counter-storying in critical race theory, our belief systems are challenged in such a way to shape a different story outside the "common culture."

In context to critical race theory, the concept of mestiza (mixed) consciousness (Anzaldua, 1999), was one that I had an awareness of intuitively but more in terms of having an insider and outsider status (Ladson-Billings, 2004). Although my heritage is Native American, I am also White and have been part of both cultures throughout my lifetime. This mestiza consciousness has been an integral part of my therapeutic relationship with culturally diverse clients; I am aware of the borders between linear and nonlinear thought and oppression and power. I resonated with Anzaldua's (1999) experience of being a mestiza:

> I am a border woman. I grew up between two cultures, the Mexican (with a heavy Indian influence) and the Anglo (as a member of a colonized people in our own territory). I have been straddling that tejas-Mexican border, and others, all my life. It's not a comfortable territory to live in, this place of contradictions.... However, there have been compensations for this mestiza, and certain joys. Living on borders and in margins, keeping intact one's shifting and multiple identity and integrity, is like trying to swim in a new element, an "alien" element. (preface)

I also am forced to navigate between different worldviews continuously, more psychologically than physically; my fair skins keeps me within the boundaries of a privileged dominant society. In spite of the physical differences, I feel accepted within my own Native culture because of my socialization within this community. Before conducting this study, I was curious to know if my mestiza consciousness would allow me to have more of a "critical gaze" on social injustices and access to the "real data." In

hindsight, the level of trustworthiness that I had gained from my previous involvement in the Coharie community seemed more significant than my bicultural perspective. My key informant over the past few years has often told me that her people feel like I am "familiar" and *listen* to the needs of her people.

As a narrative therapist and researcher who has participated in the co-construction of stories, the storytelling aspect of critical race theory was of particular interest (Ladson-Billings, 2004). In this paradigm, "truth" is derived from the storytelling process, not necessarily the facts. Ladson-Billings states this more explicitly, "The value of storytelling in qualitative research is that it can be used to demonstrate how the same phenomenon can be told in different and multiple ways depending on the storytellers" (p. 968). Stories can be told and also understood in multiple ways, and because of this, a critical race theorist, for instance, may have access to "real data" from stories about specific phenomena. However, Ladson-Billings cautions that this information might be observed from the lens of the dominant society, diminishing voice and altering text. In relation to my own study, storytelling was a central focus because of the oral tradition within the Native American culture. Storytelling from the Native tradition does not involve as much active dialoguing as in narrative therapy or narrative forms of research. This form of storytelling involved more of a listening stance and nonverbal communication. In spite of this listening stance, my role seemed to be that of an active researcher who was collaborating with her clients throughout the entire study.

Although my initial focus seemed to be more on the perception of illness and wellness from a Native American (nonlinear) standpoint, I had not considered a possible text of oppression with respect to being female, Native American, and a cancer survivor.

Accessing these stories, from a deconstructivist perspective, involved "unpacking" stories of oppression from a context of "truth as a destructive illusion" (Olsen, 1994, p. 225). As a result, the level of intersubjectivity that occurred in the deconstruction process was profound and shifted this focus of this study more in the direction of an emergent narrative ethnography than a "traditional" narrative inquiry (Tedlock, 2005)

Summary

Native people of today are the most medically-underserved racial group in the Western world because of cultural, social, and structural barriers to accessing health care. Although incidence of cancer are lower in American Indians/Alaska Natives in comparison to other racial/ethnic groups, AI/AN experience the highest mortality rates for all cancers combined and the poorest survival rates. Cancer is currently the second leading cause of death for AI/AN 45 years and older. In spite of the low incidence, specific cancer sites, such as breast cancer for AI/AN women, have been increasing over the past 20 years. Cancer statistics for AI/AN are not reliable because of occurrences of underreporting, racial misclassification, and clustering data under the "other" category. Culturally-responsive approaches in healthcare are needed to attend to the differences in belief systems about wellness and illness. Complementary therapies, comprising the expressive arts, provide a more holistic approach to psychosocial care and a means to attend to quality of life factors.

CHAPTER TWO

LITERATURE REVIEW

The aim of the literature review is to provide a comprehensive overview of healthcare policy, concepts of wellness and illness, and barriers to healthcare in relation to American Indians and Alaska Natives. Because of the disparate belief systems among the 807 federal- and state-recognized tribes (U.S. Tribes, n. d.), a broader text was considered throughout the review. Healthcare and counseling interventions comprise the middle section, emphasizing important characteristics that have helped improve these services. Cultural relevance was a focal point throughout all the sections. Culturally-responsive counseling approaches were highlighted in this section because of its relatedness to this researcher's training.

The last part of this literature review considers the applicability of healthcare and counseling interventions to the field of cancer care for American Indian and Alaska Natives. A section on emancipatory research methods was included to review the current methodology in Native American cancer research. The importance of ethical considerations for conducting research with Native Americans was underscored in a separate section to attend to these issues directly. Lastly, an overview of art therapy with cancer survivors was provided to inform readers of this contemporary application and its relevance to AI/AN cancer survivors.

Native Americans

According to the 2000 U.S. Census (2001), American Indians and Alaska Natives (AI/AN) currently comprise 1% of the population or 2.5 million individuals who self-

identify as American Indian or Alaska Native. This is a disparaging fact when one considers that there were 300 distinct languages spoken by approximately 2 to 7 million Indigenous people in North America before Columbus' arrival (Krauss, 1996). Presently, there are approximately 175 Native languages spoken by AI/AN in the United States. Native Americans are a diverse cultural group and generalizations about a race of people (much like other races) are an arduous, if not impossible feat. Native Americans can be multiracial; from different tribes, which can be federally recognized, state recognized, or have no tribal status; live in urban cities, rural communities, or one of 13 federal reservations.

> Indian tribe means an Indian tribe, band, nation, or other organized group or community, including a Native village, Regional Corporation or Village Corporation, as those terms are defined in section 3 of the Alaskan Native Claims Settlement Act (43 U.S.C. 1602), which is recognized as eligible for the special programs and services provided by the United States to Indians because of their status as Indians (16 U.S.C. 470w). (Code of Federal Regulations, 1979)

At the time of this dissertation, there were 562 federally-recognized tribes and Alaskan villages comprising 1.5 million federally enrolled American Indians and Alaskan Natives (Bureau of Indian Affairs, n. d., quick facts).

The Bureau of Indian Affairs (BIA), one of the oldest federal agencies, was established on March 11, 1824 with a mission "to fulfill its trust responsibilities and promote self-determination on behalf of tribal governments, American Indians and Alaskan Natives" (Bureau of Indian Affairs [BIA], n. d., mission statement, p. 1). Since 1949, the BIA has operated under the Interior Department and was "once an instrument of federal policies to subjugate and assimilate American Indian tribes and their peoples, the BIA has changed dramatically as have those policies over the past 177 years" (p. 1). Services for American Indians and Alaska Natives consist of programs such as the Indian

Health Service (I.H.S.) in addition to services provided by the Department of Health and Human Services (DHHS), as well as other federal agencies such as the Department of Education, Labor, Agriculture, and Housing and Urban Development. In addition to these federal services, American Indians are eligible for state programs:

> All American Indians and Alaskan Natives, whether they live on or off reservations, are eligible (citizens who meet eligibility requirements) to receive services provided by the state such as Assistance for Needy Families (TANF), Supplemental Security Income (SSI), the Food Stamp and the Low Income Heating and Energy Assistance Program (LIHEAP). (Department of the Interior, n. d., Benefits and services provided to American Indians and Alaska Natives, (p. 2)

In essence, AI/AN have a "triple citizenship" (Dixon, 2001b, p. 44) in that they are members of a tribe, U.S. citizens, and state citizens. In this respect, AI/AN are eligible for programs in all three sectors. However their triple citizenship does not denote better access to these programs; in fact, most lower-income Indian people have fewer resources than other minority and non-minority populations for several reasons discussed below.

Eligibility for these and other programs requires that an individual be a member of a federally-recognized tribe (BIA, mission statement, n. d.). The Bureau of Indian Affairs is charged with the task of issuing BIA cards to indicate official membership in a federal tribe. In general, an individual needs to have at least one quarter blood quantum from one of the 562 federally-recognized tribes to be eligible for enrollment. This enrollment process can be cumbersome for AI/AN who do not have proper documentation, who belong to two tribes, or who were not socialized among their people and are not known to their tribe (Dixon, 2001b).

Not all Native Americans are enrolled members of a federally-recognized tribe; there are also approximately 245 state- and non-recognized tribes petitioning for federal

recognition (U.S. Tribes, n. d.). State recognition means that the tribe has successfully petitioned the state for recognition as an American Indian tribe, and in some states, a Commission of Indian Affairs is established for purposes of outreach and advocacy (G. Richardson, personal communication, May 15, 2007). State recognized tribes are not eligible for services, such as medical benefits, under the Indian Health Service (I.H.S.) and must provide their own insurance or apply for Medicaid or Medicare (S. Bonner, personal communication, November 15, 2005).

Native Concepts of Health and Illness

Clements' Primitive Concepts of Disease (1932) provided one of the earliest ethnographic studies among Indigenous Peoples throughout the world. His study provided a description and classification of disease concepts from traditional practices. Duran (2006) made reference to Clements' five main types as a foundation for understanding Native concepts of healing and illness, providing a bridge between Western and non-Western perspectives. Clements' (1932) concepts were broadly defined into three categories: natural causes (modern medicine), human agency (sorcery), and supernatural agency (supernatural factors). His study extended these three categories into five main types: sorcery (human infliction), breech of taboo (guilt), disease-object intrusion (object removal), spirit intrusion (outside entity intruding), and soul loss (loss of soul). Variants of these concepts continue to represent the worldview that many Indigenous people maintain and perceptions of illness and wellness.

Broadly stated, Native Americans view wellness and illness as an interrelated system. As such, illness is caused by an imbalance or disharmony in one's life (Sue & Sue, 2008). This notion may sound simple but the belief systems, traditions, and value

systems vary tremendously between tribal cultures, and are seemingly affected by degrees of acculturation. Romanticized notions of shamanic practices and traditional healers in the dominant society have seemingly clouded the importance of these concepts and their meaning. Much of what is practiced in Western society is due in part to the influence of "Indian medicine," primarily botanical preparations and natural remedies (Vogel, 1970).

> The meaning of the term medicine to an Indian was quite different from that which is ordinarily held in white society. To most Indians, medicine signified an array of ideas and concepts rather than remedies and treatment alone. (p. 24-25)

In more recent times, efforts to reintegrate traditional medicine with Western practices have been in the forefront of healthcare reform for AI/AN.

In spite of this integration, concepts of wellness and illness differ considerably between Native Americans and non-Natives. This concept extends beyond the commonly held belief of a "harmonious relationship" (Rhoades & Rhoades, 2000, p. 404).

> The critical, and often profound, differences between Indian and Western medicine obviously derive from the underlying cultural precepts of each. A generally accepted Indian concept of health is that it is a tangible reality, not simply the state of being free of disease. This health, or wellness, is often described as the ability to exist in a harmonious relationship with all other living things, but also with a number of spirits, including a great and all-powerful spirit. The emphasis on the spirit world, supernatural forces, and religion stand in sharp contrast to the secular emphasis on disturbed physiology and purely physical explanations of Western medicine. (p. 404)

In this context, the authors suggest that Indian medicine is "metapsychiatric" (p. 404), attending to all aspects of well being:

> While expressing credit to the field of psychiatry for perhaps providing the greatest understanding and acceptance of traditional medicine, we suggest that even the inexplicable powers exercised by certain traditional healers should be thought of as "metapsychiatric." In addition, the open and public application of

> cleansing, healing, and purifying techniques, such as the sweat lodge, and the ubiquitous "smoking" with a special material, such as cedar, sage, or sweetgrass, also tend to distinguish Indian ways of thinking from those embraced by most scientists. (p. 414)

What was once deemed a primitive belief is now considered to be progressive practice leading to the integration of traditional Indian and Western medicine.

Indian Health Services

Historically, the federal government has provided health services ranging from smallpox vaccinations in 1832 (Bennett, 1958) to more comprehensive care, provided under Indian Health Services. The mission of the I.H.S. is to provide services beyond medical treatment to include preventive services, wellness, and a community focus (U.S. Dept. of Health & Human Services, Indian health services, n. d.). Community involvement in both urban (partially funded) and rural areas (fully funded) have been a primary focus within the I.H.S. with an emphasis on prevention services. A number of unique collaborations have occurred under the I.H.S. integrating American Indian traditional medicine with Western medicine. As a result, Native healers have been recognized by the I.H.S. as an integral part of the community. Initiatives such as the Medicine Man training program (Bergman, 2000) have been implemented by the I.H.S. Native healers also serve as important liaisons between Western practitioners and Native people, providing a means for Native people to continue practicing Indian medicine in Westernized medicine.

Under the current organization of the I.H.S., comprehensive healthcare and preventive services exist in 35 states serving 562 federally-recognized tribes. However, Native Americans belonging to state-recognized tribes are not afforded the same medical treatment under the I.H.S. and either provide their own insurance, go

without, or are eligible for Medicaid or Medicare (Johnson & Rhoades, 2000). Medical benefits vary from tribe to tribe, contributing to the complexity of this unique healthcare system (Dixon, Mather, Shelton, & Roubideaux, 2001).

As the AI/AN population continues to grow, the I.H.S. and funded programs are becoming financially constrained due to the lack of increased financial support from the federal government (Dixon, et al., 2001). A greater reliance on third party sources is a result of this disparity. This disparity is attributed to the I.H.S. not being considered an entitlement program by Congress:

> An entitlement means that the government defines eligibility of a program and the services that are covered, and pays for the cost of those services to the eligible population. If the services cost more than the budget for a year, then Congress does a supplemental appropriation to cover cost overruns. Medicaid and Medicare are both entitlement programs.... (p. 105)

The I.H.S. continues to lag behind other entitlement programs because of factors such as inflation and population growth, and statistically falls behind on a yearly basis. Because Native Americans comprise the smallest minority group in the U.S., new spending measures are not as likely to be considered in political agendas and programs, including I.H.S., will continue to decline in funding.

Barriers to Healthcare

In spite of eligibility for I.H.S. and Medicare/Medicaid, AI/AN experience high rates of being uninsured (24%) (Friedsam, Haug, Rust, & Lake, 2003). In interviews with tribal officials, a number of barriers to accessing services were noted. For example, problems with transportation and understanding the required paperwork were consistent barriers, prohibiting their access to these services. In addition, there is a general

consensus that outside agencies are not culturally sensitive to the needs of AI/AN and are therefore not able to advocate on their behalf.

Using a National Survey of America's Families, access to I.H.S. was compared to that of Whites' use of health services (Zuckerman, Haley, Roubideaux, & Lillie-Blanton, 2004). The findings revealed disparities in terms of lower income and uninsured AI/AN who experienced difficulty accessing I.H.S. On one hand, insured AI/AN reported similar perceptions and accessibility to that of insured Whites, suggesting that utilization of I.H.S. improved quality of healthcare for insured AI/AN. On the other hand, access to preventive services, such as mammography, was statistically lower than general and acute care provided by the I.H.S. This discrepancy was attributed to the lack of funding to supply specialized equipment.

Research studies on accessibility to health services among AI/AN consistently point to significant barriers to care ranging from social and cultural differences to "structural" barriers, such as, transportation issues, inconvenient office hours (conflicts with work schedules), lack of financial resources, and unfamiliarity with community-based services (United States Commission on Civil Rights, 2004; Duran et al., 2000; Roubideaux & Dixon, 2001; Burhanisstipanov, Christopher, & Schumacher, 2005). The fear of discrimination stemming from the lack of cultural sensitivity and confidentiality among non-Native staff was also a deterrent in terms of accessing services (Duran et al., 2000).

Healthcare and Counseling Interventions for Native Americans

The inclusion of healthcare and counseling practices under one heading was deliberate in terms of underscoring the importance of this interrelationship. A general

Native American model for healing was identified by Thomason (1991) based on the traditional belief that health is based on having a harmonious relationship with nature. Several authors, including Thomason noted that "Breaking a taboo or ignoring a tradition can result in a state of disharmony, which can be manifested in an individual as disability, disease, or distress" (Thomason, 1991, p. 322). In contemporary Native American society, traditional healers maintain a similar role as their ancestors in terms of treating the whole person through healing ceremonies, homeopathic remedies, and prayer. Moreover, the healer may include family members and the community in a healing ceremony. Understanding this model of healing could be useful for non-Native counselors in terms of how they approach and facilitate therapy with Native Americans, respecting the need for privacy, trust, and family involvement.

Healthcare interventions.

Improvements in health for AI/AN in rural communities have stemmed largely from efforts to provide proper sanitation and safe water sources (Hartz, Todd, & Rhoades, 2000). As part of their community and environmental focus, the I.H.S. has worked collaboratively with sanitation facility construction programs to provide improved services. These collaborative efforts have been the hallmark of the I.H.S., demonstrating how communities impact healthcare delivery.

> The I.H.S. Environmental Health Program is an integral component of the I.H.S. comprehensive health-care and services delivery system. It complements other curative, preventive, and rehabilitation efforts on behalf of the Indians and Alaska Natives living on reservations or in small communities and villages throughout the United States. A wide range of environmental health services are provided, including those that might be traditionally categorized within public works, urban and regional planning, natural resources conservation, and public safety. (p. 395)

Because of this environmental focus and collaborative approach, the I.H.S. and its subsidiary programs have contributed to lower mortality rates for gastrointestinal diseases. Life expectancy rates have improved because of lower mortality rates for infants, attributed to better environmental conditions.

In spite of these improvements through I.H.S., Indian health remains problematic. Johnson and Rhoades (2000a) identified three critical areas: 1. Diseases and behaviors affecting illness and wellness (diabetes, alcoholism). 2. The needs of children, elderly, and disabled. 3. Availability and access to healthcare. Based on this assessment, five health areas were identified as being most salient to future healthcare delivery systems: alcohol abuse, diabetes, cardiovascular disease, violence, and malignancies.

In reviewing much of the literature in AI/AN healthcare and counseling interventions, there were numerous references suggesting a need for more culturally-responsive approaches. This was attributed to the disparate value systems between Western practitioners and Native people. In attending to this disparity, Burhansstipanov (2005) recommended that researchers, healthcare providers, and outreach workers work collaboratively with Native American communities. She referred to this approach as a "community-driven agenda" (p. 7).

> Community-driven interventions are those that are initiated by the community itself and require community members in active decision-making roles. These sometimes evolve into community-based participatory research interventions. (p. 7)

The benefit to these interventions is that members of the Native American community can develop the "leadership and administrative skills" (p. 7) to run these programs without outside influence, allowing for the programs to potentially survive beyond the funding period. Moreover, because of this collaborative relationship, the interventions

would be more culturally responsive and less biased toward Western thinking. Although there are already a number of Indian operated programs, this form of management has not been as wide spread.

Counseling interventions.

Heinrich, Corbine, and Thomas (1990) provided a detailed overview of counseling practices with Native Americans. They identified a number of issues that non-Native counselors encounter and juxtaposed these divergent perspectives in a table of "Comparison of Value Orientations" (p. 129). What was most striking were the dissimilar views on every level from perceptions of wellness and illness, to spirituality and connectedness with extended family. The authors noted that the value orientation seemed to shift as Native Americans relocate to larger cities or assimilate. Hanson and Eisenbise (1981) referred to this shift as "dual perspective," (p. 130) in that one becomes part of both the dominant society and the culture of origin. Holism is an important concept to keep in mind because non-Native counselors often make the assumption that AI/AN do not hold traditional values unless they are from a reservation. Holism is broadly defined as such:

> The key concept of Native American philosophy is holism, and one of the most important symbols is the circle, or hoop of life....Illness is identified as a disruption of the essential harmony of life, or as an imbalance of various elements, or as a break in the hoop of life. (Heinrich, Corbine, & Thomas, 1990, p. 130).

This holistic approach involves the counselor attending to all aspects of the individual, not just the "problem area," but rather acknowledging that mind, body, and spirit are perceived as one. When there is an imbalance, such as physical illness, all aspects of the person are attended to versus treating it as a medical condition.

Herring (1992) intimated that a new counseling paradigm is needed with Native American clients. In his extensive review of culturally-responsive approaches, he contended that many of these practices, in addition to the field of counseling as a whole, are not effective in terms of attending to nonverbal communication styles, family and value systems, sociopolitical factors, and a history of coercion. Herring provided recommendations for counselors working with Native Americans to acknowledge that there are diverse worldviews between non-Native counselors and Native American clients, and that becoming a part of the community is integral for understanding the values of the culture. Moreover, he noted that individual counseling techniques have not been as effective as system approaches in family and conjoint therapy.

Herring (1990) further suggested that counselors need to have a better understanding of Native American values: "Counselors have the responsibility to consider Native Americans' values from both content and process emphasis when counseling clients from this group" (p. 134). In terms of content, Herring (1990) stated that there are six factors that influence the course of therapy: 1. diverse values systems among Native Americans, 2. presence of culture conflict, 3. resistance to Anglo-American middle class values, 4. family structures, 5. how Native Americans have been portrayed historically, and 6. prevalence of miscommunication (p. 136). The "process emphasis" centers on different forms of communication, different priorities, and degrees of acculturation. Above all, Herring found that socioeconomic status had a significant impact on counseling, that is, displays of "one-upmanship" (p. 136) on the part of the counselor would prevent a therapeutic relationship from emerging.

As part of Herring's (1997) recommendations for effective counseling approaches, he advocated for the inclusion of creative arts in counseling as part of a "collaborative approach" (p. 105). Herring recognized the need for Native art forms as a counseling intervention, stated in the following:

> In helping situations with Native populations, the use of creative arts can be extremely helpful. One obvious reason is that Native concepts of spiritualism and humanism have traditionally been infused in the production of Native creative arts. The creative arts represent avenues of emotional, religious, and artistic expression that remain an essential part of the life of most Native peoples. (p. 107)

Herring (1997) suggested that by integrating the creative arts in counseling, clients could disclose without the need to verbalize. This approach would constitute a culturally responsive way of attending to Native Americans who use silence or nonverbal forms of communication in their interpersonal relationships. The creative arts also serve as healing ritual and an expression of life.

> Traditional Native children are socialized from birth to understand and respect the spiritual aspects of art forms. This exposure to the spiritual aspects of art forms is the fundamental mode of generationally transferring Native cultures and values over time. (p. 107)

Respecting the need for privacy and reluctance to self-disclose, art therapy and related cultural arts programs have provided an effective nonverbal approach to counseling (Dufrene, n. d.; Moody, 1995). As a form of self-expression and healing mechanism, art therapy has been considered by many AI/AN as an acceptable counseling practice (Dufrene & Coleman, 1994). However, the challenge for these creative arts therapists has been learning to work in a culturally-responsive manner.

Significance of Literature and Applicability to Field of Natives and Cancer

Considering the complexities of Native healthcare, preventive services have evolved from grassroots efforts connected to organizations such as the Mayo Clinic Cancer Center (n. d., Native circle). Outreach groups, such as Spirit of E.A.G.L.E.S. focusing on leadership initiatives, was created in response to growing incidents of specific cancers and corresponding high mortality rates. For example, Native Web, a training program to educate nurses about breast and cervical screening methods, emerged in response to the needs of underserved women. Cancer has become a recent epidemic among Native Americans as the third leading cause of death for Native Americans with the poorest survival rates for cancers, such as lung cancer, of any other racial and ethnic groups (AAIP, n. d., American Indian/Alaska Native cancer statistics). Breast cancer has been an ongoing concern because of climbing mortality rates and a 49% survival rate for Native women as compared to 76% in Caucasian women (Hodge, 1999). In spite of this disparity, the perception among Native women and health officials is that breast cancer is not an "Indian problem" (p. 206) because the incident rates are still much lower than those of Caucasians.

Compounding this problem is the need for better data collection methods to address issues such as misclassification and ways to provide culturally-competent healthcare delivery systems. In the California Health Interview Study (Satter et al., 2005), communicating in a culturally-sensitive manner was the central focus in a random survey (telephone) addressing access to healthcare. Six ethnic minority groups were oversampled including AI/AN to analyze cultural and linguistic variables. The unique aspect of this survey was the inclusion of cultural competency training for all the data

collection interviewers. Interestingly, this training became the focal part of the study and the materials used to train the interviewers were actively sought out by researchers, clinicians, and state agencies. The formal outcome of the study generated interesting data concerning linguistic differences for AI/AN, that is "long pauses," "slow speaking," and "walking on words" (p. 49).

In a similar study, two Native American Navigator formats were compared in terms of their effectiveness. Risk factors were assessed through a pretest and posttest using a "Social Cognitive Theory-based intervention" (Dignan et al., 2005, p. 28). The interviewers were trained Native American Navigators referred to as "Native Sisters" (p. 30). These Native American women were recruited from the study area for the purpose of conducting the interviews in a culturally sensitive manner.

> The approach in which local Native American women have been trained as Navigators has been used successfully in previous projects with American Indian populations in rural populations. (p. 30)

The results of the study revealed that the Native Sisters were effective in reaching Native American women through telephone contact and face-to-face groups to provide an intervention designed to increase breast cancer screening. In the posttest intervention, self-reported mammograms increased by 12% in the telephone group and by 11% in the face-to-face groups.

Cancer screening and assessing risk factors comprise much of the AI/AN literature and is typically conducted using surveys that either over sampled AI/AN in randomized studies or are conducted in a culturally-sensitive manner with homogenous groups of AI/AN cancer survivors. The AI/AN community is small and statistically comprise around 2% of the U.S. population (Swan et al., 2006). As a result,

misclassification of AI/AN has contributed to this data collection problem and efforts have been made in recent surveys to define race either by U.S. census data (2001) or by methods used in reports, such as, the Center for Health Policy Research at UCLA (Brown et al., 2007). This method classifies the individual based on which racial or ethnic group they most identify with. This was helpful in distinguishing between Latino (ethnicity) and AI/AN (race). Enrolled tribal members were automatically included in the sample as AI/AN regardless if they self-identified with another ethnicity or race.

The lack of data collection in AI/AN research is in part because of misclassification and current studies have led to better efforts to report cancer-related data among national agencies and cancer organizations (The United States Commission on Civil Rights, 2004; Swan & Edwards, 2003). Cancer surveillance programs such as Surveillance, Epidemiology and End Results (SEER) (NCI, n. d., Cancer survivorship research) focus on cancer trends in specific regions of the U.S. The trend data are then statistically compared with other racial/ethnic groups using a joinplot model. This form of analysis has been more effective than other measures, as indicated in the following:

> When we compare rate levels across the four cancers, it appears that the AI/rates are among the lowest of the groups. However, if we look at the trends, then the AI/AN population seems to be having a different cancer experience than other populations. (Swan & Edwards, 2003, p. 1265)

This "different cancer experience" suggests that there are actually lower survival rates: some of the lowest rates out of all ethnic/racial groups for prostate, colorectal (female), and lung cancer. Breast cancer among AI/AN in particular had the second lowest survival rate (Swan & Edwards, 2003).

Emancipatory Research Methods with AI/AN Cancer Survivors

In terms of community-based participatory research, Linda Burhansstipanov has

authored several books and published over 80 articles on health-related issues on Native Peoples. The majority of her research has focused on eliminating barriers to healthcare in rural and urban Native American communities. She is one of a few Native American researchers who includes culturally-responsive interventions to promote cancer awareness. For example, to create a more personalized educational module, she incorporated storytelling which "continues Native traditions of using stories and legends to teach lessons and heal by providing stories about surviving cancer" (Burhansstipanov, n. d.a, para 1).

As part of the Native American Cancer Research (NACR) community-based participatory approach, these modules can be accessed by AI/AN cancer survivors through the National Native American Cancer Survivors' Support Network at www.NatAmCancer.org. NACR has conducted a number of survey research studies to inform their community-based research projects. For example, a spirituality belief measure was assessed with participating AI/AN cancer patients and the results indicated that there were "no significant differences in one's spiritual beliefs, traditionalism, acculturation, and use of western healthcare systems" (Burhansstipanov, n. d.a, para 3). This finding was instrumental in integrating spiritual practices in cancer care and provided a basis for the researchers to observe the patients' responses to the "impact of combining Western Medicine with Traditional Indian Medicine" (para 4). Community-driven agendas such as quality of life and quality of care of AI/AN cancer patients have evolved into community-based participatory research interventions (Burhansstipanov, 2005). These "community-driven interventions are those that are initiated by the community itself and require community members in active decision-making roles" (p.

7). However, Burhansstipanov makes a distinction between community-based and community-driven approaches in terms of local community members being actively involved in community-driven interventions. The aim is to create a more participatory program that can be self-sustaining after the research project is over, involving a collaborative effort on the part of community leaders.

In regards to culturally responsive interventions, The Native American Cancer Initiative (Morning Dew Computer Productions, 1995) produced a video capturing the stories of Native American breast cancer survivors from women of all Indian Nations. The purpose of this film was to share personal stories, reactions from friends and family, and the recovery process in a culturally-responsive manner, through oral tradition. This program has been instrumental in providing Native American breast cancer survivors with a community-based intervention and is a stepping stone toward providing psychosocial interventions for cancer survivors (Burhansstipanov, n. d.b). Post modern qualitative research, such as narrative inquiry, reflect some of the basic principles of the community-based participatory approach being conducted in AI/AN communities. Narrative inquiry, more recently within the medical profession, has become an accepted research practice to access patients' stories and foster meaning making around acute and chronic illness. This storying process in narrative inquiry is viewed a collaborative process that considers the "re/searcher as co-learner" (Castledon, & Kurszewski, 2000, p. 1) more so than "experts." Canadian researchers collaborating with Aboriginal Canadians support the inclusion of narrative inquiry into their community-based participatory approach.

> Our goal is to share our lived experience of the unanticipated learning that occurred during our inquiry into educational issues in Aboriginal communities.

> What stems from this inquiry is recognition that re/searchers are co-learners rather than experts. Consequently, we are endeavoring to increase awareness of ethical considerations regarding re/search. (p. 1)

From the perspective of these researchers, narrative inquiry provided a format to not only access personal stories through meaning making, it also allowed the researchers to reflect on their lived experience in response to the inquiry. This collaborative process between re/searcher and participant and Aboriginal re/searcher and non-Aboriginal re/searcher led to a "deeper understanding of the experience of working as a re/searcher in Aboriginal communities" (p. 3) by also reflecting upon the ethical considerations for conducting research in these communities. In their findings, the re/searchers' lived experiences included in this inquiry were a critical aspect in terms of reflecting upon the cultural differences and ethical considerations. This personal learning was an essential part of understanding how to collaborate research-wise with Aboriginal communities.

> As re/searchers, we need to discontinue the previous pattern of misappropriation of knowledge and wisdom. As adult educators, we need to be prepared to address and adopt alternate re/search practices and recognize auxiliary learning that occurs when re/searchers conduct re/search in Aboriginal and non-Aboriginal communities. (p. 5)

The implication of their research suggests that collaborative methods, such as narrative inquiry, enhance community-based participatory research in Native or Aboriginal communities.

Ethical Considerations for Conducting Research with Native Americans

Native American communities fully support the community-based participatory research model because of its partnership approach (Burhansstipanov, Christopher, & Schumacher, 2005). Native Americans traditionally are reticent to participation in standard research for a variety of reasons, ranging from disrespectful cultural practices to

not sharing results or following through with recommendations. The general sentiment is that Native Americans have been used as "guinea pigs" (p. 71) and their communities have not benefited from these projects long term.

Although many of these researchers may be committed whole heartedly, they neglect to include the input of the community members during the proposal stage (Burhansstipanov, Christopher, & Schumacher, 2005). Surveys are also met with great resistance because the interventions are insufficient or are seldom provided and the findings are not disclosed. Researchers also tend to lump all Native Americans into a single category not respecting the intertribal cultural differences. This has led to the perpetuation of stereotyping, blaming communities for their "problems," misuse of information, and violation of Institutional Review Board (IRB) standards. Although community-based participatory research is on the rise because of the involvement of Native American researchers, many "researchers [still] feel that Native Community-based organizations are too dysfunctional, co-dependent, and/or unstable to be reliable partners in research" (Burhansstipanov, Christopher, & Schumacher, 2005, p. 71).

Medical Art Therapy

Art Therapy is rooted in many ancient traditions and the use of art and medicine is no exception. American Indians know this relationship well even in today's world. To Native People this is not an ancient practice but a way of life. Medical art therapy is a contemporary application in the field of art therapy that has been gaining more attention as a means to address psychosocial issues for medical populations. It is important to differentiate between the "imaging" work related to psychology and art therapy interventions in medical art therapy. A number of correlation studies in the 1980s and

1990s attempted to verify the healing properties of drawing, and inadvertently gave rise to the belief that people could cure their illness through drawing (Malchiodi, 1999). In response, art therapy promoted the use of art as more of an "ancillary" approach to providing an outlet for expression of feeling than a curative intervention (Malchiodi, 1997). Since then, many new approaches within the field of medical art therapy have surfaced, focusing on wellness-based models, in additional to developing a more comprehensive understanding of the relationship between artmaking on physiology (e.g., pain management).

The practice of medical art therapy can involve bedside art interventions in hospital and medical settings. Patients can experience the benefits of art therapy while undergoing invasive treatments such as chemotherapy or dialysis. Support groups incorporating art therapy have also flourished within medical settings. These groups provide opportunities to express thoughts, feelings, and perceptions about medical treatment, coping with acute or chronic illness, and support systems through the art process. Within the medical field, art therapy is considered a complementary approach to holistic, psychosocial care (OCCAM, Categories of CAM therapies, n. d.). The role of the art therapist in this capacity is to provide art interventions with a wellness-based focus.

Art Therapy with Cancer Patients

Cancer over the past decade has been a major focus in art therapy research, leading to the development of art therapy support groups. Dreifuss-Kattan's (1990) focus on capturing cancer stories through personal artmaking and narratives provided the impetus for much of this work and has been cited regularly in the medical art therapy

literature. Her work spurred a more spiritual awareness in art therapy practice and provided much of the foundation for a holistic approach. Dreifuss-Kattan was also one of the first authors to recognize an emerging area in oncology that addressed some of the psychosocial aspects associated with cancer.

> No other disease attracts to itself such a wealth of personal symbols and metaphoric equivalences....Psychooncology tries to deal therapeutically with the psychological realties behind metaphors and with the defenses that the patient and doctor employ against these overpowering images. It examines the psychological responses to various cancer therapies and their consequences for the patient, the family, and treatment team. It also deals with the threat of death and other fears that the patient experiences from the onset and throughout all the states of his illness. (p. 2)

These psychological responses to reactions to diagnosis of cancer and treatment, among other aspects, mirror the stages inherent in grief and loss such as denial and anger. Dreifuss-Kattan (1990) attended to these responses by having her patients share their cancer stories whether through written or art expression. She also situated these stories in the foreground, positioning her voice in the background (narrator), away from being an expert on her patients' experiences. Her approach to art psychotherapy with cancer patients is multifaceted and psychodynamic, involving art as a transitional object representing inner and outer realities, form of self-repair (body image and self-concept), and an expression of immortality.

Innovative approaches such as mindfulness-based art therapy (MBAT) incorporate mindfulness-based stress reduction and visual forms of self-expression (Monti et al., in press). Art therapist Caroline Peterson collaborated with a team of physicians from Thomas Jefferson University to study the efficacy of a mindfulness-based psychosocial intervention (art therapy) for cancer patients.

> MBAT integrates mindfulness meditation skills and aspects of art therapy into an eight-week, gender segregated, supportive group therapy format. The multi-modal design is intended to provide opportunities for both verbal and non-verbal expression, enhanced support, and expanded coping strategies. (in press)

The goal of this study was to enhance quality of life factors and decrease levels of stress, and it is one of a few controlled studies that exist in medical art therapy. The results of this study demonstrated a statistically significant decrease in symptoms related to stress and an increase in concepts related to quality of life. This study also scientifically validated the efficacy of an integrated, holistic practice.

Although group art therapy was a recommended format for providing support and attending to psychosocial factors with cancer patients, most of these support groups were conducted at a medical facility in centrally located areas. What was not included in the literature were psychosocial interventions for cancer survivors in rural areas, including underrepresented minorities. Moreover, the demographics for the majority of the breast cancer support groups consisted of predominantly Caucasian females. As the profession of art therapy continues to lay the ground work for medically-based interventions, a culturally-responsive approach is needed to attend to different cultural dimensions of wellness and illness.

Summary

This literature review considered a sociohistoric focus in the review of healthcare policy, concepts of health and illness, and access to healthcare services for Native people. A central theme throughout the literature concerned "barriers" to healthcare delivery. A review of effective strategies to address issues related to misclassification, underreporting, and poor access to services was provided in context to Native-run organizations, community-based participatory models, and culturally-relevant

approaches. Approaches to counseling Native Americans promoted the inclusion of cultural art forms, such as storytelling, and supported complementary approaches such as art therapy. Medical art therapy, a specialized subfield in art therapy, was reflected upon in terms of best practices, addressing the need for culturally-responsive approaches. Approaches to conducting research in Native communities were central to discussing ethical concerns and collaborative strategies.

CHAPTER 3

METHOD

Plan of the Inquiry

This section considers the narrative approach as a culturally-responsive means of conducting qualitative research with American Indian breast cancer survivors. The process of recruiting participants is reviewed in terms of developing a collaborative relationship with southeastern American Indian communities, reflective of the community-driven and community-based participatory approaches. A collaborative focus with the participants was incorporated throughout the study, positioning the participant in the role of "expert" vs. "subject." The data collection centered on artmaking in relation to eight open-ended interview questions that were audio recorded and transcribed verbatim. Three related forms of discourse analysis were conducted to interpret the layers of the narrative and visual content. As a measure of trustworthiness and fidelity, the participants were encouraged to collaborate with the co-investigator in reviewing their transcription, analysis, and interpretations. Measures of validity such as triangulation, member check, expert witness are further outlined in the final section of the methods chapter. The reflexivive nature of this collaborative work was considered in both the transactional focus of the zoom model (Pamphilon, 1999) as well as a separate section, identifying a range of reflexive interactions and response artwork.

Purpose of the Study

The purpose of this narrative inquiry was to explore, through artmaking and storytelling, the belief systems surrounding wellness and physical illness from the perspective of Native American women diagnosed with breast cancer. This narrative

inquiry will provide the ground work for more culturally competent psychosocial interventions utilizing the expressive arts.

Focus of Inquiry

How do Native American women, diagnosed with breast cancer, experience their treatment in medical institutions? What are their beliefs surrounding wellness and physical illness? How does this belief system affect their view of treatment? How are these beliefs expressed through artmaking and storytelling?

Method

Narrative inquiry provides a conceptual framework to bridge my clinician and researcher stance. For several years, I had been part of a narrative therapy supervision group and found narrative inquiry to be a natural fit for me as a culturally-sensitive means of accessing stories. Interestingly, narrative inquiry has surfaced in a number of related dissertations as a method of accessing personal stories (Collis, 2006). Oral traditions such as storytelling are prevalent in contemporary American Indian culture (Herring, 1997). Storytelling is a complex form of communication that can convey multiple meanings within the Native American culture. The narrative perspective shares a similar stance to the storying process, "The value of storytelling in qualitative research is that it can be used to demonstrate how the same phenomenon can be told in different and multiple ways depending on the storytellers" (Ladson-Billings, 2004, p. 968). Storytelling has deep sociohistoric roots in Native culture and different implications in terms of meaning-making experiences and possible "interpretations."

Stories are also received differently. A narrative researcher who is unfamiliar with Native American culture would probably not have access to "real data" from stories

about specific phenomena and in the process could diminish voice and alter text. The critical race perspective in narrative inquiry addresses how different lenses can alter text, whether or not the researcher has an "inside" status (Ladson-Billings, 2004). Critical race theory also supposes that research conducted with underrepresented minorities be action-oriented in terms of creating social change. In this context, the participants become the experts or the co-investigators in the study who collaborate in a meaning-making experience through the storying process.

Narrative approaches in art therapy have surfaced in response to the need for a more contemporary/postmodern approach to therapy (Riley, 1997). Art therapy shares a similar framework from which images and metaphors are explored. The narrative perspective mirrors this process and extends the "life" of the metaphor by examining its origins, purpose, and intent (Warson, 2002). The integration of art and narrative therapy allows for more lasting connections to be made.

The framework for this narrative inquiry follows the recommendations of narrative researchers Josselson and Lieblich (2003), providing a foundation for this inductive process. Their framework is meant to be more of a guideline for structuring a thesis or dissertation for academic review, comprising: 1. Research question and its significance, 2. Plan of the inquiry, 3. Approach to analysis, 4. Significance of the findings, and 5. Reflexive statement about the position of the researcher in relation to the work (p. 262). This narrative inquiry incorporated these guidelines as major headings, married with a traditional dissertation format.

Why Native Americans and cancer?

My interest in this area was spurred by the grass roots efforts of the Mayo Clinic's Spirit of E.A.G.L.E.S. American Indian/Alaska Native Leadership Initiative on Cancer (n. d.). My involvement with them since 2006 has evolved from regional and national conference presentations as well as a co-sponsored grant project. In 2007, funding for art therapy workshops (Healing Pathways) for the southeastern tribes became a reality and permitted me to develop relationships with tribal leaders and communities in North and South Carolina and Virginia. Prior to my involvement with the Spirit of E.A.G.L.E.S., I provided art therapy services for Native American youth and families throughout Northern Colorado; this experience influenced my decision to focus on Native Americans for my dissertation work. As a person who appears to be part of the dominant society, I am frequently asked why Native Americans? Is breast cancer such a pervasive problem? As a Native American who has been socialized among The People, namely the Lakota, I am all too familiar with the ongoing health problems. This awareness has grown out of my relationship with my Lakota daughter (Ogalala) Fawn Rose Yellow Boy who has endured a life-time of medical problems.

Procedures

Recruitment.

Native Americans traditionally are reticent to standard research methodologies for a variety of reasons ranging from disrespectful cultural practices to not sharing results or following through with recommendations. The general sentiment is that Native Americans have been used as "guinea pigs" and their communities have not benefited from standard research projects (Burhansstipanov, Christopher, & Schumacher, 2005).

Knowing this, I have positioned myself in these communities as an art therapist, first, and secondly, as a researcher working on her dissertation study. My recruitment efforts evolved from these relationships, not from the flyers or email announcements sent to tribal leaders and Native American organizations. To gain support from the community, I contacted the North Carolina Commission on Indian Affairs to discuss my proposed research and obtained a letter of support (Appendix A). As part of the official recruitment process, I sent out packets consisting of a tribal council letter describing the study (Appendix B), copy of IRB protocol, and consent form to the tribal council members and executive directors (Appendix C). Recruitment ultimately involved the Coharie and Waccamau Siouan tribal communities because of their participation in a previous study that I conducted a year prior to my dissertation work.

Although, recruitment efforts were original scheduled to take place prior to and during the 2007 and 2008 Spirit of E.A.G.L.E.S. AI/AN national and southeast conferences, it was my prior relationship with a health outreach coordinator from the Coharie tribe who assisted me in gaining access to her community (Coharie) and a neighboring tribe (Waccamau Siouan). This individual, Miss Hope., became my gatekeeper who piloted my interventions, reviewed the script (Appendix D) and consent form (Appendix E) with prospective participants, reviewed the analysis, and was instrumental in helping me develop a relationship with my key informant, the Executive Director of the Coharie tribe. Prior to implementing the study, a "letter of invitation" was written by the Executive Director and amended to this study (Appendix F). After receiving approval from two institutional review boards, Colorado State University (Appendix G) and Eastern Virginia Medical School (Appendix F)--where I am employed

as an assistant professor—I was able start the recruitment process through the health outreach coordinator.

Collaborating with state-recognized tribes involved developing a trusting relationship to gain access to this particular rural community in central North Carolina and did not require further submission to a tribal Institutional Review Board. During the proposal stage, my intention was to collaborate with both state- and federally-recognized tribes in the southeast. Because of my prior relationship with the Eastern Band Cherokee in the Qualla Boundary, located in Cherokee, NC, I was able to forward my proposal and consent form to my gatekeeper in this community. After several email discussions and one face-to-face conversation, it seemed evident that this community would not support this study because they did not feel it was "reciprocal" enough to benefit their breast cancer survivors. My gatekeeper, a Cherokee attorney, informed me that the community was more interested in studies that had a direct benefit, such as clinical studies, that were able to be sustained in some manner. She suggested that in the future I "incorporate" my services so that I would not have to go through a tribal Institutional Review Board (IRB) to provide art therapy services. Essentially, they were supportive of the idea of art therapy but were not receptive to participating in a formal study.

Because of the letter that was generated from the North Carolina Commission of Indian Affairs, I was put in contact with a tribal officer and the head of the Cherokee review board, a female physician, Dr. Bullock from the Qualla Boundary. I was able to have a phone conversation with her to discuss the process of submitting to the Cherokee IRB (Dr. A. Bullock, personal communication, August 15, 2007). She highly recommended that I obtain a sponsor from one of the community centers, preferably the

Cherokee Women's Wellness Center before submitting to the tribal IRB. She explained this was a necessary step, although not required, in gaining access to the community. Without this sponsorship, she doubted anyone would participate in the study. Because I was unable to secure a sponsorship in the Qualla Boundary, I focused my efforts on the neighboring North Carolina state-recognized tribes.

Participants.

The participants or "experts" in the study consisted of two women who were long-term breast cancer survivors from the Coharie tribe in Clinton, North Carolina. In my proposal, I indicated that I would be interviewing ten American Indian women, between the age of 18 and 85, who have been diagnosed with breast cancer with no criterion set in terms of time since diagnosis. The decision to include ten participants was a recommendation from a prominent American Indian cancer and AIDS researcher, Associate Professor from Washington University, Dr. June Strickland. Her feedback was based on logistical concerns such as funding, timeline, and accessing participants (J. Strickland, personal communication, March 15, 2006).

Five of these women were to be enrolled members in a federally-recognized tribe and five from a state-recognized tribe. I initially wanted to focus on state-recognized tribes for this study; however, because of the complexity of the I.H.S., I decided in the proposal stage to include participants from federal tribes to explore possible differences in cancer treatment. In hindsight, the focus on state-recognized tribes was sufficient because the vast majority of AI/AN cancer studies have focused more on federal than state-recognized tribal members. From reviewing the literature, the southeastern state-

recognized tribes, in particular, had the least amount of cancer-related information available.

Although only two volunteers agreed to participate, five additional women were identified by community coordinators from the Coharie and Waccamau Siouan tribes. Phone contact was made with two women, one was screened out because her type of cancer was not breast cancer, the other woman postponed the interview and had a family crisis preventing her from participating. The remaining volunteers cancelled through the tribal office on two separate occasions. The outreach coordinator was then unable to confirm an appointment.

Data collection.

The data for this study consisted of active interviews, reflective of the collaborative relationship between researcher and participant. The community developer from the Coharie tribe, Miss Hope., scheduled the interview and contacted me with the time, date, and directions. The interviews were conducted in North Carolina at either a personal residence or the Coharie Intra Tribal Center. After reviewing and signing the consent forms, a demographic questionnaire was to be completed prior to conducting the interview (Appendix I); however, this turned into a verbal interview, which was later transcribed because of the richness of these "stories." A list of eight open-ended art directives/interview questions, broken down into three sections, was developed as a guideline for conducting the narrative inquiry and directing the artmaking (Appendix J). Each participant had an opportunity to review art directives, art materials and processes, and decide what order they would like to complete three main art tasks. The active interviews (storytelling and artmaking) did not exceed two hours. The interviews were

audio recorded, burned onto a CD, and transcribed verbatim using qualitative transcription methods (Poland, 2003). The transcriptions were completed by the co-investigator partly due to the familiarity with the dialect from this region of the country.

The audio tapes were destroyed after the final draft of the dissertation had been read, or agreed upon, by the "co-collaborators." All raw data (photographs, transcriptions) were de-identified and stored with the Principal Investigator (School of Education, Colorado State University) for 3 years and will be destroyed thereafter. It is important to note that the participants were provided with a copy of the audio tapes, written transcription, and photographs of the art productions and were contacted when the audio tapes were destroyed. This extra measure was significant because of the history of misuse of data from AI/AN communities, such as secondary analysis without prior consent, and a general lack of trust of investigators from outside AI/AN communities.

The emphasis on the artmaking was intended to help externalize their thoughts, feelings, and perceptions and provide a less threatening means to discuss their experience with breast cancer, cancer treatment, and perceptions of wellness and illness. Participants were provided with a wide array of media to observe media preferences in the categories of structured (charcoal pencils and collage materials), semi-structured (chalk, oil pastels, and watercolor) and unstructured art media (acrylic paints, and ceramic clay). Prior to completing the art directives, and at the end of the session, the participants were initially going to be asked to draw for 5 minutes, using oil pastels, inside a pre-drawn circle (10" dia). The rationale for completing the 5-minute circle drawing is to provide a centering technique and a means to close the session. However, the demographic questionnaire that became a verbal interview served as a warm-up for the art tasks. This pre/post

measure was completely omitted after the first participant's experience completing the "closing" circle. This decision to change the protocol was determined methodologically based on discovery-oriented, emergent design. In this paradigm, the researcher utilizes an open-ended approach to attend to important insights or new discoveries that might warrant modification of the research questions and protocol (Denzin & Lincolm, 2000).

Although circle drawings or mandalas have been used in art therapy research to reduce anxiety and provide a centering technique (Curry & Kasser, 2005), these circles were not a focal part of interview as I had intended. Nonetheless, the circle is symbolic to Native Americans representing the four directions, wheel of life, and reflects their holistic belief system (Willis, 2005). Circle drawings or "healing circles" have also been incorporated into my experientials at the Spirit of E.A.G.L.E.S. regional and national conferences, leading to its inclusion in the original proposal. These "healing circles" have been a consistent intervention in my art therapy workshops with American Indian cancer survivors. However, their function in this study seemed secondary to the storytelling and narrative focus.

Participants were provided with a number of choices in terms of media and paper. The purpose in doing this was to provide them with a sense of control during the interview process. In addition to the structured, semi-structured, and unstructured art media, they were provided with a choice between grey, white, black, and assorted color paper. This was later narrowed down to three different sizes of grey and white squares (10 x 10, 14 x 14, 18 x 18). The size and format of the paper (e.g. square, rectangle, circle) initially was to be decided by the participant but proved to be too cumbersome, involving measuring and cutting during the first interview. Media choices among Native

Americans have not been researched widely and because of this, I felt it was important to provide as many choices as possible and to modify the selection after each interview as part of the emergent process. The decision to stay with grey and white paper resulted from my personal experience with art therapy assessments: the inclusion of grey paper has been a consideration in art therapy assessments because of the option of using white media (Agell, 1989; Ulman, 1975; Kwiatkowska, 1978; Raymond et al, 1998/2004).

Art therapy pioneer Edith Kramer suggested in her evaluative procedure to provide choices and consider the implications of using a medium that was highly structured (pencils) and unstructured (paint and clay) (Kramer & Schehr, 1983). Her evaluation was more an observational means of gathering information pertaining to how children use art media. In my work with adults, I have modified this procedure to consider their preferences or type of expression: a continuum ranging from visual to haptic (Lowenfeld & Brittain, 1987). Historically, sculptural methods have not been included in art therapy assessments beyond the Kramer art evaluation (Kramer & Schehr, 1983), nor has it been referenced in much of the art therapy literature. Hand building with ceramic clay has a long history within many Native cultures and was included as one of the art mediums in this study.

As part of the collaborative process, member checks were completed with the participants through mail, telephone calls, and face-to-face meetings. Because of the low number of participants, additional data sources were amended to the study, consisting previously conducted interviews, which were included in the data analysis. The first source consisted of a "pilot" intervention with a member of the Coharie tribe, Miss. Hope. This pilot was originally conducted at the request of my committee to assist in the

development of my protocol. This data was collected before my dissertation study and the artwork from this pilot was included in the visual discourse analysis. The second source was an interview with an 86-year-old woman, Miss Sassafras, who is a known traditional healer from the Waccamau Siouan tribe. This person was instrumental in providing a context for traditional healing practices and her interview was included as an "expert witness" in the narrative discourse analysis. The final data source was an interview with a health outreach coordinator from the Waccamau Siouan tribe, Miss Promise that was conducted as a class assignment for my 708 Narrative Inquiry course and included in the narrative discourse analysis. It is important to note that verbal consent was obtained from all of three women and indicated, thusly, in an amended letter to the IRB. As part of the co-collaboration process in narrative research, this investigator reviewed transcripts, artwork, analysis, interpretations, and conclusions with all five individuals who took part in this study.

Approach to analysis.

Confronted with the difficulty of interpreting personal stories in discourse analysis, Barbara Pamphilon (1999) developed a framework entitled *The Zoom Model: A Dynamic Framework for the Analysis of Life Histories.* She compared this process to a camera zoom lens that extends beyond the freeze frame associated with traditional research and considers the following:

> ...with one small movement we can, and should, move between levels of interest; to zoom from the background to the foreground and out again. This movement between levels acknowledges that the levels are not discrete entities or binary opposites, for example, as with an individual or society, but are in fact in a relationship, intricately and intrinsically linked. (p. 393)

Within this framework there are four foci: the macro, meso, micro and interactional that are attended to within the context of a co-created story between the researcher and expert. The macro-zoom lens focuses on the sociocultural dimensions of a personal narrative from three levels: impact of *dominant discourse*, composition of the narrative or *narrative form*, and *cohort effect*. The meso-zoom lens focuses on the process of storying or the "oral dimensions of the life history" (p. 396): silences, pauses, and emotions. The interactional zoom lens addresses self-reflexive statements from the researcher in terms of transaction and reaction. This framework serves as a way to address the multiple layers or levels in narrative analysis from the perspective of both the researcher and expert (co-creators). The zoom model was instrumental in deciphering the layers of text in the transcripts from the two participants.

To further extend the personal narratives from the zoom model, a situational analysis comprised the second level of analysis. Situational analysis provides more of an analytical approach to understanding or interpreting narrative context (Clarke, 2005). Situational analysis is a postmodern approach to grounded theory in qualitative research, and has been used with narrative methods as a means of "locating, collecting, tracking, [and], situating" data (p. 185).

> Overall, the very design of a narrative discourse study using situational analysis (the three main kinds of maps and memos) involves the researcher in tacking back and forth between situational elements, the discourses, the social worlds/arenas, and the positions taken in the discourse(s) throughout the project. In many ways, doing the research is (re)doing the design. (p. 186)

As with traditional grounded research, basic coding methods (memoing) were conducted prior to creating the visual discourse situational maps. The analysis generated from the zoom model, provided the "codes" or data for situating the narrative discourse. This

"coding" process assisted me in knowing or "opening" my data and was not intended as a means of interpretation.

The preliminary data were situated in a random map and then presented in a more organized format (radial configuration). This mapping process provided a less formulaic means of understanding the data. Situational map "...lay out the major human, nonhuman, discursive, and other elements in the research situation of inquiry and provoke analysis of relations among them" (p.xxii). Essentially, the initial map resembled a random pattern of codes or themes that were organized into a structured map. Once organized, a more synthesized social worlds/arenas map was created. The social worlds/arenas maps "...lay out the collective actors, key nonhuman elements, and the arenas of commitment and discourse within which they are engaged in ongoing negotiations—meso-level interpretations of the situation..." (p. xxii). The three data sources that were not included in the zoom analysis were "situated" either in the visual discourse analysis, as with Miss Hope's artwork, or the narrative discourse analysis, as with Miss Sassafras's' and Miss Promise's interview.

The similarity between the zoom model's macro-zoom, meso-zoom, and micro-zoom-zoom focus (Pamphilon, 1999) and memoing, mapping procedure in situational analysis (Clarke, 2005), allowed for the data to be fully opened. This process led to the "clustering" of themes in the social world/arena map. The final positional final map considered in a graph form the different positions represented in the narratives. Positional maps "...lay out the major positions taken, and not taken, in the data vis-à-vis particular axes of difference, concern, and controversy around issues in the situation of inquiry" (p. xxii). In essence, "...situational analysis provides big picture maps that enable the

researcher to "see" better where they may be—and my not—want to go in terms of smaller portraits and/or the use of wide-angle lenses" (p. 201). This process is conducted with slight modifications depending of the type of narrative. In this study, two narratives, discursive and visual were considered.

Trustworthiness.

To address trustworthiness in post-positivist qualitative research, Lincoln (1995) proposed five criteria related to social action: voice, critical subjectivity, reciprocity, sacredness, and sharing the perquisites of privilege. Trustworthiness in this context serves as a measure of "emerging criteria for quality in qualitative and interpretive research" (p. 275) or a means of authenticating (Guba & Lincoln, 1989). In relation to this study, the criterion of voice is significant in terms of focusing on a historically marginalized, if not invisible, group of individuals (American Indians) (Lincoln, 1995). Because of this, self-reflexivity was a vital concern, examining differences in worldview that have implications for self-awareness and personal transformation.

Reflexivity was addressed through my primary means of personal expression through visual journaling. This journal was initiated during the preliminary stages of my research ideas and has since then evolved into multiple journals and other art forms. In reviewing the criterion for reciprocity, this co-collaborative process is an ongoing process that involves not only the gathering of personal stories but also the sharing of analysis and interpretation. This relationship has further implications for a sense of sacredness and a sharing of perquisites of privilege: Having an expressed concern for whom you are working with and an investment in the lives of the co-collaborators (community focus) (Lincoln, 1995).

Fidelity, another aspect of trustworthiness, concerns the telling and retelling of personal stories that reflect the co-collaborator's experience (Moss, 2004). This involves being actively engaged in the storying process and the being involved with the participant literally as a co-collaborator in research. Fidelity resembles traditional methods of member check and for purposes of this study; these two terms were used interchangeably. In narrative inquiry, fidelity involves a full collaboration with the intent of bringing about a level of social change.

> Once we recognize that just as there is no neutral education there is no neutral research, we no longer need apologize for unabashedly ideological research and its open commitment to using research to criticize and change the status quo. The development of data credibility checks to protect our research and theory construction from our enthusiasm, however, is essential in our efforts to create a self-reflexive human science. (Lather, 1986, p. 67)

In her section on "reconceptualizing validity," (p. 67) Lather offers specific guidelines (triangulation, construct validity, face validity, and catalytic validity) that reflect current notions of fidelity and trustworthiness. These guidelines seem to integrate traditional forms of validity with the post-positivist social orientation.

In reference to my study, triangulation or the gathering of "multiple data sources, methods, and theoretical schemes" (Lather, 1986, p. 67) involved literally the interview process (narrative inquiry) and participant observation (artmaking process). Results from this study were cross referenced with similar studies as well as AI/AN resources from the Native American Cancer Research (NACR) website (n. d.). In terms of construct validity, this process entailed "a systemized reflexivity, which gives some indication of how a priori theory has been changed by the logic of the data..." (Lather, 1986, p. 67). In order to strengthen construct validity, I initially proposed interviewing American Indian women from both state and federal tribes; however, this was not achieved and

triangulation with additional archived data sources and an interview from an expert witness were included, along with the two narrative interviews. Face validity or member checks (fidelity) involved an ongoing collaboration between the co-collaborators; this relationship had further implications for catalytic validity or transformative aspects (meaning-making experiences).

Summary

This narrative inquiry was conducted with two breast cancer survivors, Miss Hope and Miss Sunshine from the Coharie tribe in North Carolina. As part of the narrative focus, these two participants were "experts" in this study and maintained a collaborative relationship with me throughout the duration. The active interviews, consisting of storytelling and artmaking, were conducted at a mutually-agreed upon location and did not to exceed two hours. Both participants chose to complete all three art tasks and responded, through storytelling, to the "interview" questions. The interviews were audio recorded and transcribed, and the artwork was photographed on-site. The interviews and artwork were analyzed using discourse methods: zoom model (Pamphilon, 1999) and narrative and visual forms of situational analysis (Clarke, 2005). As a measure of trustworthiness, self-reflexivity was addressed to gauge subjective responses to the interviews. Triangulation with other data sources, consisting of two additional interviews, a pilot study, and resources such as the Native American Cancer Research website was considered and included in the analysis. As a measure of fidelity, ongoing member checks through mail, face-to-face meetings, and telephone conversations were conducted to enhance construct and face validity.

CHAPTER FOUR

RESULTS

Introduction

The collaborative relationships that were developed throughout this study were compelling in many ways because of the degree of co-collaboration that occurred not only with the participants but the with tribal community as well. This chapter is divided into four parts, detailing the collaboration and layers of analysis. The first section comprises a description of the co-collaboration, the second section consists of the discourse analysis using the zoom model (Pamphilon, 1999), the third section involves mapping and coding techniques from situational analysis (Clarke, 2005) as a means of "situating" observations from the zoom model. The inclusion of the additional data sources was considered in the narrative discourse situational analysis. The final or fourth part consists of visual narratives of the artwork from the pilot and participant interviews. The interviews were transcribed using Poland's (2003) revised format, capturing the nuances of verbal and nonverbal interactions (Appendix K) and "color-coded" according to the 10 levels of the macro, meso, micro, and transactional-zoom lenses (Pamphilon, 1999) (Appendix L).

Co-Collaboration

Interview with Miss Turtle.

The study was open for four months before a Miss Turtle agreed to meet with me at her residence in central North Carolina. I had been acquainted with Miss Turtle from her participation in one of my art therapy workshops, and had seen her perform in a

pageant. At the time of this interview, Miss Turtle was 74-years-old, a noted traditional artist from the Coharie tribe, an educator for Department of Indian Education, and a "Queen." As an artist and activist, Miss Turtle has been instrumental in reviving traditional arts with the youth in her community. We met in March of 2008 for a two-hour interview. The Health Outreach Coordinator for the tribe who I will refer to as Miss Hope., made prior arrangement for our interview and suggested that we meet at Miss Turtle's residence to view some of her gourd artwork, personal photographs, and traditional regalia. I followed Miss Turtle in my car and we socialized briefly before she left to bring back lunch consisting of North Carolina BBQ.

Appearing somewhat nervous, Miss Turtle and I reviewed the consent form verbally as well as the demographic questionnaire. Although this questionnaire was intended to be completed on their own, the questions seemed to elicit the storying process and Miss Turtle began telling stories about her cancer experience. When I realized the depth of her conversation, I asked her permission to audio tape her responses. Initially, I was going to fill out the questionnaire with her taped responses; however, the richness of her stories became an important part of this interview process and subsequently included in the transcription verbatim. Because I was working within the emergent paradigm in qualitative research, I maintained an open stance and modified procedures as I saw fit (Denzin & Lincoln, 2000). This demographic interview carried over into our art tasks which were divided into three parts. Miss Turtle was diligent about completing all three art tasks and responded to all eight questions in a very heartfelt manner. This interview was by no means structured, the questions merely served as a guide for conducting the interview, and as we became comfortable with the intimacy of the situation, many other

stories began to unfold. Because of the level of comfort from the demographic interview, the circle drawings that were included in the proposal seemed secondary to the entire experience. I realized this omission toward the end and decided to include the final circle drawing as a form of closure. Although the interview last two hours, my visit extended for five hours involving discussion about her art, family, and traditional regalia from her pageants. I left her with all my art supplies knowing she would put these to good use with her art classes.

A letter of gratitude accompanying a CD with the interview and images of her artwork was sent to Miss Hope one week after the interview. As a measure of fidelity or member check, it was requested that I meet with Miss Turtle, Miss Hope, and Miss Angel (tribal leader) for lunch to follow-up on one of the research questions, focusing on the use of traditional healing practices. We met in a traditional Southern restaurant, Miss Angel. inquired about a table that we could have some privacy. Through the support of her people, Miss Turtle was able to share her traditional practices at the risk of being called "ignorant," which was, apparently, her initial fear. This conversation was not recorded out of respect and was literally whispered over our meals. All three tribal members verbally agreed that I could include this information in my study. This information was included in the mapping procedures in the narrative discourse analysis.

Interview with Miss Sunshine.

Miss Sunshine was recruited by her close friend Miss Angel, a tribal representative. I was provided with Miss Sunshine's phone number and we were able to schedule an interview the same day that I went out to lunch with Miss. Turtle, Miss. Hope, and Miss Angel. This proved to be helpful in terms of having a better

understanding of traditional healing practices beforehand. In my transcript, I described Miss. Sunshine as "vibrant," and this was the only descriptor I could come up with to characterize her radiant complexion and glowing personality. She literally glowed! At the time of this interview, Miss Sunshine was 66-years-old. As a member of the Coharie tribe, she is active in her community and involved in her church, living and practicing her Christian faith. In the transcript, she referenced several cancer awareness programs and support groups that she is involved with. She is retired and worked previously with children with disabilities and taught for Indian Education. Miss Sunshine had a notebook in hand that listed all her appointments and medical information, which she referenced throughout the interview. We met at the Coharie Intra Tribal Center in Clinton, North Carolina for a two-hour interview. Miss Sunshine opted to read the entire consent form and completed the demographic questionnaire verbally. This was, again, recorded as part of the interview. She completed all three tasks without hesitation. The pre and post circles were omitted in this interview based on the outcome of the first interview. A letter of gratitude along with a CD with her art images and audio recorded interview were forwarded by the tribal office one week after the interview. The written transcript was mailed directly to her residence and there was correspondence over the telephone.

The Zoom Model (Pamphilon, 1999)

This model is a dynamic framework for observing personal narratives through the metaphor of zooming in and out of personal stories similar to the lens of a camera. This "zooming" process allows for different perspectives in the storying process to be explored. The "zoom metaphor" (p. 393) enables different stories to co-exist through foregrounding and backgrounding, focusing on the macro-zoom or sociohistorical

dimension; the meso-zoom or personal values, insights, or awarenesses; and micro-zoom or the nuances related to the storying process; and interactional-zoom or the intersubjectivity between co-collaborators.

Macro-zoom (life history text).

Dominant discourses.

This focus represents the collective discourse from a sociohistorical perspective, essentially a shared experience or a collective pattern that emerged from a comparison of the participants' stories. I approached this dominant lens from a cultural-generational perspective (ex., segregation laws, Indian schools, Indian Education) and a specific-cultural group lens (Southern Christian values and American Indian belief systems and practices). The life stories from both women were layered with multiple references within the context of sociohistorical influences.

Miss Turtle

In response to her cancer treatment, Miss Turtle reinforced the work ethic of her generation: "I didn't miss any work. I kept working." Similar references to "being strong," and "working harder," and "nothing being handed to (her)" were interjected throughout the entire discourse. Cultural-generational influences specific to Native people surfaced later in the life story in the following:

> And when they interviewed me that day, the county board, the school board, he said, "What do you know about Native Americans?" I said, "I don't know anything except that I went to a Native American school and church all my life and I was treated like one." He said, "Like what?" I come to tell him about eating and going in movies and stuff.

These stories were few and far between and seldom elaborated on, emerging at specific points in the discourse when a sense of trust was felt in the co-collaboration process.

What surfaced as a dominant theme within the sociohistorical lens were references to an American Indian Southern Baptist perspective, reflected in repeated responses such as "work itself out through God," and "Thanking God." These references were so closely intertwined that it was difficult to separate the two into different categories (Southern Baptist ideology and American Indian beliefs) and as a result, I viewed these comments more as a reflection of a specific-cultural group than distinct categories.

> I guess the way I was raised, it was to be strong, you know, not give into anything, just give it a chance..um, it will work itself out through God, and that was my, that was my shield, was God and my pride...

In the process of reviewing the text for this lens, two dominant themes emerged that seemed to carry over into all the lenses resulting in an alternating foreground and background story. The story that was foregrounded throughout much of the discourse centered on the sociohistorical influences that prevented Miss Turtle from experiencing her artistic talents:

> I was creative and drawed and painted..those things were pushed aside..as a kid. A pencil, you got one pencil a year, you had to keep up with it. Sometimes it would get the length of your finger and you still had ____ keep a hold onto it. So you couldn't spend your time doing those things drawing..you had to get to your lessons. So that put a hold on, I guess my ability that I wanted to do...I still love to dance and artwork but I was never able to express that coming up as a child or a teenager.

The background story that emerged from the retelling of her life history was one that reflected Miss Turtle's American Indian values:

> And I got this Indian Education job at thirty six, I think. My first flight to Buffalo, New York, I cried three weeks because I had to go, but once I got there, I realized there was something to my life other than what I had been doing.

The positioning of these two stories became a central theme throughout the discourse analysis and more importantly, became the basis of a meaning-making experience.

Miss Sunshine

The American Indian Southern Baptist perspective, as a sociohistorical specific-group lens, was a central focus in Miss Sunshine's discourse analysis and carried over into all the subsequent lenses. This perspective was reflected in the following comment addressing cancer treatment:

> So, when they called me back there, the technicians, I asked the two technicians, I said, "Do you mind if we pray before you start your procedures?" And they said, "Yes." So, I prayed to the Lord that He would direct their hands and do whatever they needed to do to show what needs to be shown.

These stories about divine healing and faith were positioned in the foreground throughout the majority of the discourse. Toward the end of the interview, an alternate story emerged foregrounding an American Indian generational perspective on traditional healing practices.

> ...My parents and my grandparents and my aunt and uncles they all, um, knew how to, um, stay well by taking certain types of herbs that you can't find now like sassafras. I know you heard tell of that. My momma would go to the ditch back there and get it and make it and give it to a baby that had colic or if you had a tummy ache, you didn't go to the doctor. (hushed voice) They fixed up their stuff...and you can't find, you know with so much industrial, people coming in here building plants and everything and all that stuff got lost, you know. You can't find those kind of roots, herbs and stuff that used to grow in the woods.

Brief references to traditional values were mentioned during the artmaking tasks, specifically when depicting a human figure: "Ah, I need to put some makeup on (laughter). Not that Native Americans need a whole lot." These experiences were further expounded upon during the storying process, elicited from the artmaking experience, such as in Miss Sunshine's description of her position with the Indian Education program:

> ...I was hired as the coordinator for the program and it had five schools that I was responsible for, um, maintaining the data on Indian children and, um, and then, it

> developed that we had to have a cultural component incorporated into the program, so, um, it became my responsibility to do the arts and crafts and take the children to things, that you know, that Native American children just didn't get outside their county.

The artmaking process seemed to be a catalyst, not only in terms of accessing stories from a socio-historic perspective, it echoed the "zoom" effect of multiple lenses being viewed simultaneously. Miss Sunshine was also influential in positioning the history of her people, the Coharie:

> For all of us because of the stand they took (Cherokee), and or course, according to, um, what, what we have been told, when they were rounding up the Native Americans in North Carolina, some of the Coharies went down to the Coharie river and hid out, and that's how we became known as the Coharie Indians cause the ones that left, that didn't go, that were rounded up to go, they migrated, some of the Cherokees migrated back this way...

This story not only served as the foundation for the sociohistorical perspective for the Coharie community, it also provided an ongoing legacy of survival and one that contributes to the shaping of individuals stories.

Narrative form.

This next level is more reflective of the cultural norms and values from the sociohistorical position of the participants. Pamphilon (1999) refers to this as "the cultural archetypes of storying available in a given culture" (p. 398). Within the culture of women, especially American Indian women, the narrative form is more relational, positioning Self in relation to others. In reviewing the life stories for this lens, I focused more on the relational Self in context to cultural norms and values.

Miss Turtle

During the demographic interview, Miss Turtle immediately positioned herself as a caregiver for her family: "I had five kids in school and through college and I had just

got through my life, fixed income, my husband had retired from teaching and I was doing two jobs." This relationship with family and Self was also reciprocal, meaning family members became caregivers during her cancer treatment but from a text of being "there" but "backed away."

> My children, my husband, they just couldn't believe that anything was going to happen to me..so, it was like they backed away from me, just gave, gave, put me in charge..of myself. They took me to the doctor and all but my husband couldn't deal with it because I lost my hair, a lot of weight, and color and everything...so it wasn't much support..other than God (whisper).

This story shifted into a discussion about being accepted by her children and grandchildren regarding her traditional ways, but not feeling as accepted by her own community in the same respect.

> Yeah, it amazes me how I do things that I don't know where it, I coming from. And, I have got to, I've considered it a lot with my four grandchildren in _____ and they always bring out the best in me or in art and what they do and they are Native American..part. They like that part of themselves and they always want to create things.

Alternately, Miss Turtle seemed to struggle with her relationship with her own community. Through her own process of re-discovering her traditional American Indian values, she made a concerted effort to share her cultural experiences with members of her community.

> I mean I've created a gourd dance, corn dance, the basket dance, a turtle dance all just coming to me at night and I get up and write the steps down. And, I was teaching to my students and we have performed in so many places with that and someone may say, "she made that up." They'd watch it and I mean we've been to Chapel Hill and a lot of places and did this and some of the people (on the side?), my own people, "she made that up"...and then it hurt me because I felt like they didn't accept it but anything is made up, right? Someone had to create it or come up with it and that's what part that I try to bring across to my students, although I did make it up and you are part of carrying it out.

Miss Turtle experienced a similar feeling of not being accepted in regards to her wanting to relate to breast cancer survivors from her community who were "ashamed" to talk about their experience with cancer. Although these and other dichotomous stories were foregrounded at different parts of the interview, they seemed to shift from the retelling of personal myths "she's crazy" to becoming a role model for any woman in need of help.

Miss Sunshine

This discourse challenged me in terms of understanding how an individual can have a "true" relationship with God. Although Miss Sunshine positioned herself as a caregiver for her family, her story involved a direct relationship with God, not a passive God, but one that was active in the healing process and present in everyday life. This relationship between God and Self was simultaneously a personal, with respect to personal narratives with God, and a collective experience, through community prayer sessions.

> I was talking to the Lord and I said, um, "Lord, I don't want to die from cancer," I said, "Now what do I need to do?" And, ah, after speaking to my spirit, he says, um, "Talk to me"...we have a prayer group...and so they anointed me, prayed for me, and I've been going ever since, just going ever since.

Much of this text was layered with felt emotion, and this is where the coding of the transcripts became a challenge to separate out or categorize. This was observed in statements such as "YES LORD!" IT WAS LIKE I COULD HEAR A VOICE, NOBODY WAS IN THE HOUSE but me, AND IT WAS LIKE I HEARD him say that." where the intensity of emotion was seemingly equal with the relational focus. Similar stories about divine healing were completely coded in green to indicate there was a more significant interaction going on than sequential or descriptive narratives. This was particularly evident in the story about "pestering" God in the healing process.

During the last artmaking task, a relational text about color interpretation spoke to the level of closeness Miss Sunshine had with her own grandchildren.: "Sunshine. One of my grandchildren, you could show him these colors, 'what color is this?' Said, 'Sunshine, sunshine.' Never said yellow until he to school." This text was also pivotal in terms of the sense of relatedness that was beginning to develop between the two of us, contributing to deeper layers of meaning in the zoom model.

Cohort effect.

This level considers the effect of sociohistorical events on the shaping of life histories. These factors were not as explicit as Pampilon (1999) suggested, e.g., effect of World War II. These references were more implicit, with the exception of Miss Hope's story about receiving Chanel perfume from a brother serving over seas. The shared cohort effect in both stories was the impact of working for Indian Education and having the opportunity to introduce various cultural arts to the youth in their community. For both women, this experience seemed to shape their life histories from a cultural perspective.

Meso-zoom (storying process)

Narrative process.

This level addresses the precise style of narration, that is, how the story is being told. This form of narration can entail description, argumentation, or theorizing (Rosenthal, 1993). Traditionally, narration focuses on stringing life experiences together, in a sequential manner, whereas description can be more explanatory in nature. Argumentation involves the inclusion of external sources in the storying process while theorizing considers the participants' current perspective in the retelling. Theorizing

represents how a story is being reflected on in the present in the form of a conclusion. Much of the discourse for both women was highlighted in blue, reflecting the sequential narration of the demographic interview. These texts became gradually more descriptive and less narrative during the artmaking segment.

Miss Turtle

Miss Turtle's narrative process was evident during the demographic interview as she reflected on the events surrounding her cancer diagnosis. She theorized early in the interview about her cancer treatment in the following statement, "It hadn't been easy still, still hard some days...and I am glad that I went through all the treatment, radiation, and all, although it took my voice, and I only have one lung..um..one breast." Toward the end of the demographic interview, Miss Turtle theorized on a more personal level, while reflecting on her relationship with her husband and receiving her initial cancer diagnosis, "Ah, (sigh) it would have been nice if he would had said I love you." (laughing).

A deeper level of meaning making was observed in the artmaking portion, when Miss Turtle became more descriptive during the artmaking tasks and less sequential. Her discussion of themes such as wellness started off in general terms, e.g., "Wellness to me is something within us, um...we can go to the the doctor and, and explain our conditions..." and progressed into a deeper level of storytelling as in:

> ...and that's how I feel..like this shape, um, this person or thing that..(sigh) can help us and is something within ourselves, and I'm making it with the symbol of (sigh) not being round but long and square. (sigh) It's something that never ends.

This shift in description from general terms to personal meaning continued throughout the three artmaking tasks, extending into theorizing and argumentation where Miss Turtle seemed to be looking at her life history from a more present-centered focus, challenging

her own assumptions in the process. This transition from description to theorizing/argumentation was evident in statements such as:

> You can't let yourself think people think you are less of a person because you've had cancer, and I wish cancer on nobody..big or small, I mean it's just, just something that really destroys you, if you let it..anything can. But, cancer has come a long ways and, and for people dedicating their time and their lives..exper..letting people experiment on them and that.

The above quote captured the part of the discourse where meaning-making experiences were beginning to come together to suggest the possibility of an alternate story. This pattern of description, theorizing, and argumentation emerged at critical parts of the story where life events were observed from a more present-centered lens vs. a re-telling of life events. This was especially evident in Miss Turtle's discussion about cutting her vocal chords with a tea cup saucer that became the background story for wanting to have a voice as a performer.

> So, I went to school my first year in school I swallowed a..a tea cup saucer, which was tin (inaudible).... I went home and didn't tell my parents. (sigh) Um, I was quiet, I sucked my tongue, I was a tongue sucker instead of a thumb sucker.... I could not talk...and they just ignored it and just looked at me as a child that I guess, was retarded.... I couldn't say words..but I could write my, my, um feelings on paper.... And, I was mistreated because I could not talk or says words plain, um, it was very confusing...and I would get into trouble because I wanted to be heard....I wanted to be listened to, but then I was made fun of. (sigh) And then I got into entertaining, just being silly, and acting stupid. ACTING DUMB was what it was. I still do act dumb when I want my way.... So, that's what, why I think that I created this ability to create...things at a young age and I didn't realize it.

Although this story had deeper implications as the discourse progressed, the pattern of describing a life event (tea cup saucer) and reflecting on the present meaning (acting dumb) and theorizing about the effects (ability to create) was pivotal in setting the stage for meaning-making experiences to emerge.

Miss Sunshine

Miss Sunshine's demographic interview consisted of a detailed sequential narration of the events surrounding her breast cancer diagnosis and subsequent medical treatment. Miss Sunshine has maintained a chronological journal of her office visits since her initial diagnosis. It is important to note that Ms. Sunshine referenced divine healing as her primary intervention and declined to participate in 5-year Tomoxifen clinical trial because of adverse reactions after taking three treatments. She referenced her journal throughout most of the demographic interview citing the specific date and corresponding life events:

E: And, um, I'm just curious to know when did you first find out that you had breast cancer?

S: Um, September the fifteenth, nineteen ninety nine. The day that hurricane Floyd came through, so it's etched in my mind.

Miss Sunshine became more descriptive in her narration about her religious beliefs, surfacing early on in the demographic interview and seemingly overlapped with other lenses from the zoom model re: dominant discourses (sociohistoric perspective) and key phrases (we believe in).

> I don't know how your faith is but we believe in, um, doing what the Bible says, any sick among you, from the Book of James in the Bible, and sick among you, let him call for the Elders of the church and let them pray over them, anointing them with oil, if they have sinned, God will forgive their sins....

This particular description of the Book of James represented a unique pattern in Miss Sunshine's discourse, that is, an overlay of multiple perspectives or lenses that began to merge and form "new" lenses. This was particularly evident during the artmaking task, when Miss Sunshine's descriptions shifted from descriptions of personal testimony to spontaneous discussion about imagery, use of color, personal symbols, and ties to

spirituality, and in this respect, all lenses of the zoom model were observed simultaneously.

> ....you take the evergreen tree, when you see an evergreen tree, what do you think of? (pause) It has a PURPOSE, the evergreen tree has a PURPOSE, you know, it's life, it's vibrant, it's got limbs, it springs, it waves, I mean, you know, there's just, THERE'S A STORY in everything, in everything, starting with tree, clay, different types of soil, there's a story.

Miss Sunshine's discussion seemed to be more reminiscent of storytelling reflecting her spiritual and cultural beliefs. Within this framework of storytelling, the concepts of theorizing and argumentation in her narration were not as apparent or as significant as the degree of storytelling in her descriptions.

Narrative themes.

These are the themes that emerge in a "secondary" analysis, that is, they are uncovered and less obvious. These themes can be the untold stories or the stories that are constructed from discourse about "others," reflecting different positions throughout the life history. This lens of the zoom model was considered as a deeper level of meaning through things that weren't explicitly stated or were implied in the discourse. Meaning-making experiences as a whole were also reflected upon in terms of metaphorical content, as with Miss Sunshine's story, and the plotting of alternate stories as in Miss Turtle's case.

Miss Turtle

When asked about Miss Turtle's use of traditional American Indian healing practices, she immediately responded that she did whatever the doctor informed her to do. This incident was the only time during the discourse that she avoided discussing a topic that was presented to her. Her avoidance of this question led me to inquire about

traditional practices in the Coharie community resulting in additional interviews with Miss Turtle, which later informed my research questions in the situational analysis. Miss Turtle also avoided the question about receiving services from Indian Health Services, attributed to a possible misinterpretation of the question.

Reflecting on the deeper levels of meaning in her discourse, Miss Turtle made references to "her ability" as an artist and performer. This seemed to contrast a number of statements about people's perceptions of her as "being crazy" or "silly." Miss Turtle made a poignant comment about the parallels between changing colors of clay and changing parts of Self, which hinted at a shaping of an alternate story.

> E: (laughing) Okay. So, what, um, made you pick the clay..to sculpt wellness?
>
> T: It looks more like sky or earth and, um, the color does..that and then, this color reminds me of myself, cause it blends in with most anything. You can put any other color with it and blend in and make it look attractive or create what you are after. That make sense?

Miss Turtle's alternate story considered her traditional American Indian values, which manifested in her traditional performances and visual art forms. This was apparent during the artmaking tasks where Miss Turtle was symbolically experiencing her changing concept of self. This meaning-making experience seemed to be contrasted by Miss Turtle's belief that she did not fit in at times or was not accepted by her community because of her assertion of traditional values.

E: And, and just sculpt a form or something that reminds you of wellness. Looks like, feels like wellness.

T: Okay (whisper). And this looks like here, being here, too, also. And, I never was a person that was like..and I think I get misunderstood because of that.

Miss Turtle's incomplete description (person that was like…) seemed illustrative of her belief that she was not accepted, and was somehow different than the women in her

community. She alluded to this belief consistently throughout the dialogue but never fully described how she was perceived. Her "true Self," or the alternate story that emerged, seemed to be the story that was explored both experientially through the artmaking and her subsequent descriptions.

The artmaking seemed to play a pivotal role in the meaning making or storying process. This was evident in Miss Turtle's depiction of her life story of "how I, I, I was accepted and where I came from there until now...." This sequentially-related figurative drawing elicited stories about physically losing her voice in her grade school, finding her voice later in her teens through drama class, and the "real" person who she feels like she is today.

> And it's STILL, I guess, in me. I don't know what, what it was the reason why I wanted to be heard. And (inaudible) I guess they would still think I was crazy, I don't know, in a good way..you know (hushed voice).... By being (pause) silly looking (hushed voice). (long pause) This way I have self-esteem about myself (hushed voice). (pause) And it make me feel important (hushed voice). Like I was somebody, yet I was hiding behind...feelings that I could not bring out from, from being the real person that I that I am (hushed voice).

The "real" person who Miss Turtle is today was further defined by her experiences in Indian Education and teaching cultural art forms to the youth in her community. However, her true Self seemed to emerge in her discussion about the "inward" thing that Native Americans have.

> It's like, you ever been to church and have this..song singing where the feeling of spirit, that kind of inward thing and you may feel it and I might be sitting beside you and I don't get it. You understand me? This is what happens to someone..that has that ability that she (teacher) says I have. I was born with it but never knew about it. I can listen to it and where a few songs and it comes to you the way you want to bring it out, and I can't teach it to you.

It was at this juncture, when Miss Turtle was engaged in a meaning-making experience that her artmaking and storying process became more emotional in her description.

Moreover, by accessing parts of her "true" Self, she was able to process emotions that were deeply intertwined with her cancer diagnosis, reflected in the following:

> So, um, you are in and out with that feeling, that's what the gap is about in here, um, you are afraid you are going to loose you family, their feelings for you and they're afraid to help you because they don't know how to handle it. Yeah. Once you get um, over that cycle..and you take all of this feelings inside, um, you kind of moves, you move in and out of it but you still have that fear that it will come back one day....

This is when the lenses of the zoom model became less defined and more "out of focus," so to speak. The emotionality of this text was the culminating experience of the entire interview.

Miss Sunshine

The sense of connectedness to community and social networks encapsulated Miss Sunshine's entire discourse. This connection extended beyond her tribal community, affiliation with her church, her place of employment, and her social advocacy work. Her relationship with God was central to all aspects of her life; moreover, this relationship was paramount in her cancer treatment a part of the healing process, e.g., "divine healing." The key phrases that were apparent in the discourse, incorporating the use of "we," reinforced this sense of connectedness.

This connection was certainly in the foreground throughout the majority of the text. However, as the conversation continued, there seemed to be a shift in meaning that was seemingly prompted by the discussion about clay. The demographic interview started off being more formal, and this was to be expected since Miss Sunshine and I had just met. Because of this lack of familiarity, questions, such as traditional American Indian practices, were not expounded upon and rather, surfaced spontaneously toward the end of the discourse, reflecting a sociohistorical perspective.

It was the story that emerged in the background, Miss Sunshine's involvement with Indian Education, which seemed most salient in terms of meaning-making experiences. This discussion emerged literally from addressing my observations about her facial expressions surrounding the clay. This occurred at three different points in the interview and each time I reflected upon her nonverbal response. Ultimately, the clay became a powerful metaphor in the storying process, reflecting a deeper cultural meaning. This interaction also set the tone for eliciting deeper meaning in the artmaking experience.

> E: So how come when you look at this clay, you're like...
>
> S: Well, when you get into clay, you know, you've really got to have time to let your hands feel it..and know that you know, with clay that's mother earth and you're feeling it and you're, you, you, you need to, um, take your time and, and incorporate it into your, to whatever your mold is, you know? So that it's an expression of, of yourself, what, what you trying to portray, but you gotta feel it with your hands first.
>
> E: So are you saying like it takes more..felt experience, more of an emotional experience?
>
> S: Yes, yes with me. And that's the way when we were, when I was working with the children, I'd tell then to feel it, you know, what's it saying to you, you know, what how's, how's it relaying to you or do you see it as something growing from it because clay comes from the ground, and, and all things start here and go up, so it has to grow....

This interaction also had implications for the transactional aspect of the zoom model, where the collaborative relationship impacts meaning-making experiences.

Key phrases.

According to Pamphilon (1999), these phrases are illustrative of the "hegemonic discourses," reflecting a collective positioning in society. In context to the American Indian women, key phrases also had a cultural text, providing a context for the

collectivist thought, such as in use of "we" to represent Self or "I." Key phrases are often repeated and appear to be part of the vernacular, reflecting the collective experience.

Miss Turtle

The key phrases that were repeated throughout Miss Turtle's discourse alternated between questioning: "What would you like for me to say?", "What else?", "Does that make sense?", and "Now what?" and phrases that were part of the southern vernacular: "you know," "it's a deep thought," and "deep subject." Phrases that reflected Miss Turtle's sociohistorical roots were evident in comments such as "You've got a lot to live for," and "Deal with it." The use of "we" was also evident throughout the discourse, reflecting Miss Hope's collective positioning as a woman and as part of her cultural group.

Miss Sunshine

The key phrases from Miss Sunshine's discourse incorporated the use of "we" throughout: "we believe in," "we know," "we were a joyous people," "we are praying people," "we hear," "there we go," and "that's the way we were." This emphasis on "we" seemed to be reflective of a collective perspective. Colloquial phrases such as, "you know" or "our people" were also referenced but not as dominant as the use of "we."

Micro-zoom (oral aspects of storying)

Pauses.

This is evident in the transcription process where the length of the pause is recorded, e.g., two dots = less than half a second, three dots = one second, and four dots = one and a half seconds (Poland, 2003). The purpose in recording pauses is to consider the nuances in the storying process and the implications on meaning making.

Miss Turtle

The degree and duration of pauses noted in Miss Turtle's transcript was not as apparent as her tendency to whisper when discussing both positive and difficult events; parts of these stories were almost inaudible at times. A pattern of whispering emerged when discussing themes related to support: "...I think he felt that I was going to leave him and he couldn't deal with that..so, it wasn't much support..other than God." This pattern was also evident in questions regarding the art tasks: "White (whisper) xx xxx xxxx?" and continued when discussing her past accomplishments:

> Sometimes we walk off with 25 to 30 ribbons out of 70 or 75, you know, and..would be my students xx xx (whisper). I just had confidence in them and then I worked with what they had. That's what we did. I didn't know I had this ability after until I got into my 50s xx xxx (whisper) near 60.

The frequency of pauses and sighs seemed to increase with the introduction of the art tasks. While in process, the affective quality of the conversation was more pronounced evidenced by the marked increase in the use of a hushed voice, inaudible words, and longer pauses.

> (pause) This is the way I saw it in here, the day that he showed me my mammogram of the picture, it was a black dot and once I saw that dot, and I asked for help..it took control of my life (hushed voice). (pause) And it took over...it took over my life (pause) several months...(xxx) change.

Moreover, the incidents of tapping, slapping hand on table, and other nonverbal gestures increased in frequency, reflecting the affective quality of the art making.

Miss Sunshine

The occurrence of pauses, sighs, whispering seemed to increase while Ms C. was engaged in the art process. This interaction with the art materials appeared to elicit a

different response, perhaps more internal, evident in her inaudible whispers. Her pauses were also more noticeable, meaning they increased from two-three seconds to more than four seconds.

> I'll get this to use on my face. A BIG SMILE (inaudible whispering). I don't see any brown. I'll use black. (pause) Let's see her (whispering). (pause) Give her a pretty waist here, she's not fat, you know (laughter). Pink pants. (pause) I have twin grandchildren, a girl and a boy, and pink is her favorite color, pink and purple. She's (xxx xx xxx) that's her favorite color.

In the above quote, Miss Sunshine's inaudible whispers were indicated in two different formats, (inaudible whispering and xxx xx xxx). The latter format was used to identify how many words could be deciphered.

Miss Sunshine spoke in a hushed voice when elaborating on personal history or storytelling. The use of a hushed voice seemed to differ from whispering in terms of being more audible and less of an internal experience.

> (hushed voice) They fixed up their stuff...and you can't find, you know, with so much industrial people coming in here building plants and everything and all that stuff got lost, you know.

These "hushed" conversations surfaced more during the latter part of interview. The artmaking seemed to be a catalyst for deeper conversations. Overall, the nonverbal responses (pauses, whispers) displayed the most variability during the actual artmaking.

Emotions.

The focus here is not only on the predictable emotions associated with the storying process but also the incongruent emotions or response to specific themes. Throughout all the lenses, the juxtapositioning of emotions with the discourse are considered on meaning-making experiences as well.

Miss Turtle

From my perspective, Miss Turtle seems to speak passionately about her life experiences. The entire discourse was punctuated with some degree of emotion as well as laughter. Laughter was key throughout even during difficult parts of the storying process. In this respect, the degree of laughter between us could have been viewed as an indicator of anxious feelings or as a defensive gesture. Rather, the laughter seemed to be reflective of her worldview. The presence of incongruent emotions was virtually nonexistent, almost as if there was no reason to mask or disguise her emotions. Reflecting on the transcript, the entire discourse could have been coded in red text. The sections where I highlighted her emotional responses were more suggestive of a cathartic experience than an emotional tone. This was especially evident in her culminating drawing of her cancer experience. While in process with this task, Miss Turtle had minimal eye contact with me, spoke and made art simultaneously, identifying each "emotional" layer of her concentric designs. She later in the discourse inquired if I had gotten meaning of each layer down, emphasizing the importance of this experience.

> And cancer destroys you..it destroys you on...mentally and physically. (pause) Regardless of what treatment you're after or got, there is still a let down in it..and it takes over your body and makes you totally a different person, it makes you angry, it makes you, um just bitter towards the whole world....I hope you can understand the difference in this (referring to her image), the, um, the colors..mean different changes, different phases I went through but this is the cancer this will never, it goes back to that.

It was during this last artmaking task that Miss Turtle became tearful, appearing to release her emotions about this experience. This was also an indication that the interview was coming to a close.

Miss Sunshine

Laughter was the most consistent emotional response elicited throughout the entire discourse, reflecting Miss Sunshine's positive attitude, belief system, and sense of humor. This degree of laughter seemed consonant with American Indian communication styles and was not viewed from a Western perspective as a defense gesture or as an indication of anxious feelings (Sue & Sue, 2008). Miss Sunshine conveyed her life stories and thoughts with feeling, meaning her responses were not intellectualized. Rather, she spoke with great conviction about her spiritual beliefs, life experiences, and reflections about life. There was"soulfulness" in Miss Sunshine's thoughtful words. Miss Sunshine seemed to be the most expressive in her retelling of the following experience:

> YES LORD! IT WAS LIKE I COULD HEAR A VOICE, NOBODY WAS IN THE HOUSE but me, AND IT WAS LIKE I HEARD him say that.

Interactional-zoom (dynamics of the co-construction)

Transaction.

This is the essence of the co-construction process, the manner in which self is seen and understood. The researcher in this collaborative experience is engaged in the interview process, not just as active listener but one who can elicit certain subtleties in the storying process. It is also through this collaboration that meaning making can occur in the retelling of life history.

Miss Turtle

Overall, the co-collaboration process between Miss Turtle and I was very fluid because of our familiarity with one another; however, this was not the case during the

demographic interview. Miss Turtle respectfully refused to discuss questions regarding Native healing practices. This clued me in that trust needed to be established before inquiring about Native practices, considering the level of intimacy associated with the narrative interview process. As a co-collaborator, I was attempting to have an active role in the interview process by asking probing questions about concepts such as wellness, while being mindful of traditional values such as listening and not interrupting while others speak. "Speaking" through Miss Turtle's metaphors seemed to deepen the level of co-collaboration. Dialoguing with her metaphors seemed to enable to me to access different stories about her life, moving beyond the constructed myths, e.g., "she's crazy," to becoming a leader in Indian Education.

Miss Sunshine

Because of my lack of familiarity with Miss Sunshine, I found it challenging to locate myself in the conversation. Much of the demographic interview had a tone of "I'm still getting to know you." At times my questioning felt too direct or premature as if I were pushing the transaction between us. It was our discussion about the clay that ultimately led to a more genuine transaction. Had I not "stayed" with the clay, the rich stories about nature, spirituality, and wholeness might not have surfaced to the level that it did. As a result, the co-collaborative aspect seemed more real during the artmaking tasks which opened the way for more personal stories to be experienced.

Reaction.

This is the researcher's emotional response, allowing for self-reflection to occur on different levels. These reactions can be on the surface with respect to empathy as well as on a deeper level as with anger and grief. Reactions are part of the subjective

experience associated with narrative inquiry and permit researchers to assume a critical gaze on their own assumptions, values, and biases. My personal responses to both participants were recorded as images in my visual journal (Figure 1 and 2). After recording these images, I engaged in reflective writing as a form of self-reflection.

Miss Turtle

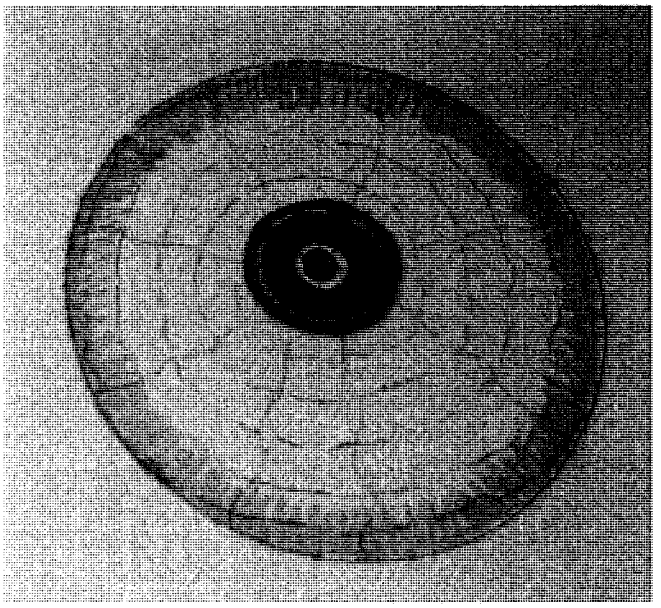

Figure 1: Visual Response to Miss Turtle

> You are the spider woman who weaves your people's stories together. You sit at the center, the heart of the web waiting for others to call your name. Some are afraid of your ways, fearing the energy you weave, while others sit back in silence and share your pain. Alone but wanting to connect, Spider woman find your path to center and back.

When I first met Miss Turtle, a spider made an intricate web outside my front door. This spider remade its web every night for several months before moving on. The experience came to mind for me when I first saw Miss Turtle's gourd art incorporating a "dream catcher" web and a red bead. This experience also coincided with a story that I heard from the Coharie about a similar spider who weaves intricate webs to catch lost children who ventured out in the night. This was also the same story, when shared

outside the community in a therapeutic setting, led to a child being "diagnosed" with a psychotic disorder. These overlapping spider stories seemed to parallel Miss Turtle's experience of being misunderstood ("she's crazy") for attempting to weave together a cultural legacy for her people.

Miss Sunshine

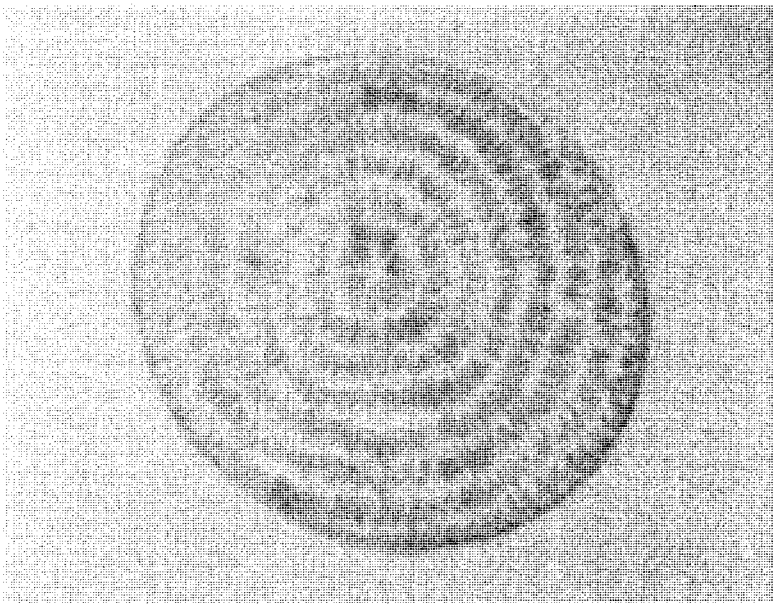

Figure 2: Visual Response to Miss Sunshine

> You are the radiant sunshine spreading good will to all. Wellness is your message in spirit, mind, and body.

In preparation for this study, I completed the art tasks on my own to experience what my participants might encounter. The image that I depicted for wellness (yellow concentric, radial mandala) came to mind, and literally felt, during and after my interview with Miss Sunshine. She seemed to embody the sense of holism that is referenced in much of the literature on harmony.

Situational Analysis: Narrative Discourse

The in-depth discourse analysis from the zoom model provided groundwork for establishing the social world for Miss Turtle and Miss Sunshine. The second level of analysis in this study, narrative discourse situational analysis, comprises three levels of "mapping" as part of a more postmodern approach to grounded theory than the traditional constant comparative analysis (Clark, 2005). The first level of mapping entails a "messy" situational map or a random means of open coding. The second level consists of constructing social worlds/arena maps leading to the development of a project map. Third level is a positional map reflecting the different positions from the deconstruction process synthesized from the levels of mapping. In this respect, the lenses of the zoom model served a method of *knowing* the intricacies of the data, paralleling the macro, meso, and micro focus of the narrative discourse analysis. The "findings" from the zoom model discourse analysis were mapped out into two separate situational maps, representing Miss Turtle and Miss Sunshine's life histories, and then compared to situational maps created from the supplementary data sources, consisting of a transcribed interview with a Waccamau Siouan health coordinator and an audio- and video-taped interview with a Waccamau Siouan healer.

The resulting four situational maps were further compared to one another as part of the second level of mapping, the social world/arena maps. Three of the five research questions were then "situated" in the social world/arena maps as the central topic and the narrative discourse from all 4 sources were "positioned" around these questions. The social maps were reconfigured into a summarizing positional map "situated" around the fourth research question. The relational aspect between the narrative discourse and

research questions was represented as a continuum in a final positional map. The fifth research question focusing on the artwork and storying was analyzed using guidelines specific to mapping visual narrative discourse.

Situational maps.

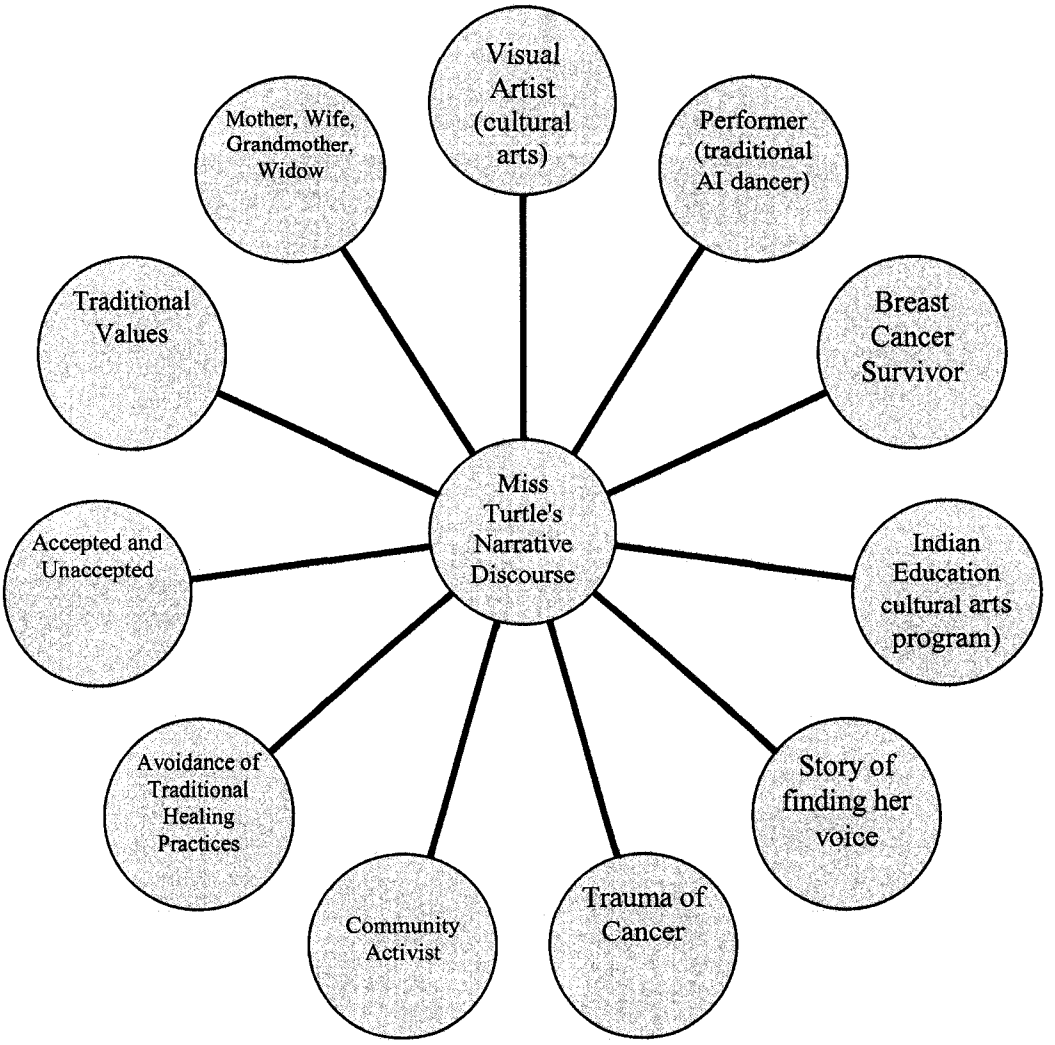

Figure 3: Narrative Discourse Situational Map (Miss Turtle)

Miss Turtle is represented in two maps. The first map considers the dominant positions reflected in her narrative discourse. These positions were viewed in relation to gender roles, traditional American values (Indian Education), personal values (activism, art, performance), and cancer survivorship. A theme that was not expressed, e.g., traditional American healing practices, was also situated in this map. This practice was addressed in a follow-up discussion, as a form of a member check, represented in the following map.

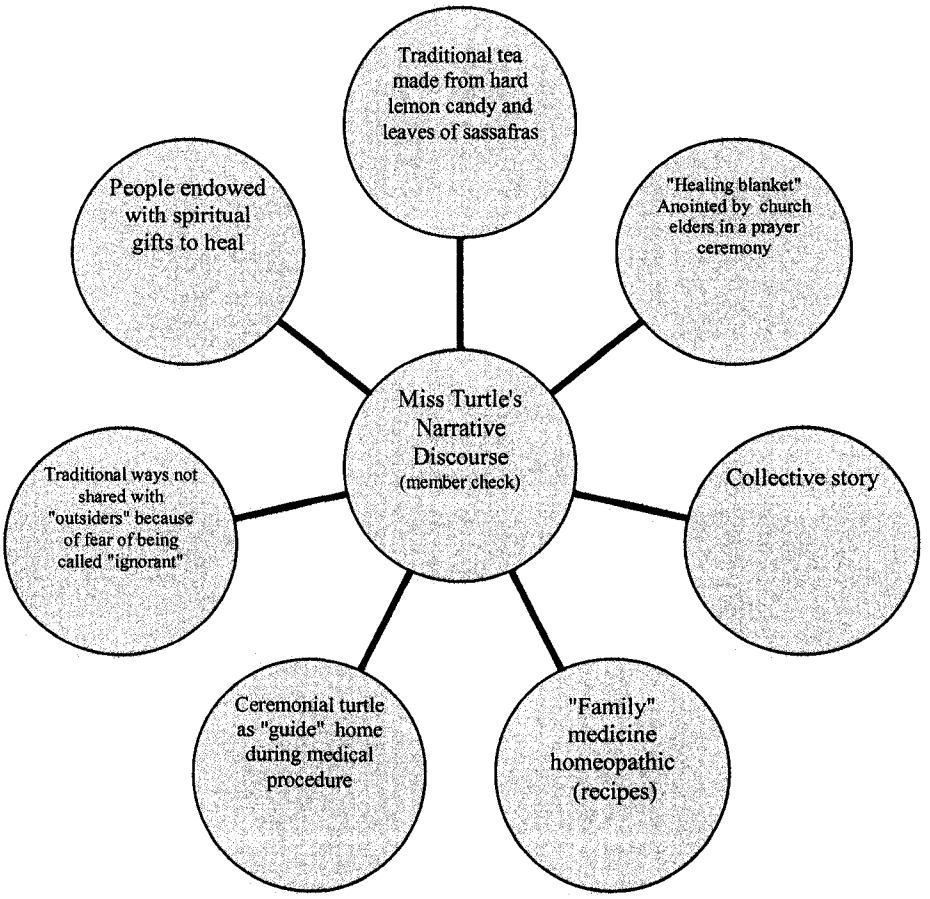

Figure 4: Narrative Discourse Situational Map/Member Check (Miss Turtle)

This follow-up map considers Miss Turtle's position on the use of traditional American Indian healing practices. The context in which this story was told needs to be

stated because it reinforces how Native people are reluctant to trust outsiders with this knowledge for fear of being called "ignorant" or "stupid." I referred to this experience in the map as a "collective" story because it literally involved the participation of two community members. These stories of traditional healing practices were "whispered" over a meal in a restaurant. From this experience, I created a random map of multiple positions resulting in an organized situational map. These stories were compared to the stories from a similar situational map from Miss Sassafras, a Waccamau Siouan healer.

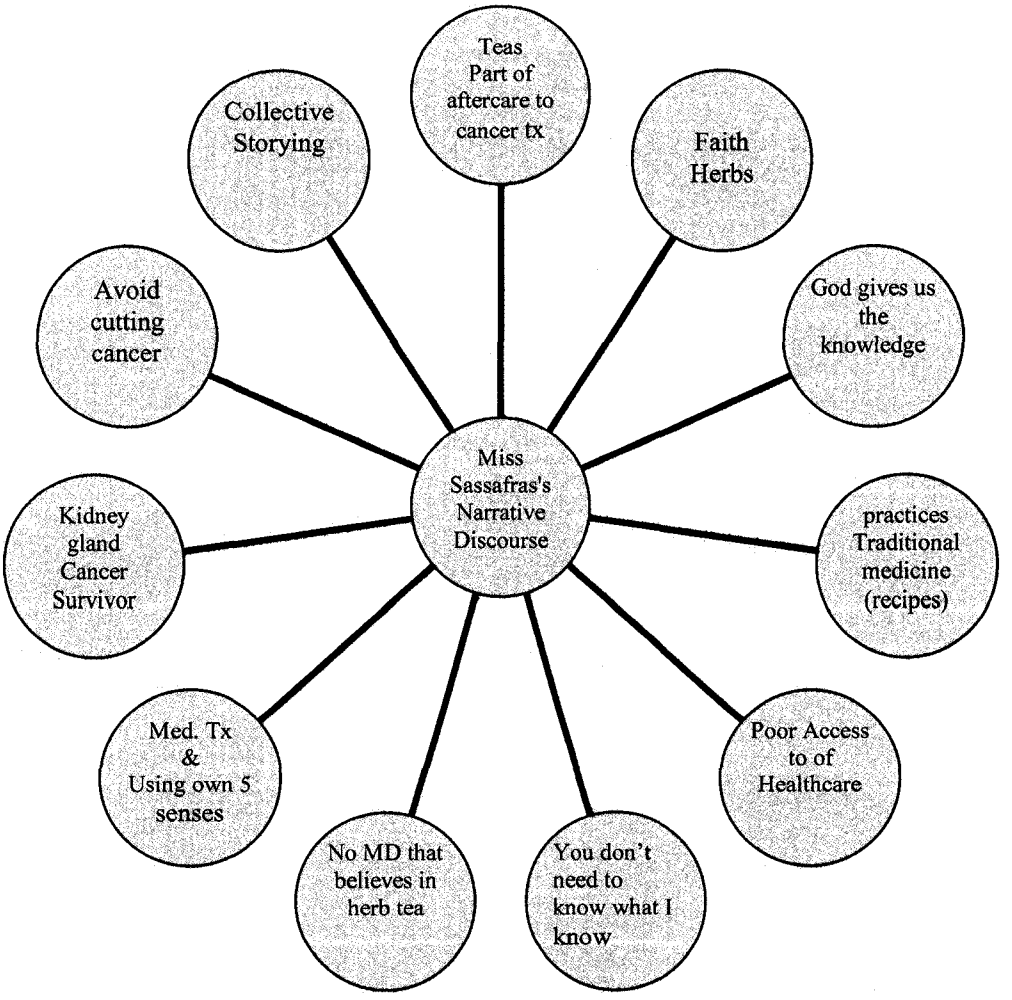

Figure 5: Narrative Discourse Situational Map (Miss Sassafras)

My experience interviewing Miss Sassafras was reminiscent of my follow-up part of a collective experience with other people from the community, and in Miss Sassafras's case, a tribal representative served as the "expert" witness. Reviewing the situational maps from Miss Turtle and Miss Sassafras, I was able to position the role of traditional healing practices in cancer care. The text from both narratives provided a rich understanding of the sociohistorical factors linked to these practices ("family recipes"), the spiritual beliefs imbued in these traditions ("anointed healing blanket"), giving voice to a marginalized belief system (e.g., "No doctor that believes in herb tea"). These discourses served as a means to position the traditional healing practices that were not addressed openly in the zoom model discourse analysis.

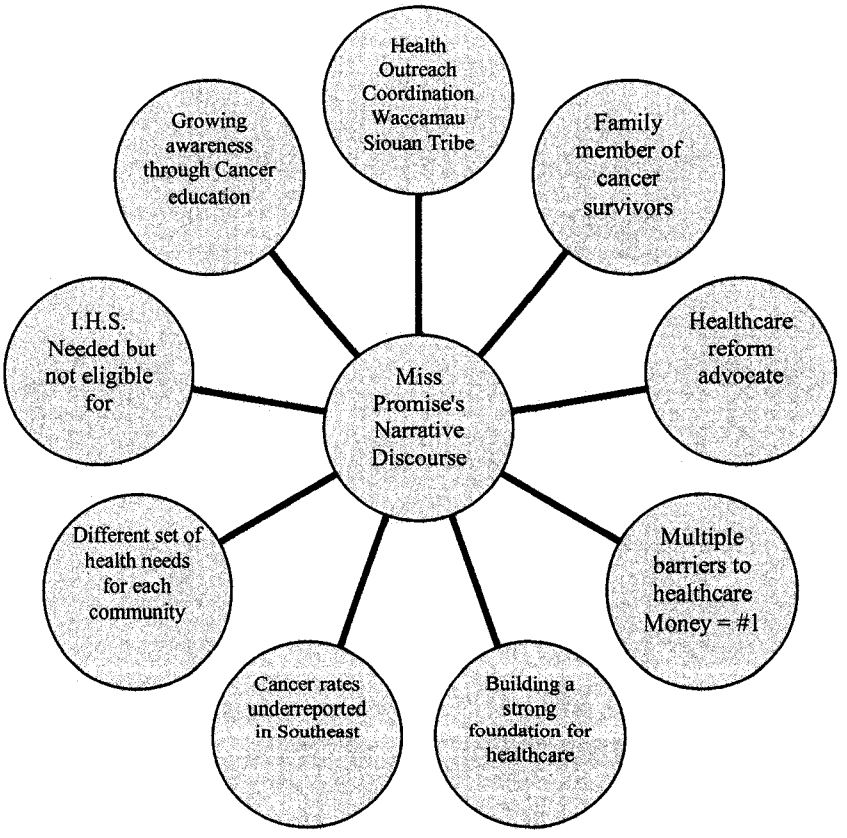

Figure 6: Narrative Discourse Situational Map (Miss Promise)

The interview with Miss Promise was conducted two years prior to this study in an effort to learn about the incidence of cancer in these communities. Miss Promise's interview was included as archival data to position the perspective of a Native Health Outreach Coordinator. Her interview was initially transcribed and analyzed using the zoom model as a class assignment for my Narrative Inquiry course. Reflecting on the themes generated from this discourse analysis, her position was quite different from the other four interviews in terms of addressing the disparities in healthcare, e.g., poor access, lack of insurance, and few resources. Moreover, her interview supported the current literature on cancer care and health disparities for American Indians, while addressing the barriers specific to southeastern tribal communities, e.g., underreported cancer rates, generalizing needs. More importantly, she addressed the lack of eligibility for Indian Health Services because of being from a state-recognized tribe. Her position also reflected a growing trend of cancer education and the impact of these initiatives in the Waccamau Siouan community.

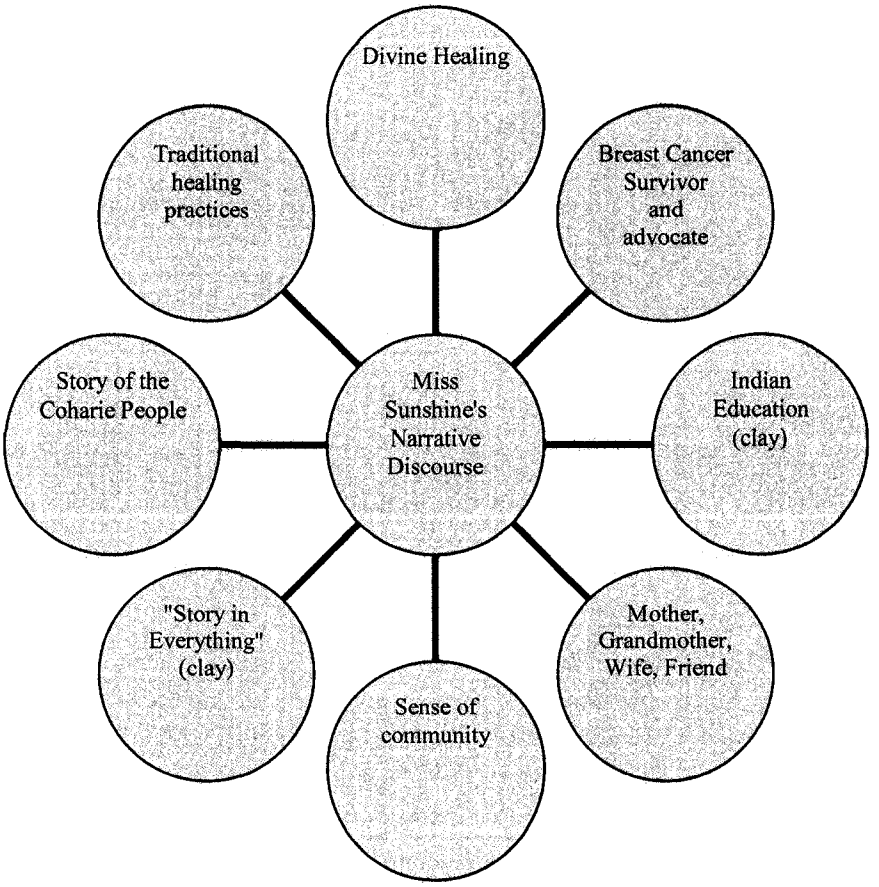

Figure 7: Narrative Discourse Situational Map (Miss Sunshine)

Miss Sunshine's situational map seemed to touch upon different positions represented in all the maps, reflecting a holistic constellation. Miss Sunshine was positioned as an advocate for her community, e.g., her involvement in her church and Indian Education; this role extended into other areas such as cancer awareness and support. Miss Sunshine's narrative discourse and resulting map seemed to weave together the art of storytelling, the importance of cultural arts (clay), a strong sense of community, a sociohistorical focus, and the interrelationship between divine healing, traditional American Indian and modern medicine. This interrelationship was a common thread throughout all the situational maps and became a central theme in the social worlds/arena maps.

Social worlds/arena maps.

1. How do Native American women, diagnosed with breast cancer, experience their treatment in medical institutions?

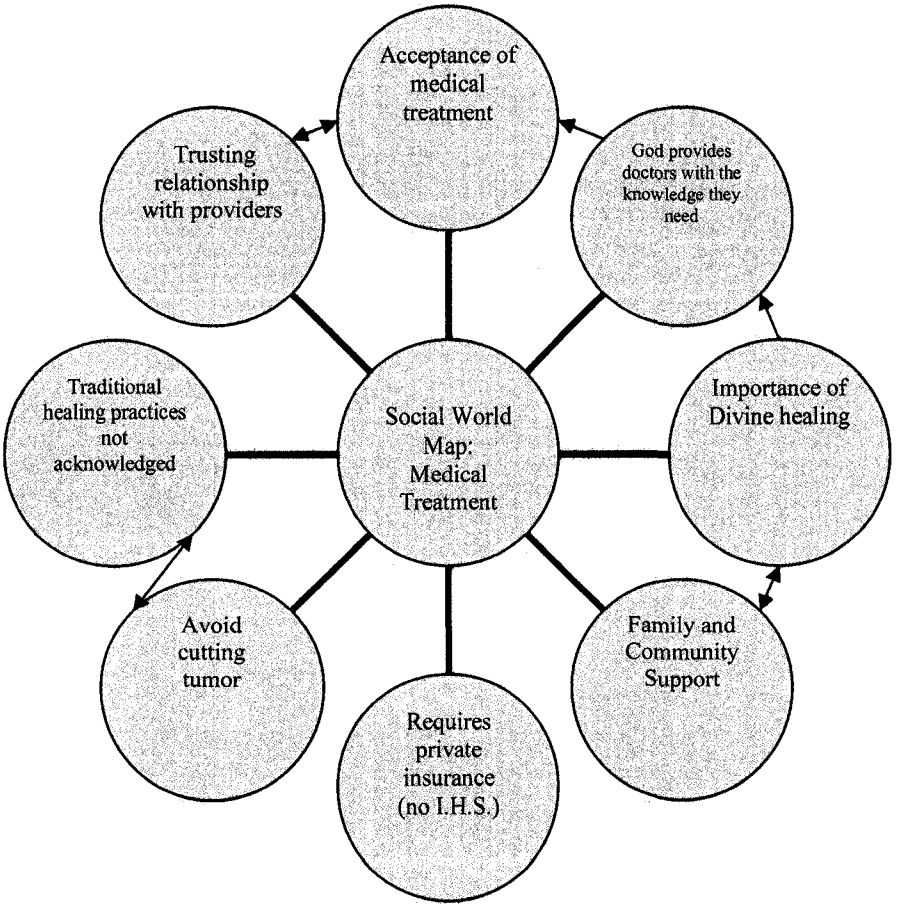

Figure 8: Medical Treatment Social World Map

From the perspective of Miss Turtle and Miss Sunshine, two breast cancer survivors, their experience with their cancer treatment was grounded in their belief in God. Miss Sunshine directly addressed this in her emphasis on divine healing to augment medical interventions. A trusting relationship with providers was implicit in all forms of care, even if the provider was not culturally aware. Moreover, these providers were imbued with the "gifts" that God wanted them to have to heal. Overall, there seemed to

be a stated acceptance of modern medicine, based on these narratives describing full participation in medical regimen.

What was not so explicit in the majority of the narratives, was the use of traditional healing practices. Through the aforementioned "collective" storying process, these narratives were able to be heard, giving voice to "unaccepted" belief systems. Miss Sassafras., in particular, characterized that she didn't feel the need to "waste her breath" on telling someone (provider) about her family recipes. Her experience was that she had never met a doctor who believed in herb tea. Even in traditional practices, faith was also the catalyst behind their potency; otherwise "you'd be drinking plain old tea." Throughout her discourse, she emphasized the importance of not cutting the tumor because she had "heard" from a provider that exposure to the air would make it grow like fire. Because of this, she opted for prolonged radiation treatments instead of surgery. It was not clear if this understanding stemmed from a cultural belief or was somehow erroneously conveyed by a provider.

Family and community support were a given but these relationships in the wake of a cancer diagnosis were not as apparent, that is, there was a degree of secrecy. The inclusion of cancer education, e.g., Cancer 101 curriculum and related healthcare initiatives seemed to contribute to this change in supportive care. Miss Promise provided an alternate narrative in the "cost" of not having access of Indian Health Services. Her understanding seemed to be directly linked to her exposure to different healthcare systems through her role as Health Outreach Coordinator, whereas Miss Turtle, Miss Sunshine, and Miss Sassafras did not reference a need for or an understanding of I.H.S.

2. What are their beliefs surrounding wellness?

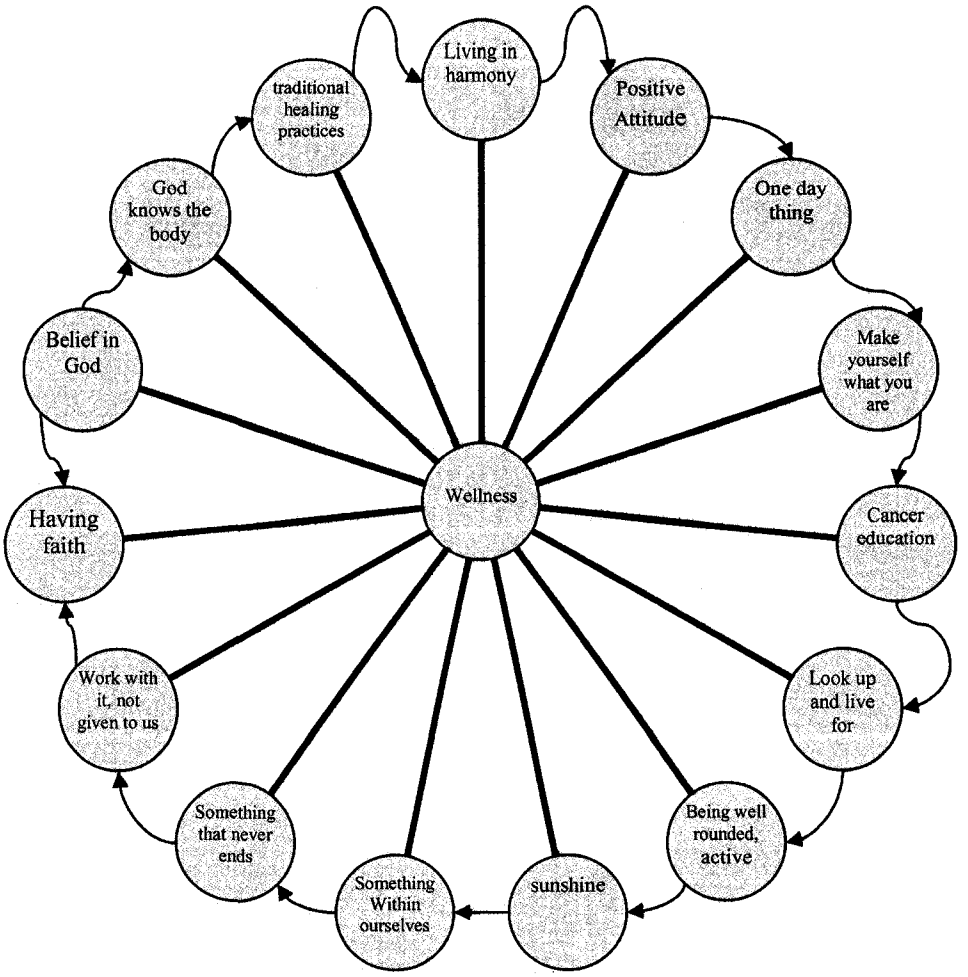

Figure 9: Wellness Social World Map

This configuration was perhaps the most complex, one that could have easily carried over into other social worlds, reinforcing this notion of wellness as a core belief. This complexity was attributed to the number of references made by all sources about the different dimensions of wellness. The first dimension or primary position seemed to suggest that the concept of being well was correlated with having a "positive attitude," living in "harmony," being "well rounded" and "active." This belief system seemed to typify the situational map represented by Miss Sunshine's discourse, suggesting a holistic framework. A second dimension was the emphasis on prevention as a precursor to

wellness, e.g., cancer education, something to work for (not given), one day thing. A third dimension that surfaced infused the notion of faith and traditional beliefs. The final dimension represented in this map reflected personal responses to wellness, e.g., "sunshine," "look up and live for," "something within our selves," reinforcing aspects of all these dimensions outlined.

3. What are their beliefs surrounding physical illness?

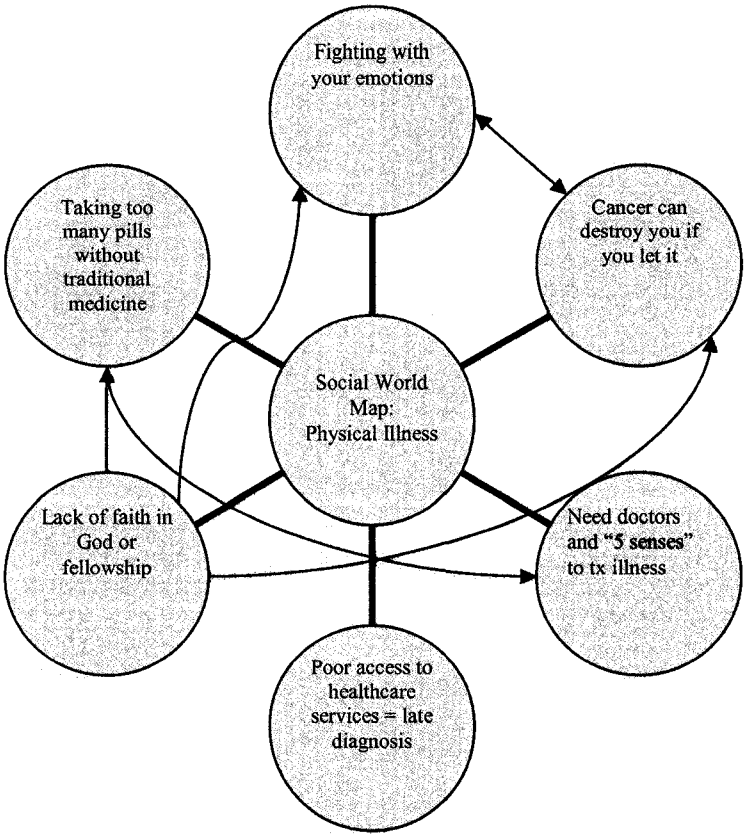

Figure 10: Physical Illness Social World Map

Beliefs regarding physical illness were mentioned in all the discourses but not expounded upon in as great of detail as wellness. In general, physical illness was seen was the absence of all the factors contributing to wellness. Spiritually and culturally speaking, this map synthesized the primary responses representing a lack of faith in God,

treatment, and traditional practices and the omission of traditional recipes in combination with modern medicine. Moreover, the notion of not maintaining a positive outlook during cancer diagnosis and treatment was linked to further health-related problems. Systemically, physical illness was correlated with poor access to healthcare, being underinsured or having no insurance, resulting in a late stage cancer diagnosis and high mortality rates.

Project map.

How does this belief system affect their view of treatment?

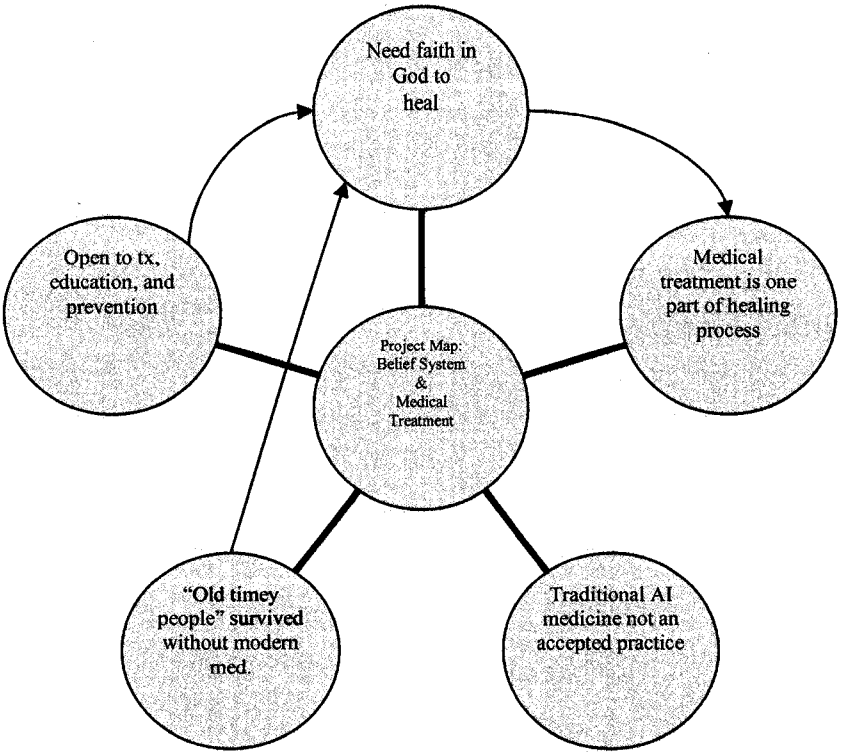

Figure 11: Project Map

The positioning of this map around this research question seemed to summarize all the social worlds into a culminating project map. The juxtapositioning of traditional

beliefs and practices with modern medicine resulted in a three core beliefs: 1. Faith in God as a healing mechanism, 2. Traditional medicine and practices work in tandem with modern medicine, 3. Lack of acceptance for traditional practices and understanding of their sociohistorical importance.

Positional map.

A positional map representing five dominant positions considered in the project map were constructed along two continuums: Axis I, continuum of traditional American Indian healing practices (accepted—unaccepted) and Axis II, continuum of cancer-related medical treatment (awareness—lack of awareness).

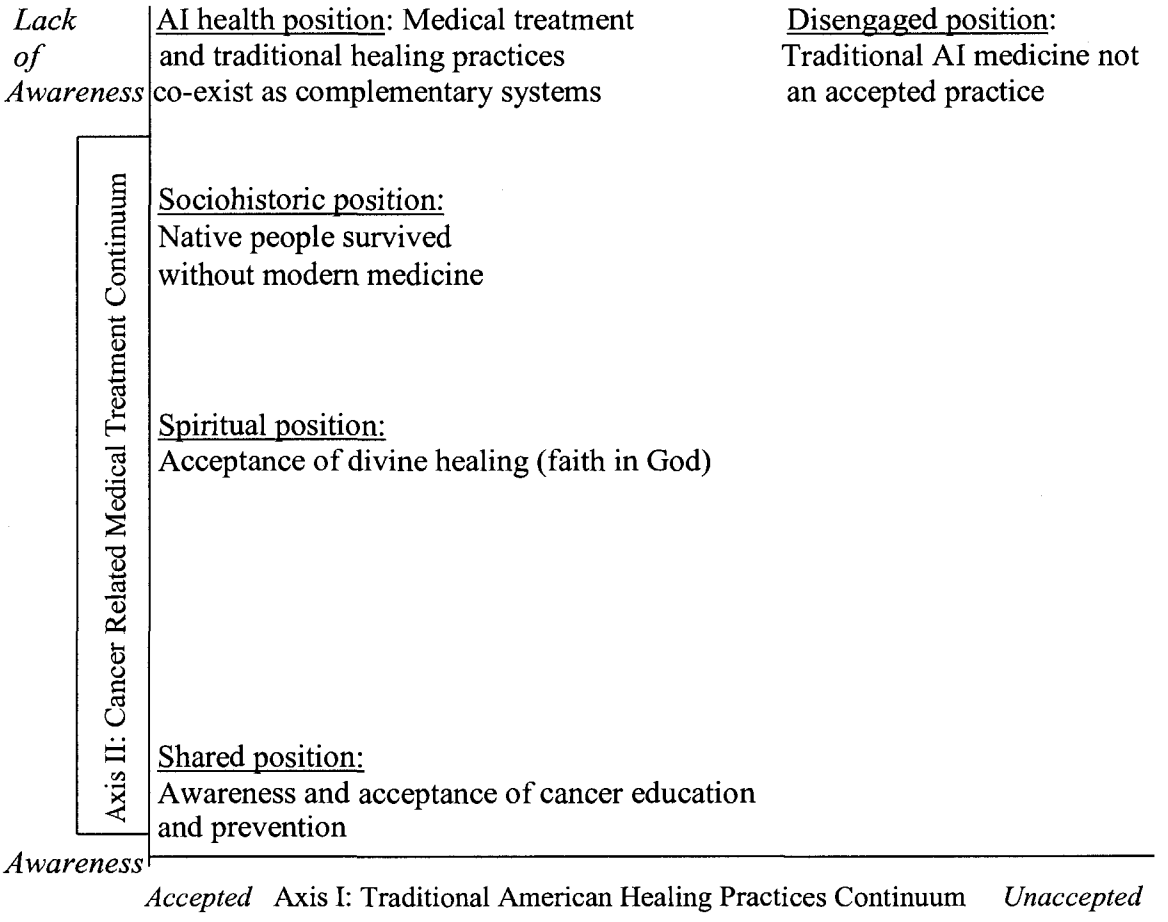

Figure 12: Narrative Discourse Positional Map

At the point of convergence between acceptance and awareness, there was a shared position on cancer education and prevention. This position reflected the growing awareness of the need for and acceptance of cancer initiatives in southeastern tribal communities. Conversely, there was a divergent viewpoint indicated in a "disengaged" position reflecting a lack of acceptance of traditional AI medicine in mainstream cancer treatment, attributed to a lack of awareness of an AI health position. Along the continuum of cancer treatment, there were three AI positions representing a spiritual position: acceptance of divine healing or faith in God as a catalyst for healing; a sociohistoric position: Native people have survived for generations without modern medicine; and a health position: medical treatment and traditional healing practices co-exist as complementary systems. Although as accepted positions in AI communities, there was little awareness, if any, of the interplay between these positions in mainstream cancer care. What was not considered in this map was a position of awareness, from the continuum of mainstream cancer care, of a position of feeling unaccepted because of traditional values held.

Situational Analysis: Visual Discourse

This form of situational analysis is similar, in terms of format, to that of mapping narrative discourse. This process considers the random and structured situational maps, social world/arena maps, and a positional map. Before the analysis, an "opening" of the visual data is recommended, consisting of deciding, locating, collecting, and tracking (Clarke, 2005). In this respect the "best range" of images is sought to represent the situation or focus of the inquiry. To facilitate this process, a log is maintained tracking issues related to "provenance" (p. 224).

In regards to this study, the images consisted of art work created in response to specific three main art tasks and eight corresponding questions during the narrative inquiry. These images were returned to the artist immediately following the interview and documented using a digital camera. The images were then uploaded and stored on a hard drive and copies were burned to a CD. A copy of the CD and images were sent to the participants along with data from their verbal interviews. In preparation for the analysis, I formatted the images and printed 8.5" x 10" color copies onto glossy photographic paper. There were 12 images total considered in this situational analysis: Four art forms resulted from Miss Turtle's interview, three images were created during Miss Sunshine's interview, and five additional images from a pilot interview with Miss Hope were included to assist with multiple readings.

Prior to the analysis, a form of entering and memoing the data is required, comparable to methods from grounded theory (Clarke, 2005). Memos are written in a narrative style and focus on literally what is being observed in the visual data. This process is broken down into three stages of memoing: locating memo, big picture memo, and specification memo. The locating stage concerns how the images fit into the situation. The big picture memo has three distinct parts: 1) first impressions (represented in list form), 2) the big picture (intertextual parts), 3) the little pictures (textual parts). The specification memo (Appendix M) enables the researcher to observe the images in multiple ways through a process of deconstructing the image.

The layers of memoing assisted with "opening" the data and was comparable to the zoom model where the researcher observes the data from different perspectives. Five different sets of memos were created for each image prior to creating the situational

maps. An organized situational map was created for each art task and was "situated" based on visual discourse related to the three main art themes of: cancer and cancer treatment, wellness, and open. Nine situational maps were created in total, three maps per individual. The pre and post circle drawings were omitted from the mapping procedure because this measure was not used consistently in the two interviews.

Artwork, memos, & visual discourse situational maps.

MissTurtle

Figure 13: Wellness Task

- Locating Memo: created in response to wellness.
- Big Picture Memo

First impressions:

Formed from different parts
Two distinct forms
Geometric configuration (elongated and rectangular)
Figurative with circle emphasizing a breast-like form
Flattened perspective

Big picture: Figure was created possibly in response to discourse about being natural and round like the earth. Conversely, a long rectangular shape was formed to represent "something that never ends."

Little picture: two separate configurations with no direct connection

- Specification Memo

Selection: clay selected to depict a form related to wellness

Framing: (inclusions, exclusions, cut off's) implied in the construction of the frame-like configuration of rectangular forms.

Featuring: (foreground, middle ground, background, present) attached round shape on figure seemed to be foregrounded (protruded). The forms appeared to be on the same "ground" with no differentiation.

Viewpoint: (close-up, medium shot, long shot, low angle, high angle) frontal viewpoint and flattened perspective.

Light: None implied.

Color: natural (gray clay).

Focus/Depth of Field: frontal, flattened perspective.

Presense/Absense: absence of right breast-like form on full-scale figure.

Intended/Unintended Audience(s): form in the background (ball of clay) was discussed as something that seemed reflective of a breast (unintended).

Composition: frontal, flattened perspective.

Texture: smooth with subtle undulations.

Scale and Format/Proportions: full-scale figure, proportional; scale of rectangular form similar to human figure.

Technical Elements: non specified.

Single or Multimedia: single, ceramic clay.

Relationship to Other Work in Same Media: None apparent.

References: human figure, possibly female based on the inclusion of one breast-like form; three rectangular shapes, varying sizes but same thickness.

Remediations: None apparent.

Situatedness: possibly situated in breast cancer social arena. Rectangular shapes situated in spiritual understanding of wellness.

Relations with Visual Culture(s): Clay forms seem connected with clay culture of the southeastern Indian tribes.

Commonness/Uniqueness: inclusion of representational human figure and abstract, geometric forms to represent concept of wellness.

Work of the Image: possibly features the self-concept of a breast cancer survivor and a spiritual frame of reference.

Injunctions to Viewers: None apparent.

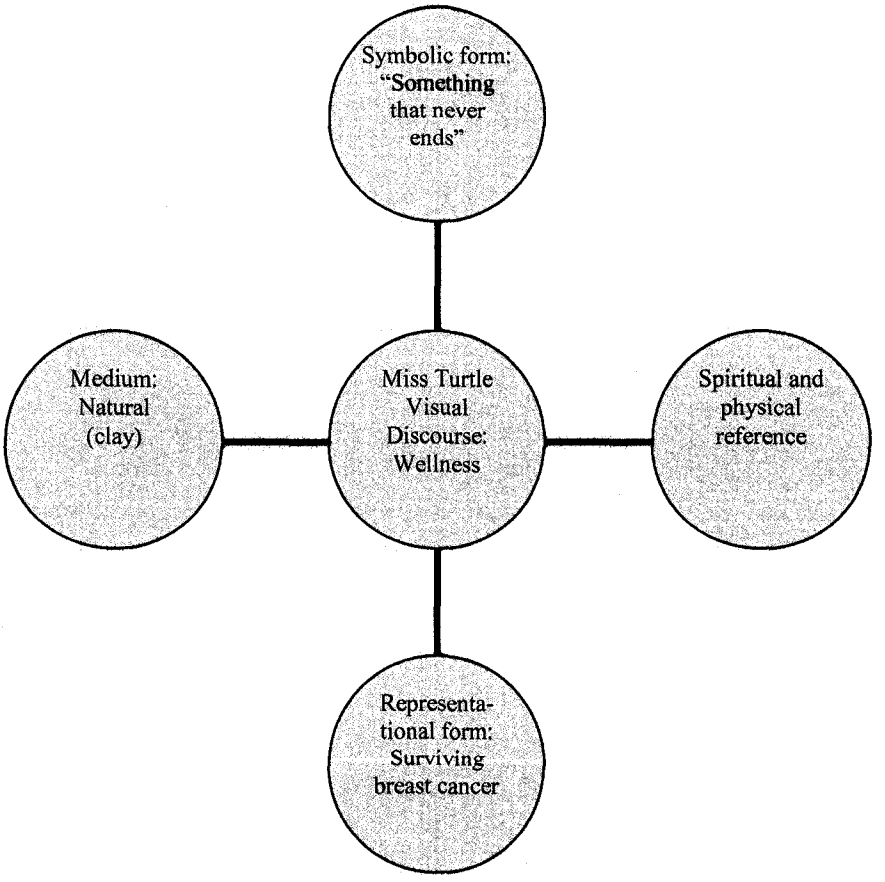

Figure 14: Wellness Visual Discourse Situational Map

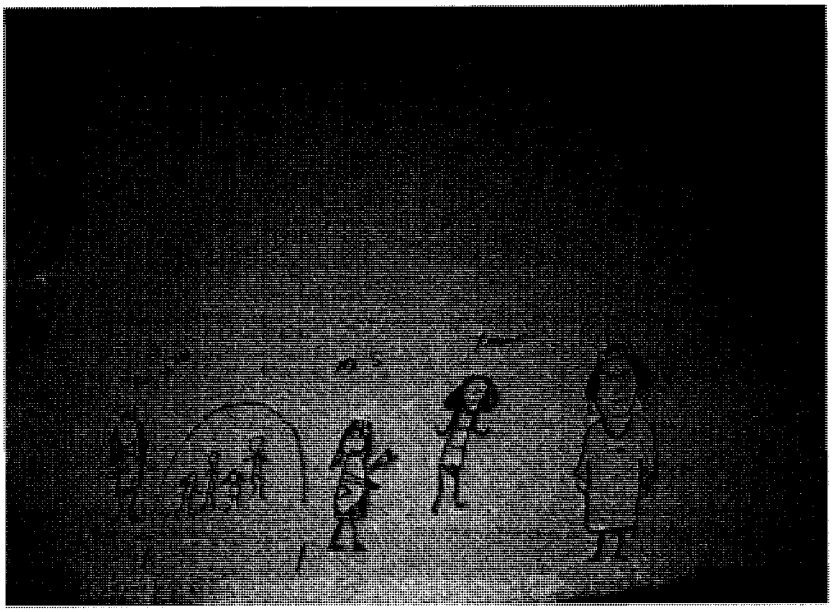

Figure 15: Open Task

- Locating Memo: spontaneous image (free choice drawing).
- Big Picture Memo

  First impressions:

  Sequential placement
  Outlined figures
  Monochromatic
  Narrative
  Pictorial
  Lifeline

  Big picture: represents Self from little girl, beginning at age 6 to present age.

  Little picture: timeline configuration with arched line enclosing four smaller scale human figures.

- Specification Memo

Selection: depiction of Self beginning age 6, middle school, teen, and present.

Framing: (inclusions, exclusions, cut off's) inclusion of arched line encapsulating 4 smaller human figures.

Featuring: (foreground, middle ground, background, present) present Self foregrounded based on larger scale. Four encapsulated figures appear to be in background because of smaller scale.

Viewpoint: (close-up, medium shot, long shot, low angle, high angle) frontal, sequential.

Light: none implied.

Color: monochromatic (black pastel).

Focus/Depth of Field: no depth of field, sequential placement representing passage of time (past to present).

Presense/Absense: presence of multiple selves.

Intended/Unintended Audience(s): sequential placement suggests a narrative story being told to viewer.

Composition: frontal, sequential.

Texture: charcoal paper.

Scale and Format/Proportions: full-scale human figures, proportionate.

Technical Elements: none apparent.

Single or Multimedia: single, oil pastel.

Relationship to Other Work in Same Media: sequential placement, frontal format, linear emphasis.

References: American Indian "crown" referencing status or "Queen."

Remediations: none apparent.

Situatedness: timeline emphasizing marginalized voice of female girl from American Indian community to present day Self as traditional woman with a voice.

Relations with Visual Culture(s): culture of American Indian female from past to present.

Commonness/Uniqueness: Self as Queen (visual identification as Native Queen).

Work of the Image: story of finding true Self in the wake of being marginalized as an American Indian female.

Injunctions to Viewers: story of one's life history.

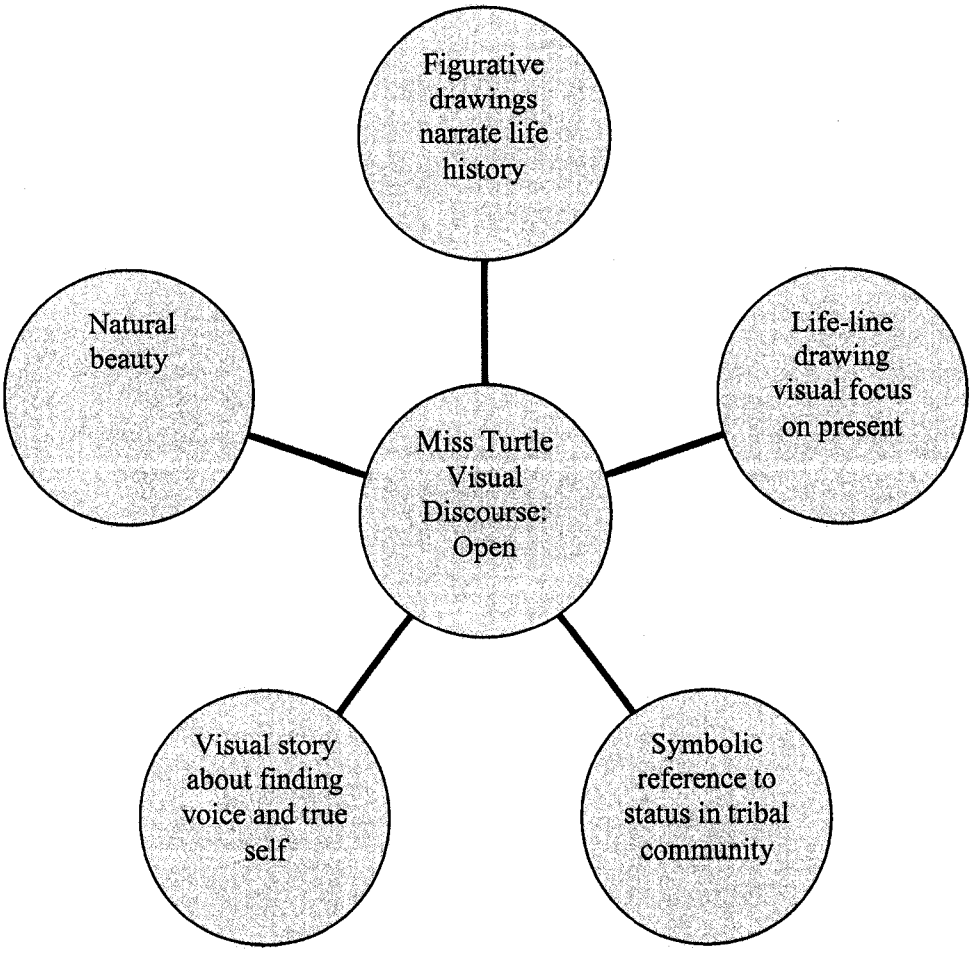

Figure 16: Open Visual Discourse Situation Map

Figure 17: Breast Cancer and Treatment Task

- Locating Memo: Abstract image representing cancer.
- Big Picture Memo

First impressions:

circular symmetry
concentric circles (filled-in and monochromatic)
overlapping bisecting lines
central focus
sporadically placed filled-in circles
sketchy lines toward outer circle

Big picture: image was created in consecutive layers in response to different emotional states associated with the cancer experience.

Little picture: symmetrical concentric layers, filled-in black circles seemed to be placed strategically (not evenly).

- Specification Memo

Selection: image of cancer, abstract circular design.

Framing: (inclusions, exclusions, cut off's) circular.

Featuring: (foreground, middle ground, background, present) filled-in black circles and corresponding black lines seem to be foregrounded.

Viewpoint: (close-up, medium shot, long shot, low angle, high angle) frontal, close-up view.

Light: source not suggested.

Color: idiosyncratic.

Focus/Depth of Field: flattened perspective, central focus.

Presense/Absense: presence of black central point.

Intended/Unintended Audience(s): none apparent—highly personal.

Composition: central, symmetrical, concentric, layered.

Texture: implied in line quality.

Scale and Format/Proportions: utilizes majority of picture plane.

Technical Elements: none apparent.

Single or Multimedia: single, multi-colored oil pastels.

Relationship to Other Work in Same Media: frontal, linear, sequence implied.

References: seems reflective of circular imagery in Native American art. The inner black lines and fill-in circles suggest a "dream catcher" reference, reflective of Miss Hope's gourd art.

Remediations: none apparent.

Situatedness: situated in circular designs reflected in Native art forms and in context to the emotional states associated with the cancer experience.

Relations with Visual Culture(s): None apparent.

Commonness/Uniqueness: seems to be a highly personal use of a Native imagery.

Work of the Image: express felt emotions.

Injunctions to Viewers: to understand different emotional states associated with the cancer experience.

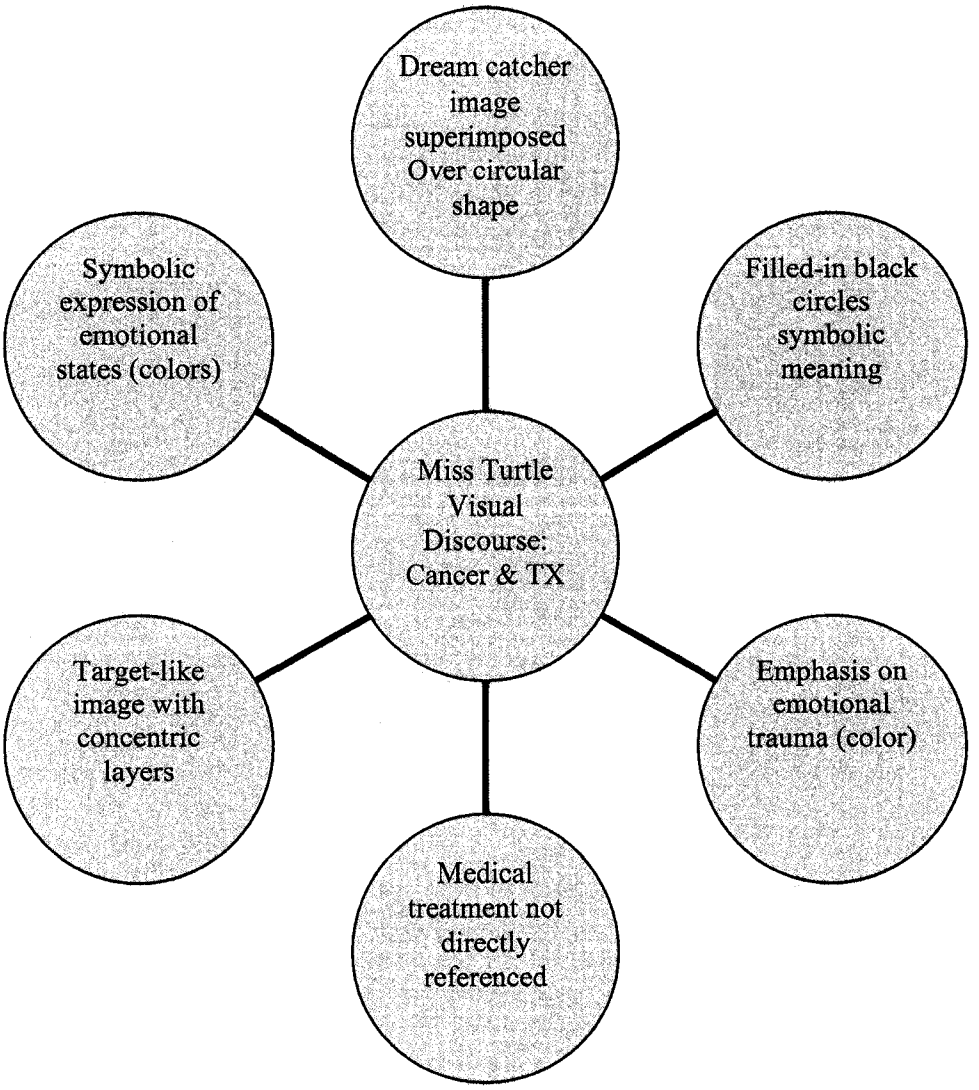

Figure 18: Breast Cancer and Treatment Task

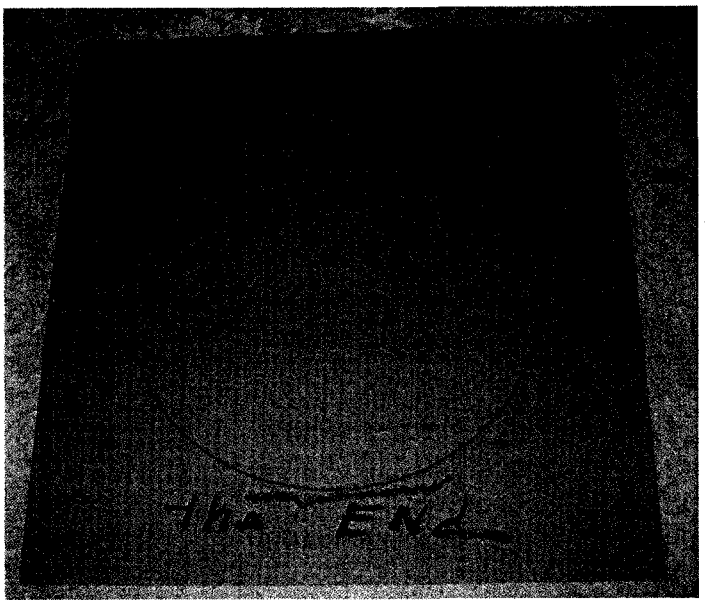

Figure 19: Closing Circle Task

- Locating Memo: closing circle drawing.
- Big Picture Memo

  First impressions:

  Empty
  Ending
  Wanting to stop
  Underline (reinforcement)

  Big picture: left the circle empty and referenced her experience with cancer as being all there "behind a closed shade."

  Little picture: empty circle with words illustrating the meaning ("The End").

- Specification Memo

Selection: closing circle.

Framing: (inclusions, exclusions, cut off's) empty.

Featuring: (foreground, middle ground, background, present) words foregrounded as well as a black underline positioned under the circle and above the words "the end."

Viewpoint: (close-up, medium shot, long shot, low angle, high angle) none apparent.

Light: none apparent.

Color: black.

Focus/Depth of Field: focus on words to illustrate meaning.

Presense/Absense: absence of an image.

Intended/Unintended Audience(s): closed off.

Composition: none apparent.

Texture: none apparent.

Scale and Format/Proportions: none apparent.

Technical Elements: none apparent.

Single or Multimedia: single, black oil pastel.

Relationship to Other Work in Same Media: emphasis on titling.

References: closed shade.

Remediations: none apparent.

Situatedness: context situated in pre-drawn circle.

Relations with Visual Culture(s): none apparent.

Commonness/Uniqueness: black underline.

Work of the Image: provide an ending to the interview.

Injunctions to Viewers: direct message to end interview.

Summary

Miss Turtles's image of cancer consisted of a mandala-like shape (circular configuration). Each layer of color was added on in a concentric manner to convey a felt experience related to cancer and appeared to be more experientially-based than a symbolic representation. A "dream catcher web" was the central focus of the image with

filled-in black circles strategically placed; this image seemed to reflect Miss Turtle's interest in traditional American Indian art. In terms of omissions, Miss Turtle's medical treatment was not referenced, rather the emphasis seemed to be on depicting emotional states. Two sculptural clay forms were created to represent wellness. Clay was referred to as something "natural" and used to represent an abstract form of "something that never ends" as well as a full-scale human figure with one breast-like form. The connection between the two forms appeared to an interconnectedness between the spiritual and physical. The full-scale human figure seemed to represent a different text, suggesting one could experience wellness as a breast cancer survivor. Miss Turtle's free choice task consisted of a drawing and was depicted in a representational manner focusing on a sequential depiction of past to present self-portraits. The emphasis was more on her present status in the community (traditional elder) vs. her past experiences as a little girl searching for her "voice." The figurative references highlighted her natural or "plain" beauty.

Ms. Sunshine.

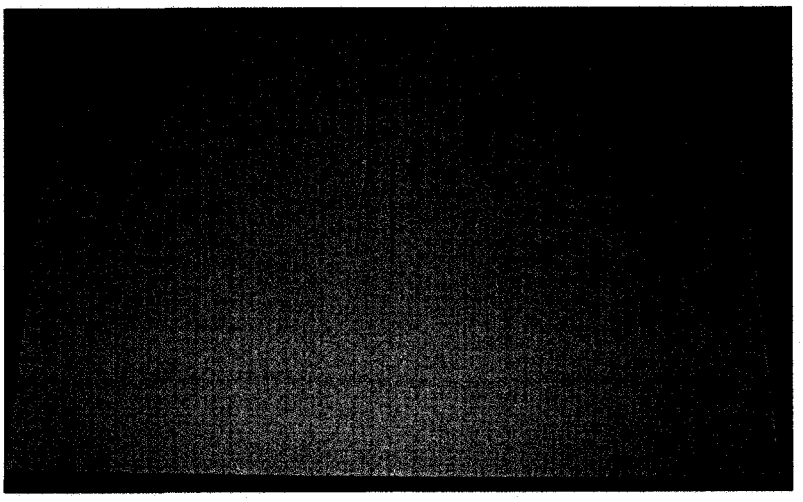

Figure 20: Breast Cancer and Treatment Task

- Locating Memo: image representing cancer and cancer treatment.
- Big Picture Memo

First impressions:

Schematic drawings
Diagrams of breasts
Cut off figures (hands, neck, waist)
Black dot representing cancer

Big picture: drawing representing presence of breast cancer (left figure) and the results of treatment (mastectomy), cancer removed and skin, not breast, is represented.

Little picture: figures depicted in upper left quadrant of paper.

- Specification Memo

Selection: Image of cancer and cancer treatment.

Framing: (inclusions, exclusions, cut off's) figures cut off at hand, neck, and waist.

Featuring: (foreground, middle ground, background, present) cancer foregrounded (black dot encircle in image of "breast.").

Viewpoint: (close-up, medium shot, long shot, low angle, high angle) front, diagrammatic.

Light: no source implied.

Color: monochromatic, reddish brown oil pastel.

Focus/Depth of Field: focus on alterations of breast.

Presense/Absense: presence of cancer (black dot) and absence of full-scale human figure.

Intended/Unintended Audience(s): explanatory diagram.

Composition: frontal, position upper left quadrant.

Texture: none apparent.

Scale and Format/Proportions: partial figure, proportions implied, frontal format.

Technical Elements: none apparent.

Single or Multimedia: monochromatic, reddish-brown oil pastel.

Relationship to Other Work in Same Media: narrative, descriptive.

References: culture of breast cancer.

Remediations: none apparent.

Situatedness: culture of breast cancer.

Relations with Visual Culture(s): none apparent.

Commonness/Uniqueness: unique cut-off figures.

Work of the Image: naturalized.

Injunctions to Viewers: explanatory.

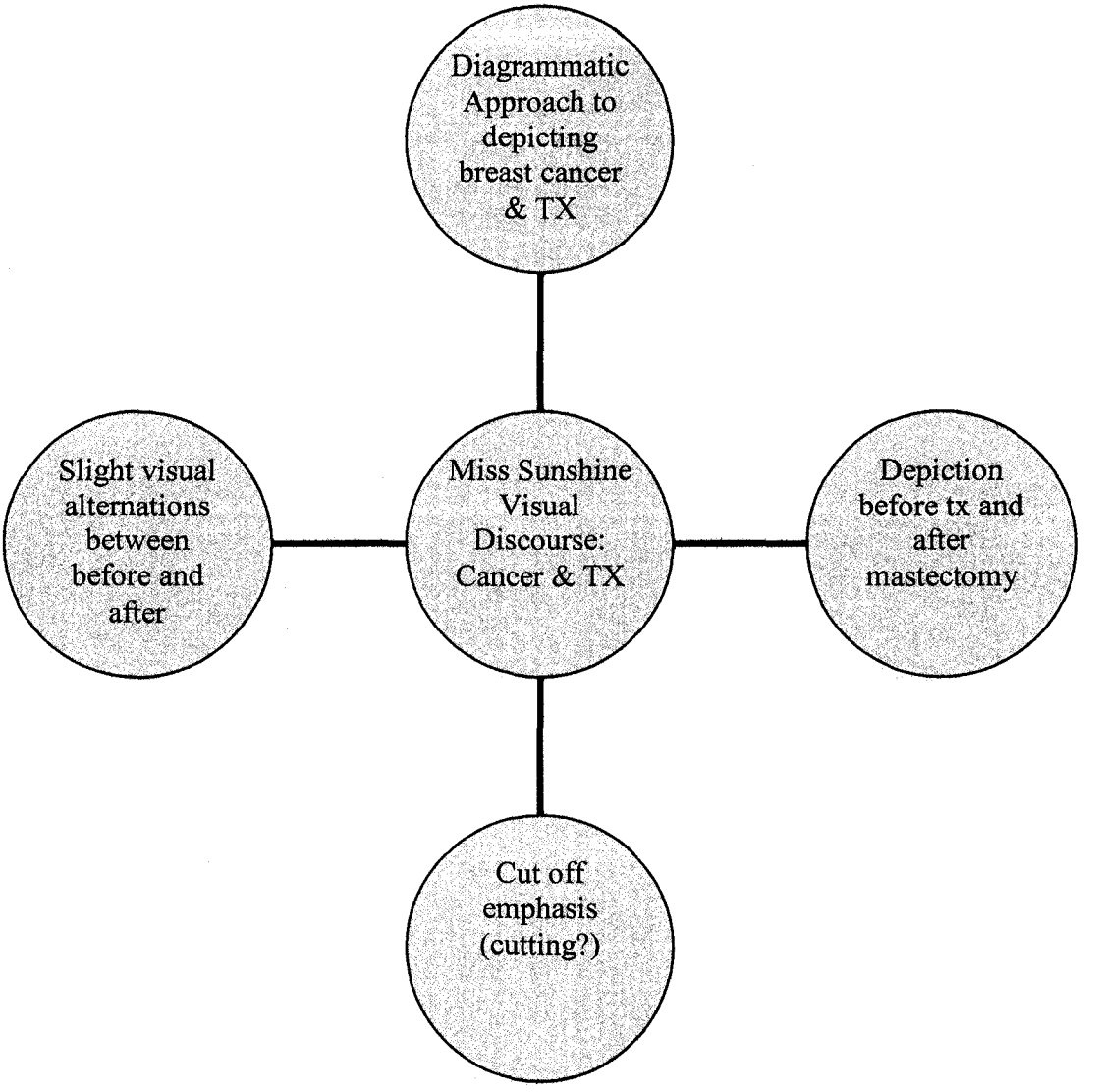

Figure 21: Breast Cancer Visual Discourse Situtational Map

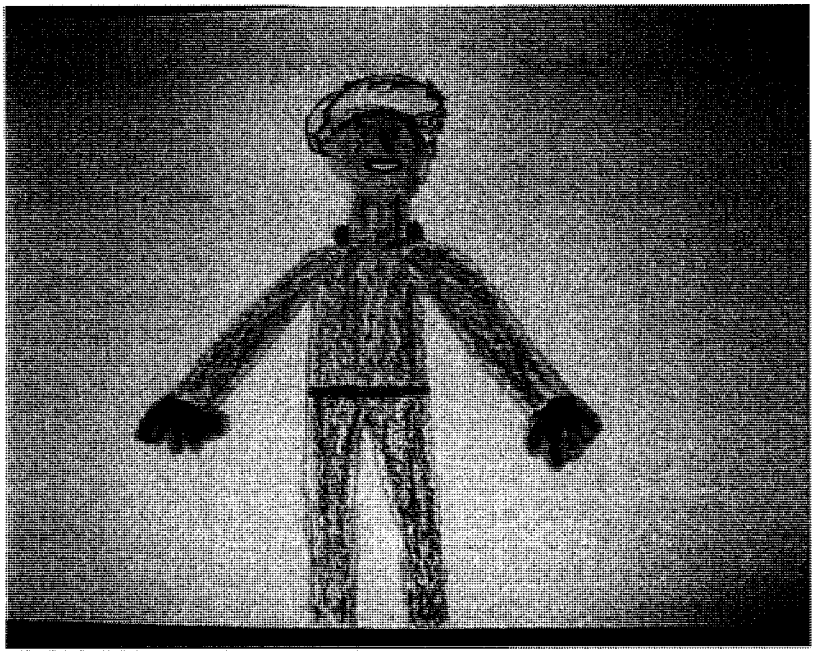

Figure 22: Wellness Task

- Locating Memo: image representing wellness.
- Big Picture Memo: "Sunshine" representing well person. Positive colors emphasized.

  First impressions:

  Positive
  Detailed
  Strength
  Outlined in yellow
  Bright colors

  Big picture: "Sunshine" representing well person. Positive colors emphasized.

  Little picture: centrally placed figure, overlapping all 4 quadrants.

- Specification Memo

Selection: image representing wellness

Framing: (inclusions, exclusions, cut off's) feet cut off.

Featuring: (foreground, middleground, background, present) hands appear to be foregrounded because watercolor medium.

Viewpoint: (close-up, medium shot, long shot, low angle, high angle) frontal.

Light: "sunshine."

Color: bright, used watercolor to accurately depict skin tone, yellow used to outline shapes.

Focus/Depth of Field: flattened sense of space, frontal focus.

Presense/Absense: absence of feet.

Intended/Unintended Audience(s): intended audience (viewer)

Composition: central, even.

Texture: implied in application of media.

Scale and Format/Proportions: full-scale figure, proportionate.

Technical Elements: none apparent.

Single or Multimedia: multimedia, water color and oil pastel.

Relationship to Other Work in Same Media: emphasis on bright colors, images are incorporated to illustrate a thought.

References: personal in terms of using pink because granddaughter's favorite. Story about "sunshine" surfaced later in story about grandson.

Remediations: none apparent.

Situatedness: concept of wellness, Self, and family.

Relations with Visual Culture(s) "natural" appearance or "plain" beauty associated with American Indian women.

Commonness/Uniqueness: "sunshine" to outline figurative elements.

Work of the Image: naturalized.

Injunctions to Viewers: think of wellness as a form of "sunshine" encircling the body.

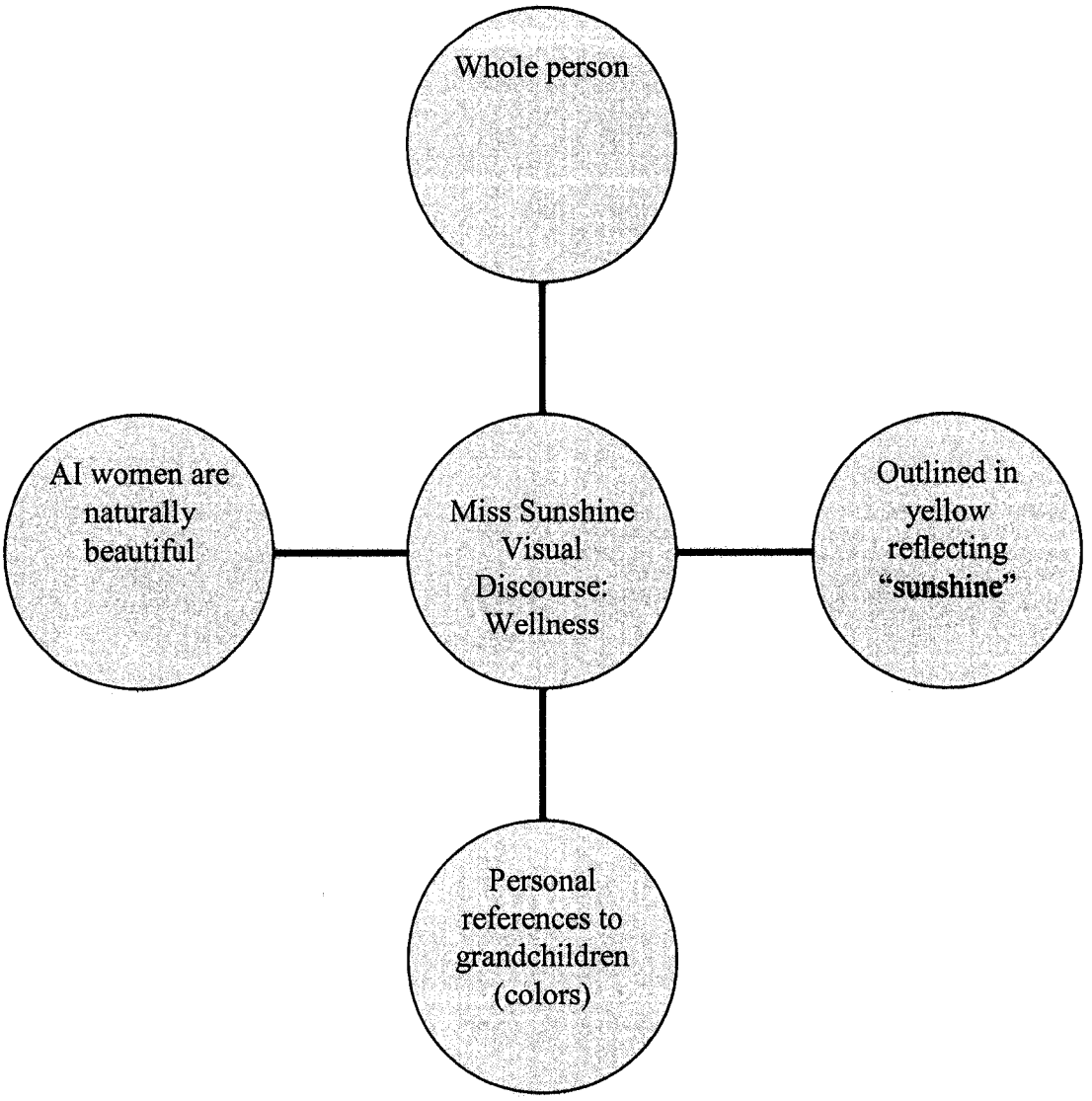

Figure 23: Wellness Visual Discourse Situational Map

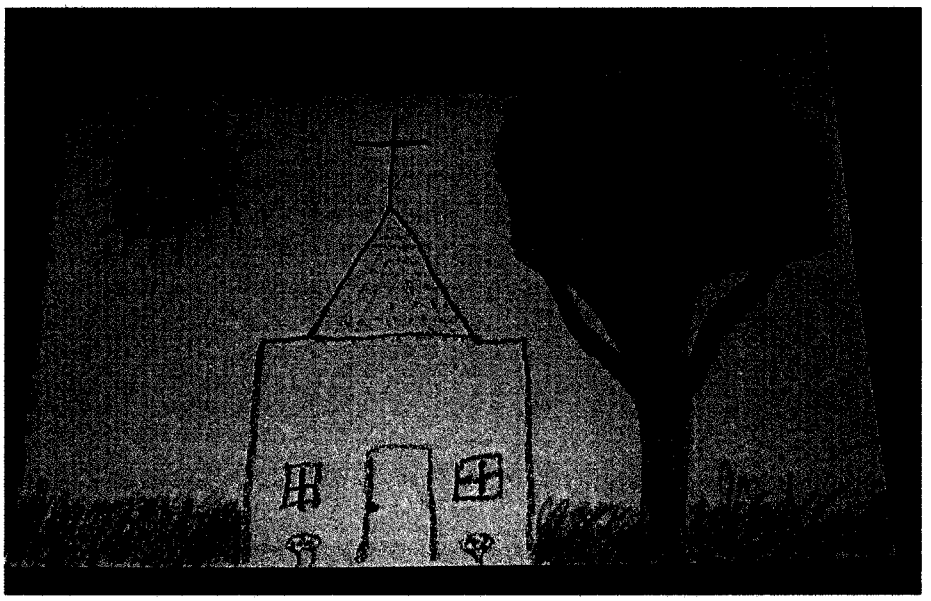

Figure 24: Open Task

- Locating Memo: image of choice representing an environment including a church, tree, and sunshine.
- Big Picture Memo:

First impressions:

Naturalistic
Spiritual
Peaceful
Central

Big picture: "My church, my tree, my sun, my sky, my flowers, and my grass," "God made it all." "I like the white church cause I think white represents purity and green represents air, the sun is warmth, the flowers are breathtaking, and the church is everything"

Little picture: church overlaps into all four quadrants. The tree comprises the top right and lower right quadrants. Sun sits in the upper left quadrant.

- Specification Memo

Selection: image of choice representing importance of church and environment.

Framing: (inclusions, exclusions, cut off's) church and tree have "cut-off appearance" based on positioning on implied baseline.

Featuring: (foreground, middleground, background, present) the central placement of the church and emphasis of the color green to depict tree contributed to foregrounded effect.

Viewpoint: (close-up, medium shot, long shot, low angle, high angle) frontal.

Light: reference to sun and natural light.

Color: bright naturalistic colors, tree is depicted all over in green.

Focus/Depth of Field: focus on church (placement) and tree (color), flattened sense of depth.

Presense/Absense: absence of people, presence of nature and place of worship.

Intended/Unintended Audience(s): viewer intended audience.

Composition: central, filled entire picture plain, representational.

Texture: implied in application of media.

Scale and Format/Proportions: full-scale and proportionate, sequential format.

Technical Elements: none apparent.

Single or Multimedia: multimedia, oil pastel and watercolor.

Relationship to Other Work in Same Media: symbolic, narrative, tells a story.

References: white church representing purity related to use of white to symbolize purity (north) in the four directions or wheel of life. Natural elements referenced in stories about God, signifying God exists in everything.

Remediations: none apparent.

Situatedness: American Indian spirituality and interconnectedness with God and the natural world.

Relations with Visual Culture(s): Reflective of past and present American Indian belief system.

Commonness/Uniqueness: anthropormorphic quality of tree.

Work of the Image: naturalized image representing core belief systems.

Injunctions to Viewers: Tells a story about the interrelationship between spiritual beliefs and the natural world.

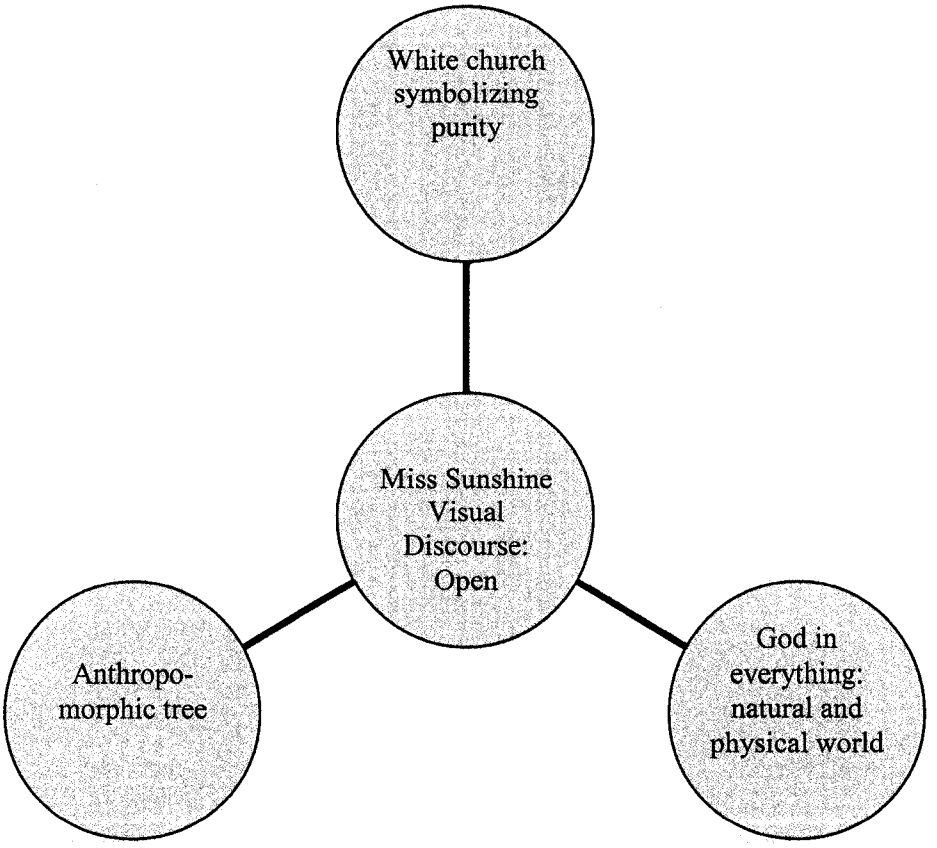

Figure 25: Open Visual Discourse Situational Map

Summary

Miss Sunshine had a diagrammatic approach to depicting breast cancer and cancer treatment in her before and after drawing. There were slight alterations between both figures, perhaps implying that a mastectomy does change one's self-worth. One unique aspect in the drawing was the cut-off extremities, reflecting a possible emphasis on

cutting out the cancer. Alternately, a full-scale human figure was depicted to represent a "whole" person for the theme of wellness. Identified as a female, the breasts appeared to be deemphasized in lieu of "natural" beauty associated with being American Indian. The entire figure was outlined in yellow "sunshine." References to her grandchildren were made with respect to color selection. Miss Sunshine's symbol of choice centered on her church, represented in white to signify purity. The notion of God being in everything was referenced in relation to environment (natural world) and church (physical world), this idea seemed to be reinforced by the anthropormorphic quality of the green tree.

Miss Hope.

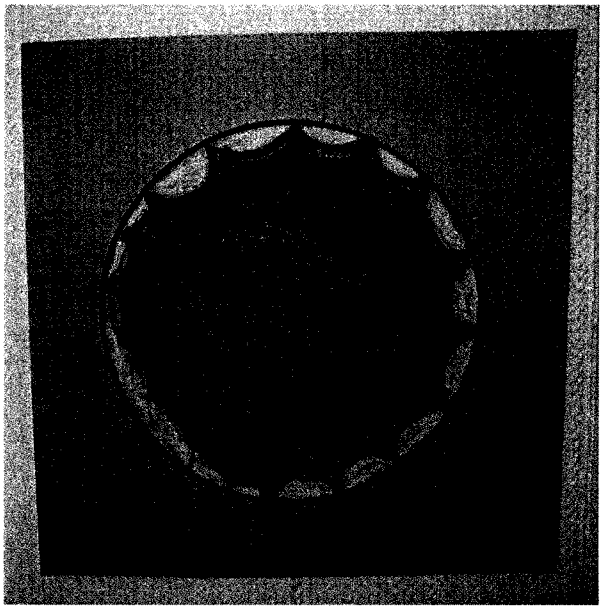

Figure 26: Opening Circle Task

- Locating Memo: Opening circle drawing for pilot study.
- Big Picture Memo

First impressions:

Reinforced border (2 colors: red and white)
Filled-in circle with varied bands of colors (yellow, green and blue)

Big picture: created as warm-up to intervention.

Little picture: juxtaposition of circular symmetry and bands of colors.

- Specification Memo

Selection: warm-up drawing.

Framing: (inclusions, exclusions, cut off's): reinforced border.

Featuring: (foreground, middleground, background, present) border is forgrounded because of contrasting colors and three bands of color situated in background.

Viewpoint: (close-up, medium shot, long shot, low angle, high angle) frontal and appears to be a "close-up" image because of outline of pre-drawn circle.

Light: source not indicated.

Color: idiosyncratic (personal and symbolic).

Focus/Depth of Field: focus shifts between border and bands of color. No depth of field indicated. Flattened sense of perspective.

Presense/Absense: presence of a border.

Intended/Unintended Audience(s): none apparent.

Composition: nonobjective, symbolic, circular symmetry outside of circle (border), bands of color layered, dominance of yellow.

Texture: implied in use of media.

Scale and Format/Proportions: filled-in entire surface of pre-drawn circle.

Technical Elements: none apparent.

Single or Multimedia: single, water-based oil pastel.

Relationship to Other Work in Same Media: linear and filled-in elements, symbolic or personal use of color.

References: personal expression, colors may reflect American Indian beliefs.

Remediations: none apparent.

Situatedness: situated in a circular configuration.

Relations with Visual Culture(s): pattern may reflect American Indian motifs (outside border). Color scheme is representative of cultural arts from this region.

Commonness/Uniqueness: contrasting circular border with bands of color.

Work of the Image: container and a means to warm-up for interventions.

Injunctions to Viewers: none apparent.

Figure 27: Open Task

- Locating Memo: free choice drawing consisting of a story from participant's childhood.
- Big Picture Memo

  First impressions:

  Naturalistic environment
  Emphasis on red swing
  Used entire picture plane
  Green foliage
  6 birds flying overhead

Big picture: while depicting this image, participant shared story about being discriminated against for being American Indian as a child.

Little picture: swing in lower right quadrant, birds in upper two quadrants, tree is centered and carries over into all quadrants.

- Specification Memo

Selection: free-choice drawing focusing on childhood memory and present story.

Framing: (inclusions, exclusions, cut off's) inclusion of a red swing.

Featuring: (foreground, middleground, background, present) red swing foregrounded because of color, background with birds, tree in middleground.

Viewpoint: (close-up, medium shot, long shot, low angle, high angle) medium shot (view).

Light: no direct light source. Implied light in background.

Color: naturalistic.

Focus/Depth of Field: focus on tree and slanted (moving?) swing.

Presense/Absense: absence of people, presence of nature.

Intended/Unintended Audience(s): picture seems to narrate a story.

Composition: frontal, full, detail, environment and object, representational, naturalistic.

Texture: implied in use of medium, emphasis in depiction of red swing.

Scale and Format/Proportions: proportionate, full-scale tree, frontal format.

Technical Elements: none apparent.

Single or Multimedia: single, chalk pastel.

Relationship to Other Work in Same Media: naturalistic and blended.

References: nature, simultaneous depiction of childhood memory and present day story.

Remediations: none apparent.

Situatedness: personal environment and natural world.

Relations with Visual Culture(s): narrative, tells a story.

Commonness/Uniqueness: direction of tree branches (bending).

Work of the Image: purpose is to illustrate a story connecting childhood memory with present event.

Injunctions to Viewers: tells a story.

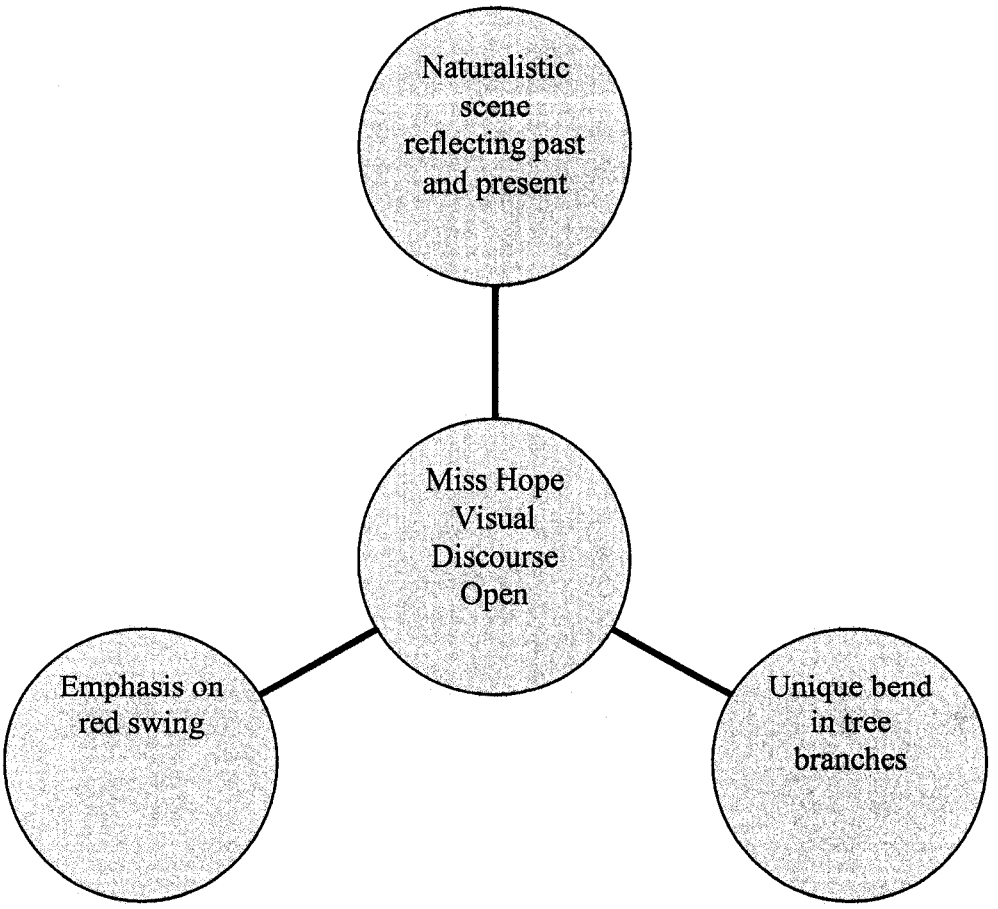

Figure 28: Open Visual Narrative Discourse Situational Map

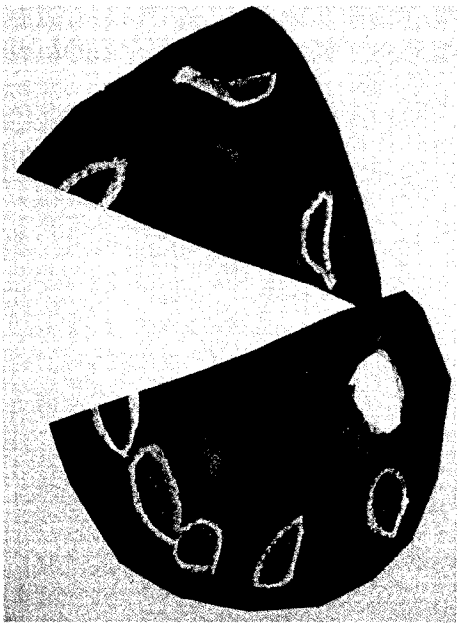

Figure 29: Breast Cancer and Treatment Task

Locating Memo: image created in response to perception of cancer and cancer treatment.

- Big Picture Memo:

First impressions:

Oval shape cut in half
Cut out forms and pierced holes
Separated but connected
Circles contained within a circular shape

Big picture: the creation of this image incorporated piercing holes in circular forms, cutting out circle, and cutting entire shape in half.

Little picture: divided into two shapes representing the whole. Negative and positive space considered.

- Specification Memo

Selection: interactive piece detailing what breast cancer looks like and how treatment is perceived (cutting out).

Framing: (inclusions, exclusions, cut off's) cut in half, cut into circle, inclusion of negative space.

Featuring: (foreground, middleground, background, present) negative space comprises the background. The white chalk lines on black background creates a foregrounding effect.

Viewpoint: (close-up, medium shot, long shot, low angle, high angle): close-up of cancer cells.

Light: contrast noted between white chalk on black background.

Color: black and white.

Focus/Depth of Field: zoom focus, depth implied with used of negative space.

Presense/Absense: absence of one circle (treatment?), presence of a split.

Intended/Unintended Audience(s): intended audience was me in terms of observing the sequence of steps.

Composition: abstract image of cancer, defined by outer edge and cut dividing circular shape.

Texture: incorporated with use of needle tool to make "holes," rubbed fingers over holes to reinforce texture.

Scale and Format/Proportions: size proportionate to a breast.

Technical Elements: none apparent.

Single or Multimedia: single, chalk pastel.

Relationship to Other Work in Same Media: unrelated, more diagrammatic.

References: diagram of breast cancer, cancer cells, and treatment.

Remediations: none apparent.

Situatedness: experience of having breast cancer.

Relations with Visual Culture(s): not apparent.

Commonness/Uniqueness: unique experiential approach (several stages of altering piece).

Work of the Image: explanatory.

Injunctions to Viewers: inform viewer of what breast cancer looks like and the emphasis on cutting out the cancer.

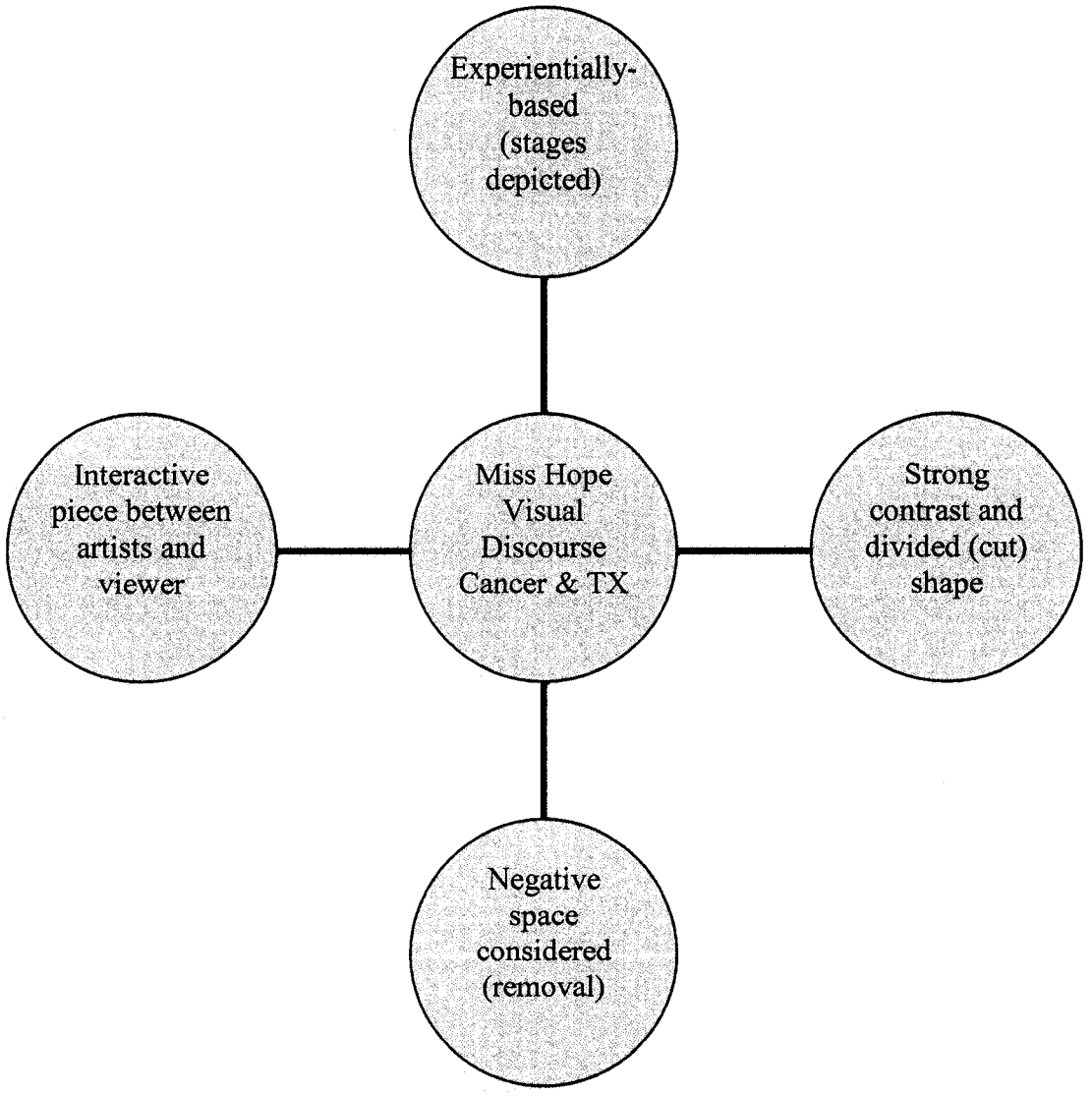

Figure 30: Breast Cancer and Treatment Visual Discourse Situational Map

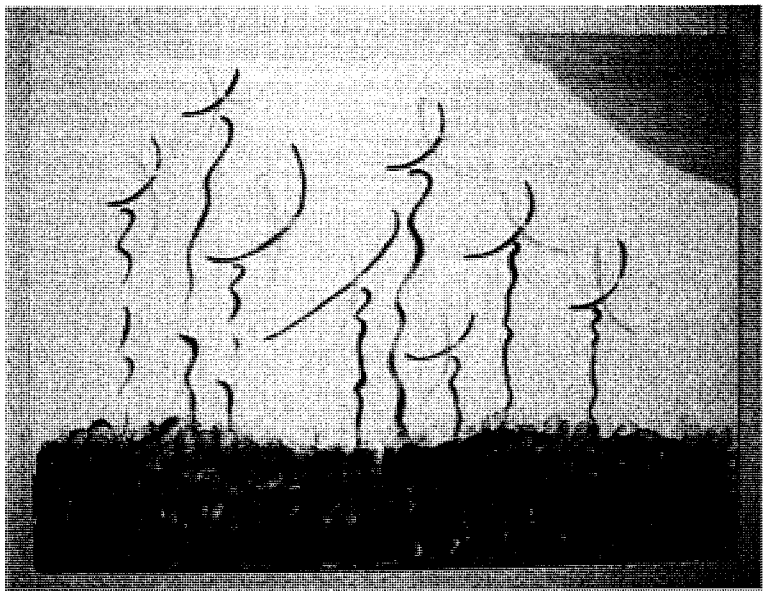

Figure 31: Wellness Task

- Locating Memo: image representing the importance of community to promote wellness.
- Big Picture Memo

  First impressions:

  Symbolic environment
  Motion
  Finger marks comprising blue area
  Sunlight
  Symbolic shape and use of color (overlapping of yellow, black, white)

  Big picture: image representing wellness as a collective experience.

  Little picture: movement depicted throughout all four quadrants.

- Specification Memo

Selection: mediated and unmediated image of wellness.

Framing: (inclusions, exclusions, cut off's) inclusion of finger marks in blue "baseline."

Featuring: (foreground, middleground, background, present) symbolic shapes (overlapping arcs of color) are foregrounded and reinforced by blue curvilinear line leading to the blue "baseline." Sun positioned in background.

Viewpoint: (close-up, medium shot, long shot, low angle, high angle) long shot, distance implied.

Light: direct light source indicated (sun) and possibly reflected in abstract symbols.

Color: idiosyncratic, symbolic, naturalistic.

Focus/Depth of Field: central focus, a sense of depth implied.

Presense/Absense: 8 symbolic images.

Intended/Unintended Audience(s): viewer intended audience but message not overt.

Composition: repetition of form, naturalistic, balanced, baseline/skyline implied.

Texture: deliberate re: finger marks.

Scale and Format/Proportions: abstraction with "realistic" scale and proportions.

Technical Elements: none apparent.

Single or Multimedia: single, acrylic paint on canvas.

Relationship to Other Work in Same Media: more fluid utilizing a new medium (acrylic paint).

References: sense of community, coming together, spiritual connection—integral to wellness.

Remediations: none apparent.

Situatedness: images are personal and symbolic, reflecting collective way of thinking.

Relations with Visual Culture(s): combination of symbols and natural world reflective of Native forms of art.

Commonness/Uniqueness: overlapping arcs of color unique as well as the curvilinear line connecting to blue "baseline."

Work of the Image: demonstrate symbolic a collective sense of well being.

Injunctions to Viewers: symbolic meaning conveyed.

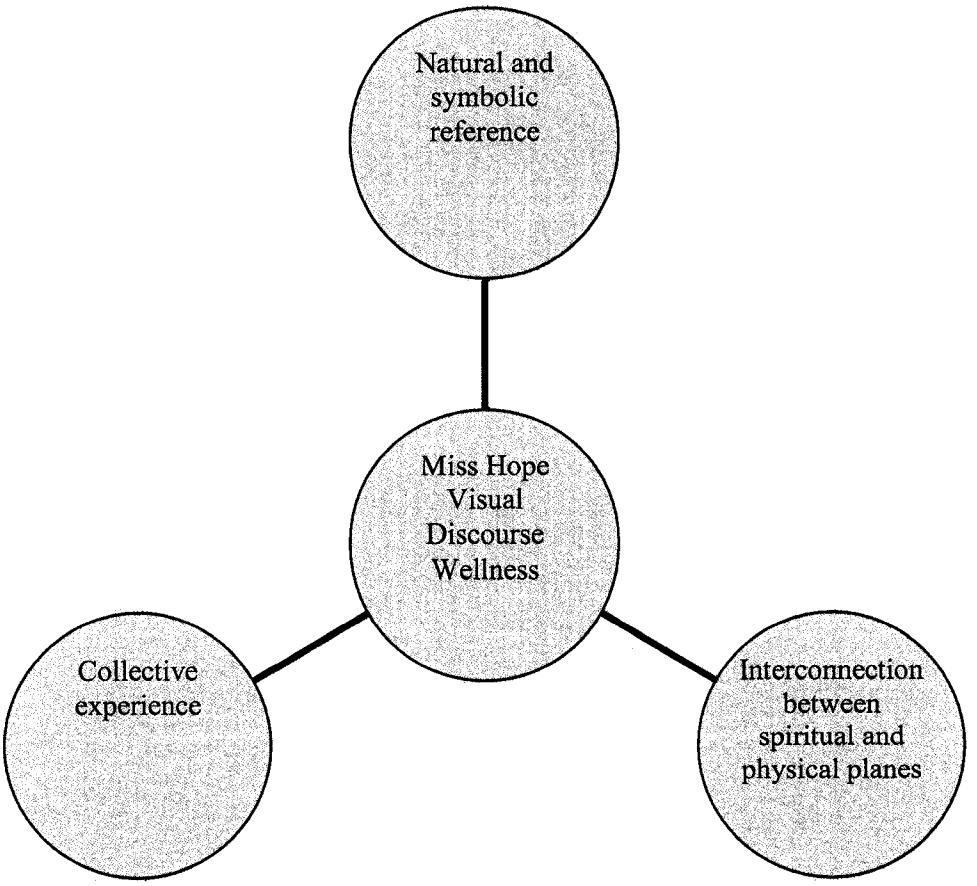

Figure 32: Wellness Visual Discourse Situational Map

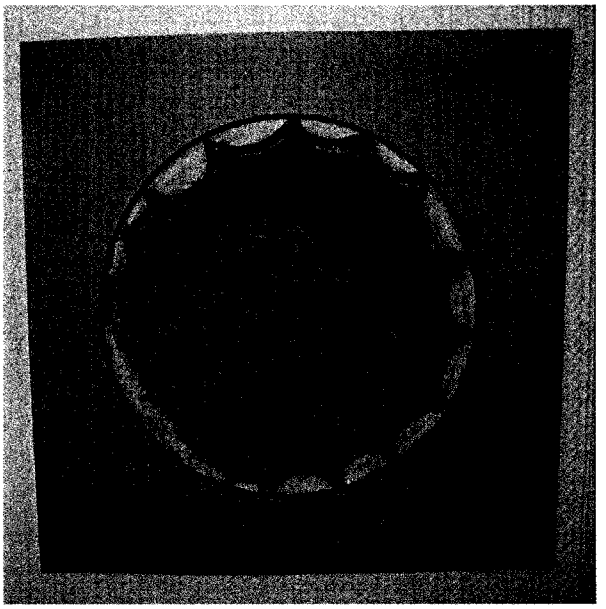

Figure 33: Closing Circle Task

- Locating Memo: closing drawing to end interview.

- Big Picture Memo

  First impressions:

  Utilized space inside and outside circle
  6 plant-like images inside circle
  4 figurative references surrounding circle
  Personal use of color
  Stylized images

  Big picture: content of imagery unclear.

  Little picture: one figure per quadrant was represented, "anthropomorphic" plant-like images overlapped into all four quadrants.

- Specification Memo

Selection: completed second circle (no directive) as a form of closure.

Framing: (inclusions, exclusions, cut off's): inclusion of figures and plant-like forms.

Featuring: (foreground, middleground, background, present) outside and inside space shift in terms of background and foreground (not static).

Viewpoint: (close-up, medium shot, long shot, low angle, high angle): plant-like images appear to be close-up because of pre-drawn circle has a "zoom" effect.

Light: implied in background yellow color.

Color: idiosyncratic, highly personal.

Focus/Depth of Field: focus on plant-like images (filled-in with yellow).

Presense/Absense: presence figurative references and plant-like forms.

Intended/Unintended Audience(s): viewer intended audience.

Composition: inside/outside space, symmetrical quality, balanced, central focus, repetition of forms.

Texture: implied in use of medium.

Scale and Format/Proportions: figures and plant-like forms have similar proportions, giving the plant-like forms an anthropomorphic quality.

Technical Elements: not apparent.

Single or Multimedia: single, water-based oil pastel.

Relationship to Other Work in Same Media: more stylized than other 4 images.

References: relationship between nature and people.

Remediation: not apparent.

Situated ness: Native belief system.

Relations with Visual Culture(s): stylized representational imagery.

Commonness/Uniqueness: stylization common in Native art. Unique in terms of colors and symbolic imagery.

Work of the Image: close a long interview.

Injunctions to Viewers: centeredness.

Summary

Miss Hope produced the most interactive conceptualization of breast cancer and cancer treatment. Created in several stages, Miss Hope cut out a breast-like form out of black paper, depicted white circles in chalk pastel, used a "needle tool" to poke holes in the surface representing cancer growth, cut out a circle to indicate treatment (removal), and then cut the entire shape in half to represent a mastectomy. In her painting of wellness, personal symbols and natural references were utilized to convey a spiritual connection with the physical world. This interrelationship was reinforced by a symbolic representation of collective well being, evident in her visual depiction of blue finger marks ("people"). For her free drawing, Miss Hope focused on a naturalistic theme incorporating a detailed red tree swing. This drawing elicited storying about past and present events. The stylized tree branches noted a unique bend in the upper branches, suggestive of movement.

Social worlds/arena maps

Focusing on the three main art tasks, each directive was situated in a social world/arena map comprising a symbol of breast cancer and breast cancer treatment, symbol representing wellness, and a free choice drawing.

1 Using lines, shapes, and colors, or using clay, please make a symbol that represents what it means to have breast cancer and undergo breast cancer treatment.

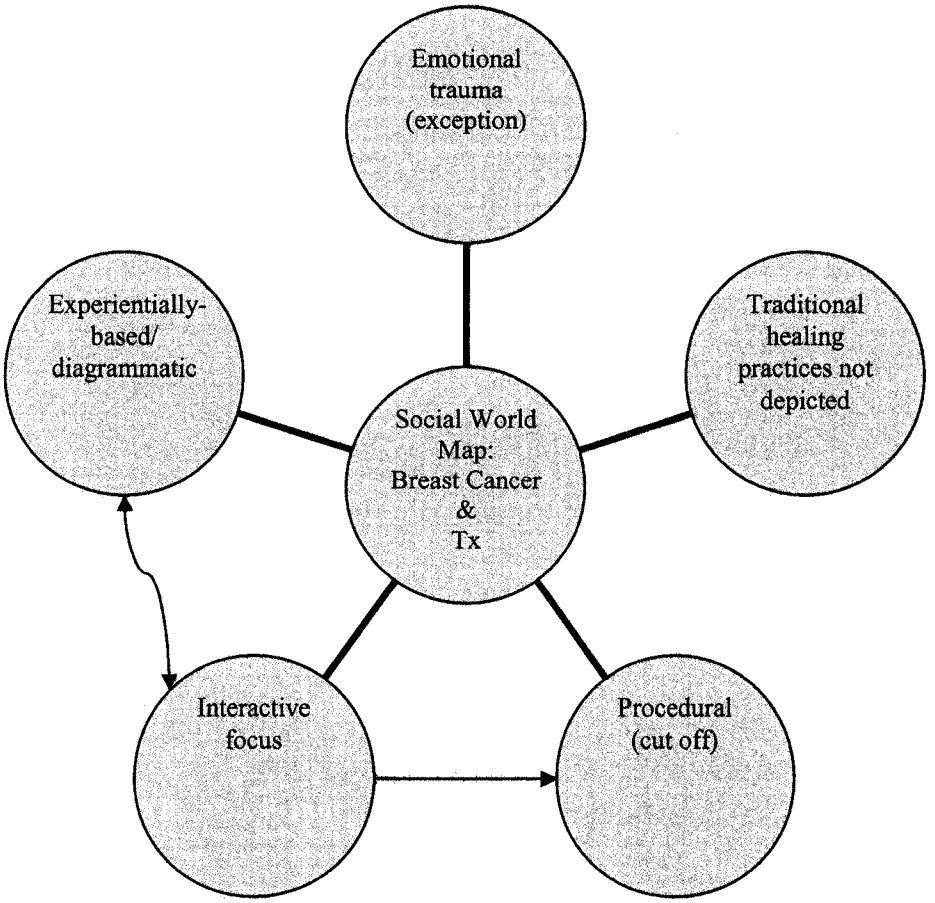

Figure 34: Breast Cancer and Treatment Social World Visual Discourse Map

This social world map consisted of an experientially-based or diagrammatic approach to depicting breast cancer. Whether centered on emotions or procedures, there were specific stages noted in the process of creating these drawings from all three participants. Moreover, an emphasis on cutting out the cancer was indicated in two of the

drawings. Traditional healing practices were not represented in the artwork, although one participant, Miss Hope incorporated her own cultural art form.

2 Using lines, shapes, and colors, or using clay, please make another symbol that represents wellness.

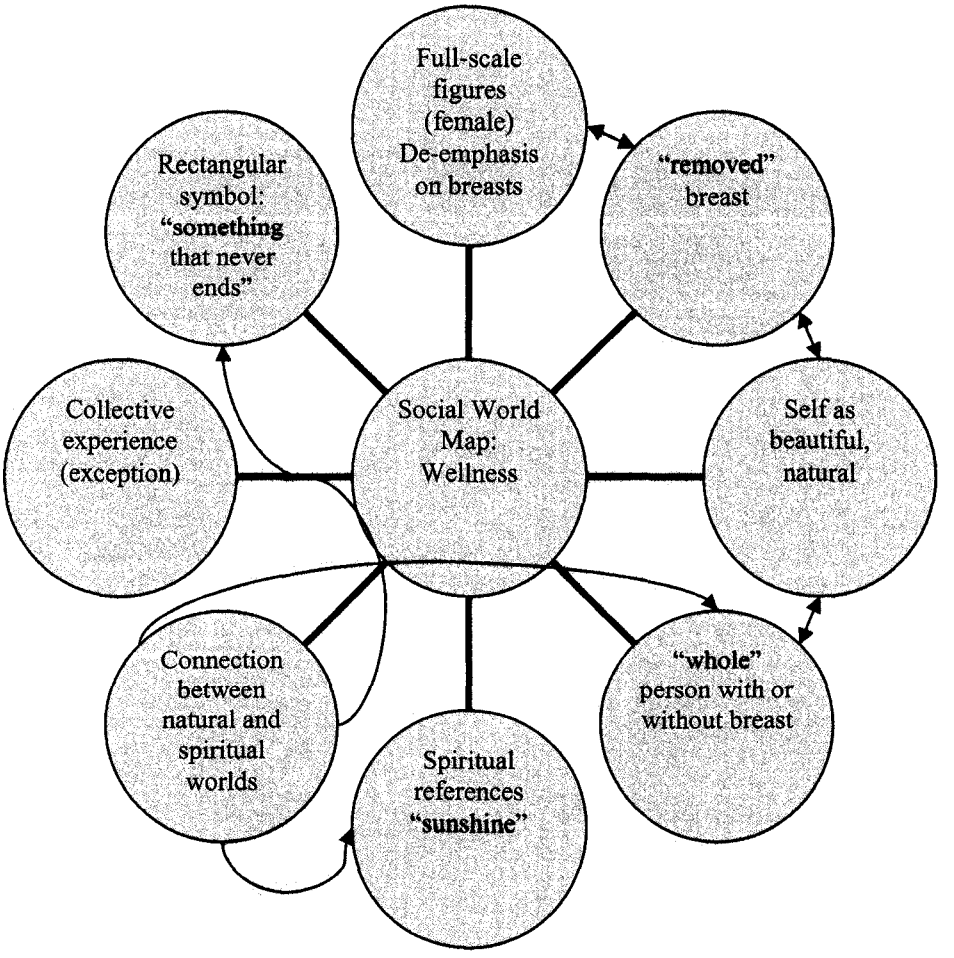

Figure 35: Wellness Social World Visual Discourse Map

Wellness demonstrated the most complexity in both the situational and social world maps. Depictions of spirituality were prevalent in all three pieces reflected in abstract clay forms ("something that never ends") as well as symbolic compositions (painting). Wellness was also portrayed in a literal manner incorporating a female form; both representations (clay and mixed media) deemphasized breasts, and in Miss

Hope's case, included only one breast-like form on her clay person. In spite of this, the figure was viewed a being "whole" and having attributes unique to American Indians, such as, "plain" (natural) beauty. The exception to depictions of Self was Miss Hope's portrayal of a collective experience involved with wellness.

3 Create a symbol of your choice. What can you tell me about this image?

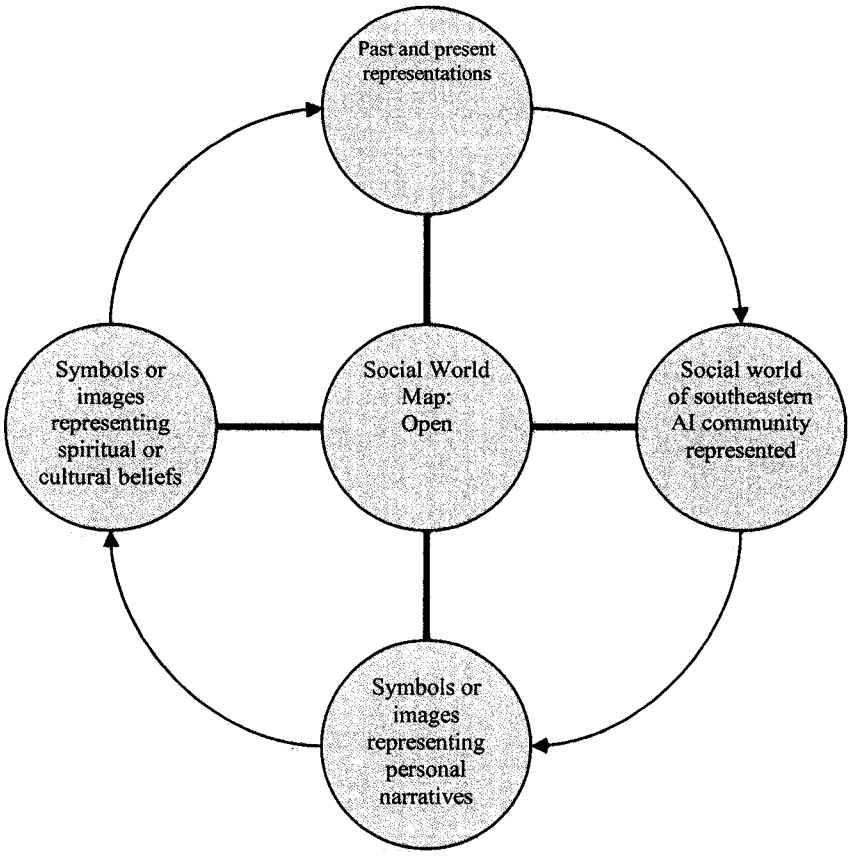

Figure 36: "Open" Social World Visual Discourse Map

In the map the social world of this community was literally being represented through realistic or naturalistic imagery detailing personal narratives. Images from past and present references were included as with Miss Turtle and Miss Hope. Symbols conveying spiritual beliefs were evident in Miss Sunshine's depiction of her church, whereas Miss Hope included a self-image in traditional regalia. All three images were distinct from

one another more so than the responses to wellness and breast cancer and cancer treatment. These visual "discourses" seemed to convey personal narratives from a sociohistoric and present perspective.

Positional map.

A positional map representing five dominant positions considered in social worlds map were constructed along two continuums: Axis I, continuum of breast cancer and cancer (understanding and lack of understanding) and Axis II continuum of wellness (mind/body and mind, body, spirit).

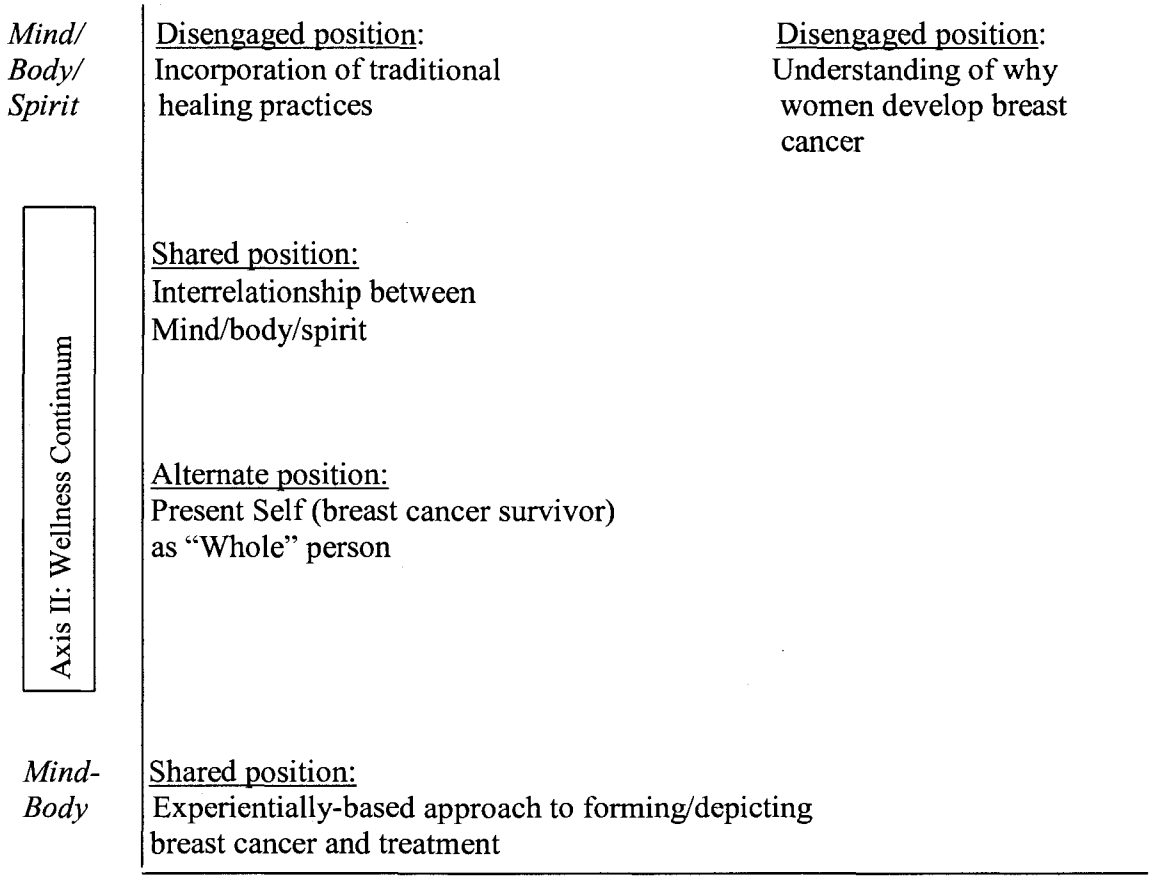

Figure 37: Visual Discourse Positional Map

At the point of convergence between understanding and mind/body, there was a shared position on breast cancer and cancer treatment. This position was apparent in the interactive or experientially-based approach to depicting or forming cancer. This process involved sequential stages to convey perceptions of cancer cells or growth in breast region, cutting or removal of cancer cells, and the emotional "phases" associated with the cancer experience. Miss Turtle's position on diagnosis, treatment, and emotional "phases" carried over into two of the art tasks (wellness and breast cancer and cancer treatment). Miss Turtle's visual narrative supported an alternate position on the breast cancer and cancer treatment continuum, reflecting a lack of understanding regarding the degree of emotional trauma associated with the cancer experience. A shared position between all three visual narratives was the connection between mind/body/spiritual practices in conceptualizing wellness. Miss Turtle and Miss Sunshine, both breast cancer survivors, presented a unique understanding of wellness, that is, present Self (breast cancer survivor) as a "whole" person. What was not included in the understanding of the mind/body/spirit was a "disengaged" position on the incorporation of traditional healing practices in this equation. Furthermore, a lack of understanding as to why people develop cancer was another "disengaged" position that was not considered in the visual narratives, and was included in this map thusly.

Summary

In preparation for the discourse analysis, a description of the co-collaboration process was provided. The method of transcription for the zoom model analysis was outlined as well as the "coding" procedures for the 10 lenses considered in the macro-zoom, meso-zoom, micro-zoom and transactional-zoom focus. The second form of

discourse analysis consisted of a two-part approach to situational analysis comprising methods of narrative and visual discourse. Both forms of situational analysis involved mapping techniques based on the "opening" of the data incorporating the observations from the zoom model and memoing procedure with the artwork. Additional data sources were included in the situational analysis to provide more in-depth supplemental information. The findings from the situational analysis resulted in two positional maps exploring or "positioning" the dominant themes from the narrative and visual discourse analysis representing the current position of American Indian health within two southeastern tribal communities.

CHAPTER FIVE

DISCUSSION

Introduction

It was through my involvement with the Spirit of E.A.G.L.E.S. that I was able to build partnerships with Native communities. In their view, art therapy was "very valuable to enhancing support services for Native American breast cancer patients in culturally acceptable ways" (Dr. J. Kaur, personal communication, August 28, 2006). There was a general acceptance of art therapy as a form of self-care and personal expression; this acceptance was apparent from the participants, community members, providers, and North Carolina Commission of Indian Affairs, and North Carolina Coalition of American Indian Senior Citizens, among others. It wasn't art therapy per se that "made sense" but the collaborative focus associated with a community-driven approach, allowing the participants' to have a voice in this study.

However outside these communities, from the inception of this study, I was confronted with the perennial question "Why are you researching American Indian breast cancer survivors, don't they have the lowest cancer rates?" Most people seemed to be befuddled that cancer was a problem in Indian Country. The chilling fact is that when I started this study, cancer was the third leading cause of death for American Indians (AAIP, n. d.), it is now the second leading cause of death for adults and elders 45 and above (AAIP, n. d., cancer para. 1). Unfortunately, occurrences of underreporting, misidentification, and inconsistent methods of surveillance have led to inaccuracies in

reporting cancer incidence (Kaur, 2005). What is known is that American Indians/Alaska Natives 45 years and older have the poorest survival rates for "all cancers combined" than any other racial and ethnic groups (ICC, n. d., iccnetwork.org./cancerfacts, para. 4). Within the southeast, in less than two years, I witnessed multiple occurrences of individuals being diagnosed with cancer. Over this brief period of time, it was not uncommon to hear about a recent diagnosis, a suicide because of cancer, or a family in distress because of lack of resources. This was concurrent with the 2007 Annual Report to the Nation (Espey et al., 2007), indicating that a rapid increase in cancer incidence for AI/AN. Moreover, in three of the twelve I.H.S. regions (Alaska, Northern Plains, and Southern Plains) cancer rates are equal to that of Whites. What is not known is the true impact of cancer in areas of the southeast, such as North Carolina where the population of AI residents is more than 100,000 (U.S. Census, 2001). To address this rise in incidence, the North Carolina Commission of Indian Affairs is assembling a tribal health board to create new policies related to cancer as well as establish a review board for their state-recognized tribes (Dr. R. Cummings, personal communication, September 5, 2008)

Again, why breast cancer? This question was often presented with puzzlement, especially in conjunction with the focus on American Indian women. Silence was often the response I received, and I can only speculate that this was attributed to the lack of awareness that there were American Indians in the southeast. My focus on breast cancer stemmed initially from the art therapy cancer literature and later from my involvement with the Spirit of E.A.G.L.E.S., where I was surprised to learn that the rates for breast cancer were the lowest of any racial or ethnic group. As I immersed myself in the data sources, I realized that the poor survival rates were disproportionately high considering

the low incidence and mortality rates for breast cancer, in particular. Intercultural Cancer Council seemed to present a different trend in terms of cancer rates increasing for AI/AN over the past 20 years, noting that AI/AN experience the poorest survivorship from cancer five years after diagnosis than any other medically underserved population (ICC, 2006). In spite of this disparity, the perception among health officials is that breast cancer is not an "Indian problem" (Hodge, 1999, p. 206) continue to be reinforced because the incidence rates are the lowest (Espey et al., 2007).

What impact can the stories from two American Indian breast cancer survivors have on psychosocial care? This is the question that stayed me throughout the study and one that will be touched upon throughout this discussion. Related to this, how do I know when the stories have achieved a level of saturation? This was a consideration in terms of collecting the narratives and the means for determining how many participants should be included in this study. It didn't work that way, instead the community "decided" for me. Two women graciously came forward to share the intimate details of their lives for this purpose. There were other women who were interested or had questions, but the level of involvement in this study might have been a deterrent. Based on my limited experience of conducting art therapy workshops in these communities, I discovered that group interventions are often well attended, whereas individual meetings are more intimate and require a level of trust between the co-collaborators. This finding was consistent with the literature supporting group therapy because of the group emphasis in American Indian communities in healing practices (Coylis, 1999). Individual encounters by people outside their community, whether Native or non-Native, are viewed a form of intrusion and suspicion (Dufrene & Coleman, 1994) until a level of trust can be

established. This observation seemed to counter the idea that one can have an "insider status" as a Native person (Lewis, Duran, & Woodlis, 1999).

I have found that collection and analysis of stories can make a difference. Reviewing the literature, narrative inquiry has a number of different approaches from in-depth studies of personal narratives or "full stories" (Tierney, 1994) to single-interviews or "small stories" (Safarik, 2003). This study, because of its emergent perspective, evolved into something in between a full and small story. Miss Turtle's interview leaned toward a more in-depth, storying process involving multiple re-tellings. Miss Sunshine's narrative seemed to be in keeping with my expectation, that is, a single interview with follow-up member check. Because of my open-ended approach, I was able to modify the protocol to include additional data sources to consider multiple perspectives, which became instrumental in providing a text in the situational analysis.

In this chapter, I will reflect on the process of analyzing my data and discuss relevant findings from the zoom model and two forms of situational analysis. In addition, the culminating "positions" from the narrative discourse and visual discourse positional maps will be discussed and considered in terms of their implications for practice and future research. Throughout this final chapter, the existing literature will be reviewed in conjunction with how these findings may or may not support current research and/or provide an alternate conclusion. This chapter is divided into four main sections: a summary of results, implications for practice and research, reflexive statement, and a final conclusion.

Summary of Results

Zoom model.

The process of transcribing the interview (Poland, 2003) in preparation for the zoom analysis (Pamphilon, 1999), allowed me to experience the storying process from a "third-party" perspective. Moreover, this form of transcription that was recommended focused more on *how* things are stated or expressed than transcribing verbatim (Poland, 2003). Although this process was time consuming, rather it was helpful for me to experience and concentrate in the interview the members' nonverbal inflections, laughter, and tone of voice. In retrospect, had I hired someone to do the transcribing, I would have lost out on this experience entirely. These stories were more or less permanently embedded in my mind and as I went through the analysis, I could literally "hear" the text from the transcript.

In order to observe the different "angles" of the zoom lens, I "coded" this information creating a color key identifying different "lenses" of the zoom model. This process helped me to visually observe patterns and trends to make inferences from, serving as yet another means of "opening" the data. Moreover, as a visually-sensitive individual, I was able to clearly see the interplay between the different macro, meso, and micro lenses. Laying out these color-coded transcripts side-by-side (Appendix N), enabled me to observe unique aspects of the narratives, such as when lenses or multiple views were "held" simultaneously. More predictable patterns emerged such as the focus on descriptive narratives in the beginning of the interview, most notably the demographic interview, and in-depth or emergence of felt expression toward the latter part of the interview.

The zoom model was a means to ground a sociohistorical frame that was held in both life stories. Each lens was more or less "held" to allow for narratives to be foregrounded, merge into the background, or become part of a middleground. This process of reflection from macro to micro perspective is reminiscent of the deconstruction process in narrative therapy. At times I found that my therapist self emerged in this process of deconstructing personal "truths" as with Miss Turtle's restorying of losing her voice. In the analysis, I referred to this as a meaning-making experience that resulted from this dialogue, providing an important alternate story to unfold. This story of finding one's voice, as a traditional American Indian woman endowed with different cultural art forms, seemed to be one of the dominant stories in Miss Turtles's discourse. Miss Turtle's story also reflected the "historical trauma" that seemed to characterize American Indians from her generation, losing one's voice, one's culture, and one's identity (Duran, 2006). For Miss Turtle "re-discovering" her voice seemed to parallel the many contemporary events (Civil Rights era, American Indian Movement) and reforms (N.C. Commission of Indian Affairs) over the past 40 years, leading to Miss Turtle's involvement with Indian Education through the N. C. Advisory Council on Indian Education (Richardson, 2006).

Miss Sunshine provided a multifaceted text interweaving the importance of spiritual beliefs and practices in every day life, and an understanding of breast cancer treatment, as well as a sociohistoric text. A dominant theme in her discourse was a holistic perspective that encompassed mind, body, and spirit, reflecting "core" American Indian beliefs about wellness. This holistic approach comprising "Native medicine" is distinct from conventional medicine as well as integrated medicine in holistic healthcare.

> The medical approach focuses on physical symptoms, etiology, and interventions. Native medicine uses a holistic approach that includes individual health dimensions: the physical, mental, spiritual, and environmental context of the person. (Murillo, 2004, p. 113)

In my experience, it was the primary emphasis on the spiritual dimension that made this form of holism separate from mainstream complementary and alternative approaches. Storytelling is another spiritual component of Native medicine, and is a different form of storying than what occurs in narrative therapy or narrative inquiry. As Miss Sunshine. so succinctly stated, "EVERYTHING has a story." Storytelling is often referred in AI/AN literature as an oral tradition and method of teaching spiritual values (Gorman & Balter, 1997), as well as a culturally-sensitive approach to therapeutic interventions (Garrett & Garrett, 1994).

After completing the zoom analysis, it was not clear how I was going to capture the richness of these stories through maps and diagrams, nor how I was going to address my research questions. The richness of the stories shifted my focus away, which seemed to follow a more phenomenonological course of methodology and less of a traditional narrative inquiry. Questioning my decision to include such an array of analyses, I later realized that the purpose of the zoom model was to open the data for the narrative discourse (situational analysis). Immersed in my data, I began to "distance" myself through the process of creating random and structured maps from my data sources which included additional interviews (archived and expert witness). The findings from my zoom analysis provided themes to "situate from" and were constructed into social worlds/arena maps situated around my research questions. Through a similar macro-meso-micro zoom focus, the different mapping techniques from the situational analysis enabled me to observe multiple "positions" related to my research questions. What made

this form of analysis different from grounded theory was *how* the data was situated, meaning it shifted the data away from dominant worldview and positioned the data, in this instance, in a sociohistoric, cultural, and spiritual framework. Had this data not been "situated" according to the participant's worldview and a broader AI "social world," the possibility of marginalizing these narratives or worse, yet, "pathologizing" their meaning existed. Critical race theory, in particular, addresses the importance of the storying process in narrative analysis, emphasizing the power of the counter-story in creating a different dialect (Delgado, 2000) or in this case, a "situated" position. This process of counter-storying in critical race theory complements the "situatedness" of the narrative discourse in constructing a "definitive position" beyond the "themes" or "patterns" belonging to a dominant mindset.

Art tasks.

As an art therapist, I was intrigued by the second form of situational analysis, referred to as visual narratives or discourse; however, I was somewhat unsure about how to situate these personal art forms. Most of the exemplars from Clark's (2005) text focused on situating visual forms mostly related to printed material, photographs, and other graphic art forms. Personal forms of artistic expression were not elaborated on, although referred to. In art therapy research, artwork is typically coded using classical content analysis either inductively or deductively (Kaiser, St. John, & Ball, 2006). Interpretations of art associated with projective assessments is also dependent upon the perspective of the art therapist, thus their worldview is a consideration in this process (Hays, 2001). However, through the systematic levels of memoing associated with visual discourse, a "situated" or more contextual means of opening the visual narratives was

provided. Through measures of "deconstruction," the visual narratives comprising of symbolic references were observed independent of the narrative discourse, permitting me to create a separate context for these images. This was critical in "situating" the visual narratives because the interrelatedness between storying process and image making was so intertwined, they seemed to "co-exist." This interrelationship represented a different orientation from the "traditional" approach to processing or discussing art, whereby an active dialogue between the researcher or participant is encouraged. However, in relation to this inquiry, the storytelling and image making seemed to be experientially-based for the participant and observer-based for the researcher, reflecting culture-bound values (Sue & Sue, 2008).

The situational maps created from the memoing procedure helped to ground the symbolic references in *context* to the individual, that is, her belief systems, personal values, and worldview. At this level of the analysis, there seemed to be such variation in the imagery that moving on to the social world/arena maps was overwhelming. Moreover, it felt counterintuitive to make generalizations about the artwork. But these did not become generalizations about stylistic features in American Indian art, which could have resulted in what Duran, (2006) and others refer to as "cultural glossing." Instead, these social worlds maps, oriented around the three main art tasks, became a means to position multiple perspectives derived from the visual narratives, in this case, personal symbols. As with the discourse analysis, a more definitive position emerged from the process of mapping the visual narratives.

Positional maps.

These simply constructed diagrams represent complex positions derived from the layers of analysis. These "synthesized" positions addressed the dominant trends posed in the research questions. Initially, I attempted to separate this content into four sections, that is, presenting the research question and "answering" it based on the positional maps. Because of the interrelatedness of the different positions, I approached this from a primary and secondary focus implied in my research questions. The primary seemed to be centered on perceptions of breast cancer and breast cancer treatment. The secondary considerations (although equally important) considered the remaining research questions oriented around concepts and belief systems related to wellness and illness. The art and storytelling were not separated out and were reflected upon in both sections.

- How do Native American women, diagnosed with breast cancer, experience their treatment in medical institutions?

This position seemed to be best represented in the visual discourse map, indicating an "interactive" or experientially-based approach to depicting/forming a symbol reflective of breast cancer and breast cancer treatment. This position converged at the point of *mind/body* on the wellness continuum and *understanding* in the breast cancer and breast cancer treatment continuum. The experience of observing the women (Miss Hope, Miss Turtle, and Miss Sunshine) create symbolic image was reminiscent of a performance in many ways. In this respect, I was the intended audience, a witness to these accounts. Kapitan (2003) articulated this role as a "collaborative witness" assisting in the transformation of personal stories.

What was omitted in these visual narratives was an interrelationship between mind/body/spirit, a dominant theme in the narrative discourse. In retrospect, the emphasis on the mind/body connection, as well as emotional response in this visual narrative, were rather straightforward reflecting a direct response to a direct task. In my experience in working with Native communities, cooperation is a shared culture-bound value (Sue & Sue, 2008) and their straightforward approach seemed to reflect this value.

What was not apparent was a position on why people develop breast cancer. There were references at times but not an open discussion. I wondered if this tied into belief systems about wellness and illness: "The spirit, mind, and body are all interconnected. Illness is a disharmony between these elements" (Sue & Sue, 2008, p. 351). Similarly, positive emotions have a healing effect (M. T. Garret & Wilbur, 1999); this was reflected in Miss Sunshine's visual and narrative discourse. As a result, there may be an avoidance to discuss illness because of its relationship with disharmony.

A growing trend was indicated in a shared position on acceptance and awareness of cancer education and prevention, suggesting that collaborations between the medical and AI communities are having a positive impact. This position was supported by Miss Promise's description of the Cancer 101 classes for the Waccamau Siouan tribe. However, access to healthcare services was not a position that was not articulated by the women, nor was the absence of Indian Health Services, with the exception of Miss Promise's interview in her role as health outreach coordinator. Considering the degree of "over reporting" of cancer program barriers for AI/AN (Burhanisstipanov, 2006a) the position of state-recognized southeastern tribes was not clearly defined, possibly because of their marginalized status in cancer research and the lack of reporting.

- What are their beliefs surrounding wellness and physical illness? How does this belief system affect their view of treatment? How are these beliefs expressed through artmaking and storytelling?

Concepts related to wellness were positioned on both the visual and narrative map, suggesting a level of resonance among all the participants. Moreover, wellness was its own continuum displaying a variance between mind/body and mind/body/spirit. Interestingly, in my literature review, wellness was not clearly defined in my proposal defense and something that I struggled to define in everyday language. Creating the maps, viewing the artwork, and discussing wellness in the interviews enabled me to "experience" this concept for myself. In retrospect, wellness involved a more spiritual connection than I had previously thought; in fact, spirit/body/mind would be a better sequence to represent this concept. Reflecting back on this experience, I understand wellness as less of a concept and more as spiritual connectedness, a state of harmony. In the interviews, I referenced this being "balanced"; however, in hindsight this interpretation doesn't seem to accurately represent the extent to which spirituality plays a part. In the words of Miss Turtle, "it's a deep thought" and something that is not easily defined.

Holism from a Native perspective is where "mind, body, spirit, and nature are perceived as one process and little separation exists between religion, medicine, and the activities of daily life" (Heinrich, Corbine, & Thomas, 1990, p. 130). This understanding differs from the emphasis on mind-body interaction in integrated, holistic medicine, and alternative and complementary medicine (OCCAM, n. d.). Among the Lakota, this perspective is also referred to as the "Red Road," or a journey to wellness (Weaver,

2002). Although practiced differently, Native people share similar ideas about the interconnection between spirituality and wellness.

Because of the emphasis on wellness, perceptions of illness were more or less positioned in the background as state suggesting the absence of spirituality. In hindsight, illness was probably not elaborated upon because it was not referenced directly in the art tasks. In context to wellness, what really challenged my assumptions was the idea that a female breast cancer survivor is still "whole" with or without breasts. Much of the literature on breast cancer is oriented around psychological self-repair, suggesting that a period of mourning, depression, anger, and denial associated with the loss of a "beautiful and highly libidinal organ" (Dreifus-Kattan, p. 151). This sense of loss was not an overt theme in the discourse analysis nor did this surface in the artwork as conscious or unconscious material. This could have been attributed to a reparation of self-image through the grieving process as well as years of survivorship. Either way, spirituality seemed to be a dominant factor in concepts of wellness, more specifically, conceptualizing the breast cancer survivor as a "whole" person.

Traditional healing practices, referenced in the demographic interview, were not addressed openly. In fact this understanding required multiple meetings, a separate interview with Miss Sassafras, a known healer, in order to ascertain how these practices factored into cancer treatment, further defining concepts related to wellness and illness. I referred to this position as "disengaged," to indicate that there was a collective understanding of the importance of traditional practices which existed outside the visual data collected for this study. This apparent "omission" challenged my ideas about personal art making in terms of the widely held belief in art therapy that individuals tend

to reveal more through the art process than they realize. Many art therapists refer to this as "making the unconscious conscious." Most of the content from the 12 images seemed to represent latent content (conscious material), whereas the manifest content (unconscious material) seemed to reinforce what was already "known" about the imagery.

> ...Indians in particular have understood for centuries that art is fundamentally a way of seeing. It is not a stylish and refined decoration; it is not a luxury remote from the necessities of daily life; and it is not the property of an elite. For Native peoples art is an essential human process which vividly depicts human diversity. It reminds us that the eye is a real physical and sensual organ and not simply an orifice leading into the logical brain, where it dutifully delivers pragmatic information. (Highwater, 1980, p. 26)

This way of seeing is evident in all the images, such as in the emphasis of greenness of Miss Sunshine's tree and the yellow outlines of her human figure, the circular layers of Miss Turtle's colors to represent emotions, and the personal use of blue in Miss Hope's painting of wellness. These are a few examples that suggest that *seeing* is also a way of *experiencing* individually and collectively.

Although references to traditional healing practices were not explicitly depicted in the artwork, it was through the "collective" storying process that I was able to access some of these stories. Because of these narratives, I was able to position the "co-existence" of traditional healing practices and conventional medical treatment as an accepted practice within this community. However, outside this community, there was an acknowledgement that this was not an accepted practice, e.g., use of herb tea because of either a lack of awareness or adequate knowledge about their use.

What was common between the medical and Native community was a spiritual position addressing the importance of divine healing or faith in God in cancer treatment. However, the sociohistoric position (e.g., Native people survived without modern

medicine) supported the lack of awareness of an American Indian health position that medical treatment and traditional healing practices can co-exist and do co-exist as complementary approaches. This is the approach that I.H.S. supports and has provided funding for to train traditional healers to work with medical communities (Dr. Trujillo, personal community, August 15, 2007). Because of the lack of access to I.H.S., this understanding of an AI health position is not supported by either community, reflecting a "disengaged" position.

Implications for Research and Practice

It was Dr. Kaur's repeated recommendations about research that helped me understand how to put theory and practice together. This was not fully clear to me until I attended a Spirit of EAGLES conference in Savannah, GA and participated in a grant writing class with Dr. Strickland or "Auntie June." Through experiences such as this and resources such as the *National Cancer Institute's Theory at a Glance: A Guide for Health Promotion Practice* (2005), I realized the importance of theory building (micro-macro focus) in context to community-driven and participatory models.

Considering this theory-building framework, how does narrative inquiry support this position? This was a question that I posed to "Auntie June" in our grant writing course. My understanding is that by "situating" the research in a specific community through needs assessments or focus groups, you are providing a context for the project vs. imposing outside ideas. The interview process and collaborative focus groups provide a means to not only collect data but to also prioritize health issues. Interviews and focus groups also assist with developing a basis for a cultural context and building theory. From this data, a culturally-relevant, holistic, pilot program can be co-constructed

through partnerships and community involvement. An infrastructure to sustain these programs within the community is developed through "train the trainer" programs and outcomes are considered in terms of what is transferable to other Native communities. In this respect, personal narratives can serve as a foundational means of building theory into practice.

Related to this, in working with tribal communities, there is a high level of involvement from the community that extends beyond the tribal Institutional Review Board procedure. This involvement can take the form of partnerships, an overseeing advisory committee, gatekeepers to assist in recruitment, and even in the data collection process, e.g., the "collective storying." In my experience, the tribal review process is one stepping stone in conducting research in Native communities; it is the support of the community that is paramount. This is what my friend spoke of when she addressed the degree of "reciprocity" in my study. These questions relate to *current* concerns about conducting research with AI/AN, for example, the misuse of research findings (secondary analysis), questions about who "owns" the data, and not reporting the research findings to the community.

What was my plan after the study ended? Was I going to take the data and publish my findings and leave? My ultimate aim is to continue working in these communities to co-construct a culturally relevant approach to psychosocial care incorporating the expressive arts. What I have discovered in the literature is that the inclusion of cultural art forms is integral to making therapeutic interventions culturally appropriate (Paniaquia, 1998). Most traditional researchers would probably balk at the idea of being involved with the participants once the study has ended. Native

communities are shifting toward a decolonizing agenda in supporting research and guidelines for practice, what is referred to as decolonizing research, are being established to support "ongoing life-time commitment to the Indigenous people" (Prior, 2006, p. 166).

Reflecting on the "methodology," a recommendation to go "full" story in repeated, multiple retelling of cancer experience is being made as well as the bringing in of the "collective" storying process ("witness"/expert from the community) in ethnographic forms of narrative inquiry. In retrospect, this study seemed to incorporate three different narrative approaches, multiple storying as with Miss Turtle, a "traditional" narrative inquiry (single interview) as with Miss Sunshine, and a "collective" storying focus with Miss Sassafras and Miss Turtle. The emergent design throughout this study enabled me to openly modify the narrative focus and artmaking directives to allow for a more culturally relevant approach to unfold.

Although, narrative inquiry was an appropriate "methodology," it was not entirely culturally relevant. For example, a less "active" form of interviewing was required, that is, listening to the individual, respecting her as the "expert" of her story. This was consistent with a culture-bound value of listening, especially in relation to an elder or person in position of authority (Sue & Sue, 2008). Moreover, observations or inferences made beyond a request for this information, would have been contrived since interjection and "feedback," in the form of encouragement, is not a communication style among American Indians. When an opinion was sought or direction needed, conveyed nonverbally or verbally, this was an invitation for me to speak and be verbally engaged in the interview. My role as researcher seemed more like a silent "witness" at times and in

keeping with my personality and experience interacting with Native people. These differences in worldviews or culture-bound values suggests that a more culturally-responsive method of conducting narrative inquiries is needed.

Focusing on the text and the visual art forms seemed to take away from the process of making art. Both narratives indicated significant changes in terms of meaning making experience, elicited by making art and expressed through nonverbal or preverbal cues (hushed voice, silence, whispers). Procedural recommendations would consider the use of video to capture nonverbal communication and process of making art. This would be of great importance because of the degree of high-context communication that occurs within Native culture (Hall, 1976). This primary form of communication involves the explicit use of nonverbal cues to convey meaning that is specific to a cultural group.

The interaction with the art materials and the degree of interplay between storying and artmaking confirmed my position, and the position shared by another Native art therapist, Phoebe Dufrene (Dufrene & Coleman, 1994), that art is not a universal language that is accessible to all. This perspective requires a revising of art therapy to be more culturally responsive: "The use of art forms in helping situations involves more than merely analyzing the doodle or drawing of a client. Rather, helping professional work with clients to identify the image(s) they have created" (Herring, 1997, p. 237). Person-centered approaches in art therapy is one means of responding to cultural differences; however, if the therapist has not evaluated her own biases and assumptions that contribute to her worldview, then one remains blind to the differences. To address differences in worldviews, recommendations by Native practitioners have considered the following: an understanding of Native perspectives of wellness and healing, an

awareness of within group differences, an understanding of the sociohistoric factors resulting in the mistrust of outsiders, adapting an integrated approach to therapy, and a willingness to devise and implement culturally-appropriate art therapy techniques (Dufrene & Coleman, 1994; Herring, 1997). The list of recommendations does not end here because what is essential in working with any Native community is the role of collaboration and an understanding of individual and systemic worldviews. Moreover, because of the within group differences among AI/AN, a general approach to providing art therapy services for Native people cannot be assumed. Reflecting back on the community theory and practice model (NCI), the inclusion of culturally-relevant art forms in expressive arts therapies are not imposed, but rather stem from a process of co-collaboration.

Reflexivity

This notion of personal transformation was addressed in my research log throughout the proposal development phase and during the actual study. The research log prompted me to explore some of these ideas about reflexivity into 14 art pieces. This allowed for my artist self and researcher self to merge. My preliminary thoughts about reflexivity were more Self-oriented, that is, as a form of self-awareness and personal transformation. This idea evolved as I immersed myself into the study and my personal art making. What resulted was a deeper understanding of the different dimensions of reflexive work and the implications it had on this community. This body of work involved a layering of different perceptions and feelings through the process of assemblage. The quadrangular format and color references, associated with the southeastern conceptualization of the four directions (white, yellow, red, and black),

provided a "foundation" to work from. This series was exhibited at a local gallery and incorporated an artist talk addressing the notion of reflexivity.

My visual entries and written responses in my research log provided a means to explore personal biases and assumptions prior to implementing this study as a form of "personal reflexivity" (Appendix O) (Willig, 2001). This process of self-awareness enabled me to explore my worldview. As I became more involved with the AI/AN cancer community through the Spirit of EAGLES conferences, I was engaging in a form of "positional" reflexivity (Appendix P) and beginning to understand the worldview of this community (MacBeth, 2001). By positioning myself in the cancer community in North Carolina through conference workshops and a related study, I began to immerse myself in their social world, providing more of a "text" for the collaboration process.

This form of "textual" reflexivity (Appendix Q) involved more of a reciprocal relationship and was vital in terms of becoming more grounded in Native epistemology (Duran, 2006). To further explore this way of knowing, I was encouraged to conduct a pilot intervention, and did so on myself and a member of the Coharie tribe, exploring through an "epistemological" form of reflexivity (Appendix R). In my response work to this intervention, I focused on assumptions and biases that were previously held through a more "introspective" form of reflexivity (Appendix S) (MacBeth, 2001). The collaborative meaning-making experiences that emerged from the narrative inquiry comprised a type of reflexivity referred to as "constitutive." This collaborative or "constitutive" process was the impetus for the culminating body of work involving an "interweaving" of different thoughts, feelings, stories, and responses to these relationships (Appendix T). Art processes incorporating techniques such as burning,

cutting, layering, covering, filling were utilized to symbolically represent my thoughts, feelings, and concerns about my participants and their community and a means to process some of the stories related to trauma, discrimination, survivorship, and resiliency. Transformed on so many levels by this experience, I am currently in the process of constructing a body of work focusing on "disengaged" reflexivity or response work to the "outcomes" of this study.

Conclusions

Where do we go from? What impact can two art-based narrative inquiries, a pilot, and two interviews have on a community that has not been included in much of the AI/AN cancer literature? Little is known about cancer incidence, access to health services, and psychosocial care for state-recognized tribes. This study is one of many cancer-related initiatives occurring within these communities to create a position for American Indian health for southeastern state-recognized tribes. Through presenting my findings for the North Carolina Commission of Indian Affairs I hope to contribute to shaping a position.

On a more "micro" level, this study served as a means for Miss Turtle to retell her story and engage in a process of counter-storying (meaning making) the importance of her role in her community. As an aside, her involvement in this study led to her decision to share her life story with her children. At a Coharie Powwow last October, I was able to see Miss Turtle in her traditional regalia. She confided in me that her daughter was so moved by her mother's story that she was considering it for a possible book with her mother's blessings. For Miss Sunshine sharing her story has been an important part of her survivorship and her participation in this study was articulated at

the end of our interview: "I hope it will help to, to help someone else or or help, you know, get the story together, you know, cause everybody has a part and your part is trying to pull it together, so."

The "collective" storying process associated with Miss Sassafras's interview enabled a revered 86-year-old Waccamau Siouan healer to not only have a voice but to speak out about traditions, beliefs, and practices that are seldom shared with "outsiders" and be heard. Miss Sassafras's interview was documented in two formats (audio and visual) and are now part of the archives of the Waccamau Siouan tribe with her blessings as well. For Miss Hope and Miss Promise. this study provided a form of recognition for their advocacy; their work has provided a much-needed health focus in their respective tribal communities.

As I end this study, I am often confronted with the question, "what's next?" assuming that my involvement in this community is over. I think one of the main differences between Native and non-Native researchers is the importance of contributing to one's community; this is something that is expected of all Native people, that is, to participate in a collective way of knowing. What's next for me has already started with the submission of a NIH grant co-written by the Native American Cancer Initiatives, Inc. Linda Burhanisstipanov, the Executive Director, has graciously served as my mentor in this respect. Through this partnership and ongoing support from the Spirit of EAGLES, my focus is to develop culturally-relevant art therapy workshops to address quality of life factors their effect on cancer survivorship.

Summary

This final chapter was divided into four main sections focusing on the summary of the results, implications for practice and research, and reflexivity. The process of analyzing my data was described, and a summary of the relevant findings from the zoom model and situational analysis was presented. The culminating "positions" from the narrative discourse and visual discourse positional maps were further discussed in relation to the research questions. Two dominant positions emerged from these maps, indicating a shared position, among the participants, on the mind/body/spirit emphasis in wellness and a sociohistoric position suggesting a lack of awareness of traditional American Indian healing practices among providers. Finally, an American Indian health position was established focusing on the acceptance of medical treatment and traditional healing practices as complementary approaches. Implications for practice and future research considered emergent design and participatory models as a means to build theory in development of culturally relevant approaches. Throughout this chapter, the existing literature was reviewed in conjunction with how these findings may or may not support current research and/or provide an alternate conclusion. Reflexivity, comprising the layers of self-awareness and intersubjectivity with the participants, constituted the last section of this chapter before the concluding statement.

VI. EPILOGUE

One unfortunate casualty, which resulted from this study, related to a lack of understanding and support from my colleagues. Because narrative inquiry "looks" like therapy at times and involves participating after the interview, the suggestion that I was providing counseling services without a license or malpractice insurance. This scrutiny was more hurtful than anything and led to my resignation prior to my defense date. What resulted from this study in terms of our graduate program was a removal of narrative inquiry and all postmodern forms of qualitative research from the research options. Not only did this leave me feeling marginalized as a research, supervisor, instructor, thesis advisor, it made me realize that collaborative methods of research needs to be supported by a culturally-responsive institution. Because of the innovativeness of this approach, narrative researchers Jossellson, Lieblich, and McAdams (2003) co-edited *Up Close and Personal: The Teaching and Learning of Narrative Research* to partially address misconceptions about narrative inquiry as a form of research.

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Appendix A

Letter of Support from North Carolina Commission on Indian Affairs

AUG-14-2007 15:07 FROM:NC COMM. INDIAN AFF. 9197331207 TO:7574466179 P.003/003

North Carolina
Department of Administration

Michael F. Easley, Governor
Britt Cobb, Secretary

N.C. Commission of Indian Affairs
Gregory A. Richardson, Executive Director

August 14, 2007

Colorado State University
Research Integrity and Compliance Review Board
321 General Services Building
Ft. Collins, Colorado 80523-2011

Re: Dissertation of Elizabeth Warsaw

To Whom It May Concern:

Allow me to express my deepest support for the dissertation of Elizabeth Warsaw. Elizabeth Warsaw's commitment to work with American Indian tribes in North Carolina is greatly appreciated. Her genuine interest in helping our people through the Art Therapy Program at Eastern Virginia Medical School is truly an outstanding contribution to our communities. Her program has generated acceptance and interest on the part of American Indian leaders in our state. It is our desire to have Elizabeth continue to provide this unique service to American Indian communities in North Carolina.

The North Carolina Commission of Indian Affairs is committed to advocacy and it is our mission to bring to American Indians good and valuable programs such as the Art Therapy Program. I encourage each one of you to give your wholehearted approval and support to this important work on behalf of American Indians in North Carolina.

Sincerely,

Gregory A Richardson

Gregory A. Richardson
Executive Director

Mailing Address:
1317 Mail Service Center
Raleigh, N.C. 27699-1317

Telephone (919) 789-5900
Fax (919) 420-1373
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Location:
100 E Six Forks Road
Raleigh, North Carolina

An Equal Opportunity/Affirmative Action Employer

Appendix B

Tribal Council Letter

Dear Tribal Council Member:

To follow-up on my letter of introduction [referring to a previous study], I am sending you a letter briefly outlining my proposed art therapy study. I am also enclosing a copy of the approved protocol and consent form from my institution for your review process. I will be contacting you over the coming weeks to answer any questions that the council may have.

Project Title

"Art Therapy Narrative Inquiry with American Indian Breast Cancer Survivors" is an art therapy dissertation study for American Indian women who are breast cancer survivors.

Purpose

The purpose of this narrative inquiry is to explore, through artmaking and storytelling, the belief systems surrounding wellness and physical illness from the perspective of American Indian breast cancer survivors. This narrative inquiry would provide the ground work for more culturally competent psychosocial interventions utilizing the expressive arts.

Rationale

Rates of breast cancer have increased among Native American women in urban and rural communities. Translational studies in cancer research with underrepresented minorities have focused primarily on prevention, education, and barriers to healthcare. Perceptions of Native American cancer survivors have been addressed in ethnographic studies, suggesting a need for more culturally sensitive healthcare. What is lacking in the research is a culturally competent psychosocial intervention (art therapy), and a postmodern approach (narrative inquiry) to collecting breast cancer stories.

Anticipated Outcome

The anticipated outcome is to create a culturally competent art therapy workshop for American Indian cancer survivors. The results of this study and any related publications will be shared with the Commission on Indian Affairs and participating American Indian communities.

Please let me hear from you. My phone number is: (757) 446-5895 or (757 636-6395. Email is: warsonea@evms.edu

Sincerely,

Elizabeth Warson

Appendix C

North Carolina American Indian Tribes and Organizations
Updated: July 31, 2007

Tribe/Executive Director	**Address**	*Telephone/Fax/Email*	*Chair*
Coharie Tribe Elizabeth Maynor Executive Director	7531 N U.S. Hwy 421 Clinton NC 28328	Phone: Fax:	Gene Faircloth Chief
Cumberland County Association for Indian People Gladys Hunt Executive Director	2173 Downing Road Fayetteville NC 28301	Phone: Fax:	Roy Maynor
Eastern Band of Cherokee Paxton Myers Tribal Administrator	PO Box 455 Cherokee NC 28719	Phone: Fax:	Michell A. Hicks Principal Chief Albert Crowe, Chair
Guilford Native American Association Rick Oxendine Director	PO Box 5623 Greensboro NC 27435 1100 Revolution Mill Drive, Studio # 6,	Phone: Fax:	Frances Stewart Lowry
Haliwa Saponi Indian Tribe Archie Lynch Executive Director	PO Box 99 Hollister NC 27844	Phone: Fax:	Gideon Lee
Lumbee Tribe of North Carolina	P.O. Box 2709 707 Union Chapel Rd Pembroke, NC 28372	**Phone:** **Fax:** **Fax-Adm:**	Jimmy Goins, Chair
Meherrin Indian Tribe	PO Box 508 Winton NC 27986	Phone: Fax:	Thomas Lewis
Metrolina Native American Association **Donald Strickland** Executive Director	8001 N. Tryon Street Charlotte, NC 28262	Phone: Fax:	Mr. Robin Lynn Strickland
Occaneechi Band of Saponi Nation	PO Box 356 Mebane, NC 27302	**Phone:** **Fax:**	W.A. "Tony" Hayes Tribal Chair
Sappony Dante Desiderio Executive Director	4218 Virgilina Rd Virgilina VA 24598 PO Box 3265 Roxboro NC 27574	Phone: Fax:	Dorothy Crowe
Triangle Native American Society	Post Office Box 26841 Raleigh, NC 27611	Phone:	Lana Dial President

		www.tnasweb.org	
Waccamaw Siouan Development Association	P. O. Box 69 Bolton, NC 28423	**Phone**: 910-655-8778 **Fax**: 910-655-8779 siouan@aol.com	Paula Jacobs, Chair 462 Willie Jacobs Avenue Clarkton NC 28433 910-646-3964

Appendix D

Recruitment Text (verbal) for Health Outreach Coordinators

Elizabeth Warson is an art therapist who is currently working with American Indian cancer survivors in our community. She is interested in interviewing individual breast cancer survivors as part of her dissertation work. This interview will include making art and talking about your experience with breast cancer and cancer treatment. The interview will not take more than 2 hours of your time and can take place at your home, a family member's home, or a local community center. She will provide the art supplies and will bring snacks. She will need to photograph your artwork and tape record your stories to include in her dissertation paper. Your name and who you are in the community will not be shared in this paper. If you are interested in the study, I will let Elizabeth know and we will arrange a meeting to discuss any questions or concerns you may have. Elizabeth thanks you for listening to her request.

Appendix E

Consent to Participate in a Research Study
Colorado State University

TITLE OF STUDY:
"Art Therapy Narrative Inquiry with American Indian Breast Cancer Survivors"

PRINCIPAL INVESTIGATOR: Nathalie L. Kees, Ed. D., School of Education, 224 Education; (970) 491-6720; Nathalie.Kees@colostate.edu.

CO-PRINCIPAL INVESTIGATOR: Elizabeth Warson, Assistant Professor, Eastern Virginia Medical School, P. O. Box 1980, Norfolk, VA 23501; (757) 446-5895; (757) 446-7101; warsonea@evms.edu.

WHY AM I BEING INVITED TO TAKE PART IN THIS RESEARCH?
You are being asked to participate in this research project because you are an American Indian female between the ages of 18 and 85 years of age and have or had a diagnosis of breast cancer.

WHO IS DOING THE STUDY?
Elizabeth Warson is an American Indian doctoral student, art therapist, and a faculty member in the Graduate Art Therapy Program at Eastern Virginia Medical School in Norfolk, Virginia. This study is being partially funded through a scholarship from the Barbara Rosenblum Foundation for the Study of Women and Breast Cancer.

WHAT IS THE PURPOSE OF THIS STUDY?
The purpose of this study is to explore, through artmaking and storytelling, the belief systems surrounding wellness and physical illness from the perspective of an American Indian breast cancer survivor. This study will provide the ground work for developing more culturally respectful programs, utilizing art therapy, for American Indian cancer survivors.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?
The art making and storytelling will take place at a location convenient to the participant (for example, a personal residence or community center) for up to 2 hours. After the art making session, ongoing communication will be encouraged between Elizabeth Warson and the participant to discuss the analysis and how your information will be incorporated into the study. The communication could occur as part of a face-to-face visit, phone call, email correspondence, or through regular mail.

WHAT WILL I BE ASKED TO DO?

As a participant in the study, you will be making art individually with Elizabeth Warson. You will be provided with a choice of different art materials (drawing, painting, clay, collage) and asked to make art in response to one, two, or all three the following tasks:

Task 1:

4 Using lines, shapes, and colors, or using clay, please make a symbol that represents what it means to have breast cancer and undergo breast cancer treatment.

5 What can you tell me about this symbol?

6 If you could alter or change this symbol in any way, what would you do?

7 Please make those changes (if any) on your drawing or clay.

8 How is this reflective of your circumstances now?

Task 2:

9 Using lines, shapes, and colors, or using clay, please make another symbol that represents wellness.

10 If you could alter or change this symbol in any way, what would you do?

11 Please make those changes (if any) on your drawing or clay.

Task 3:

12 Create a symbol of your choice. What can you tell me about this image?

13 If you could alter or change this image in any way, what would you do?

14 Please make those changes (if any) on your drawing or clay.

ARE THERE REASONS WHY I SHOULD NOT TAKE PART IN THIS STUDY?
You should not take part in this study if you are not an American Indian or Alaska Native breast cancer survivor between the ages of 18 and 89. Experience in art is not a requirement for this study, and therefore, not a reason why you should not take part in this study. If English is not your primary language, you are not eligible to participate in this study.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?
It is not possible to identify all potential risks in research procedures, but the researcher(s) have taken reasonable safeguards to minimize any known and potential, but unknown, risks. In the event you should experience an adverse reaction (becoming enraged, feeling excessive sadness, or may have thoughts of hurting yourself or someone else), you will be referred back to your healthcare system or community outreach coordinator.

ARE THERE ANY BENEFITS FROM TAKING PART IN THIS STUDY? If you agree to take part in this study, there may or may not be direct benefit to your and your community. It is hoped that the benefits of participating in this study will lead to the development of art therapy programs for American Indian cancer survivors and their family members in rural and urban communities. The results of the study will be shared with the American Indian community through a presentation to tribal council members, presentations at American Indian cancer conferences, American Indian publications

DO I HAVE TO TAKE PART IN THE STUDY? Your participation in this research is voluntary. If you decide to participate in the study, you may withdraw your consent and stop participating at any time without penalty or loss of benefits to which you are otherwise entitled.

WHAT WILL IT COST ME TO PARTICIPATE? There are no costs associated with this study. Art supplies and a stipend for travel will be provided by Elizabeth Warson. All costs related to any phone calls or mailed material associated will be covered by Elizabeth Warson.

WHO WILL SEE THE INFORMATION THAT I GIVE?
We will keep private all research records that identify you, to the extent allowed by law.

Your personal information (artwork, taped stories) will only be reviewed by Elizabeth Warson. After the study has been completed, the tapes will be deleted and the pictures of your artwork will be coded with a number and stored under lock and key. With your written permission, your artwork may be reproduced in future publications and/or included in presentations.

Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be

identified in these written materials. The results of this study will be presented to the Commission on Indian Affairs and shared with your tribal community; however, we will keep your name and other identifying information confidential.

CAN MY TAKING PART IN THE STUDY END EARLY?
You may end the art making or interview any time before the two hour period.

WILL I RECEIVE ANY COMPENSATION FOR TAKING PART IN THIS STUDY?
A small gift of art supplies will be provided to all participants after the interview.

WHAT HAPPENS IF I AM INJURED BECAUSE OF THE RESEARCH?
The Colorado Governmental Immunity Act determines and may limit Colorado State University's legal responsibility if an injury happens because of this study. Claims against the University must be filed within 180 days of the injury.

WHAT IF I HAVE QUESTIONS?
Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the co-investigator, Elizabeth Warson at (757) 446-5895 or warsonea@evms.edu or the principal investigator, Nathalie Kees at (970) 491-6720 or Nathalie.Kees@colostate.edu. If you have any questions about your rights as a volunteer in this research, contact Janell Meldrem, Human Research Administrator at 970-491-1655. We will give you a copy of this consent form to take with you.

WHAT ELSE DO I NEED TO KNOW?
Your tribal council has been informed of the study and has granted Elizabeth Warson permission to conduct the art therapy interview.

Your signature acknowledges that you have read the information stated and willingly sign this consent form. Your signature also acknowledges that you have received, on the date signed, a copy of this document containing 5 pages.

_____ _____

Signature of person agreeing to take part in the study Date

_____

Printed name of person agreeing to take part in the study

_____ _____

Name of person providing information to participant Date

_____

Signature of Research Staff

Appendix F

Coharie Letter of Invitation

Coharie Intra-Tribal Council, Inc.

7531 North U.S. 421 Hwy.
Clinton, N. C. 28328

Phone (910) 564-4905
(910) 564-6909
Fax (910) 564-2701

October 11, 2007

Colorado State University
Research Integrity & Compliance Review Board
321 General Service Building
Ft. Collins, Colorado 80523-2011

Ref: Dissertation of Elizabeth Warson

To Whom It May Concern:

I would like to convey my heart felt desire to say this is a different approach to healing for the cancer victims and family members who have suffered along with the cancer patients. Elizabeth Warson presented this project to our Tribe, the Coharies, and we agreed to plan a proper date to receive this project not knowing what it entitled.
I sat in at the workshop titled Art Therapy and Story Telling. I thought to myself this has never been done with our Tribe, it will work because they love and relate to art and story telling. We had so many to sign up for this event that we had to turn some members away. I welcome these types of therapy workshops and I thank Ms. Warson for her hard work and consideration. I am speaking for the Coharie Tribe as supporting this project 100% and will do whatever it takes to see it to the end. I pray to the creator to continue with the healing tool for our people, the last people, Native American Indians, but not forgotten. It's a worthwhile, first time acknowledgement of such a blessing and we thank you. The Coharie Tribe again supports your project.

Sincerely,

Elizabeth Maynor
Coharie Tribe Executive Director

Appendix G

Letter of Approval from Colorado State University

Colorado State University

Research Integrity & Compliance Review Office
Office of Vice President for Research
Fort Collins, CO 80523-2011
(970) 491-1553
FAX: (970) 491-2293

Notice of Approval for Human Research

Principal Investigator: Nathalie Kaoa, Education, 1588
Co-Principal Investigator: Elizabeth Warson, Education, 1588
Title: Art-Based Narrative Inquiry with Native American Breast Cancer Survivors
Protocol #: 07-218H **Funding Source:** n/a

Number of Participants/Records: 2 participants
Committee Action: **Approved on:** August 31, 2008 **Expires:** August 30, 2009

IRB Administrator: Janet Barker

Consent Process:
The above-referenced project was approved by the Institutional Review Board with the condition that the attached consent form is signed by the subjects and each subject is given a copy of the form. *NO changes may be made to this document without first obtaining the approval of the IRB.*

Investigator Responsibilities:

- It is the PI's responsibility to obtain this consent form from all subjects.
- It is the responsibility of the PI to immediately inform the IRB of any serious complications, unexpected risks, or injuries resulting from this research.
- It is also the PI's responsibility to notify the IRB of any changes in experimental design, participant population, consent procedures or documents. This can be done with a memo describing the changes and submitting any altered documents.
- Students serving as Co-Principal Investigators must obtain PI approval for any changes prior to submitting the proposed changes to the IRB for review and approval.
- The PI is ultimately responsible for the conduct of the project.
- A status report of this project will be required within a 12-month period from the date of review. Renewal is the PI's responsibility, but as a courtesy, a reminder will be sent approximately two months before the protocol expires. The PI will be asked to report on the numbers of subjects who have participated this year and project-to-date, problems encountered, and provide a verifying copy of the consent form or cover letter used. The necessary continuation form (H-101) is available from the RICRO web page http://ricro.research.colostate.edu.
- Upon completion of the project, an H-501 should be submitted as a close-out report.
- If approval did not accompany a proposal when it was submitted to a sponsor, it is the PI's responsibility to provide the sponsor with the approval notice.
- **Should the protocol not be renewed before expiration, all activities must cease until the protocol has been re-reviewed.**

This approval is issued under Colorado State University's OHRP Federal Wide Assurance 00000647.
Please direct any questions about the IRB's action on this project to me for routing to the IRB.

Attachment Date of Correspondence: 9/1/08

Animal Care and Use | Drug Review | Human Research | Institutional Biosafety
101 General Services Building | http://www.vpr.colostate.edu

Appendix H

Letter of Approval from Eastern Virginia Medical School

EASTERN VIRGINIA MEDICAL SCHOOL
OFFICE OF RESEARCH SUBJECTS PROTECTIONS
INSTITUTIONAL REVIEW BOARD

November 8, 2007

Elizabeth Warson, M.A., ATR-BC
Graduate Art Therapy Program
EVMS Lewis Hall, 700 W. Olney Road
Norfolk, VA 23510

IRB # 07-11-EX-0270

Dear Dr. Warson:

This form provides additional information to the "APPLICATION FOR APPROVAL OF RESEARCH INVOLVING HUMAN SUBJECTS" form that accompanies this letter. The Application is the official document that confirms IRB review and type of approval and includes the IRB#, study title, and an appropriate chair, vice-chair or IRB member signature.

The following documents approved by Colorado State University have been accepted by the EVMS IRB:

☒	Application for Approval of Research Involving Human Subjects	
☒	Protocol: "Art-Based Narrative Inquiry with Native American Breast Cancer Survivors" (including Appendices A through E)	(not dated)
☒	Consent Form	(not dated)

This approval is a result of an **Expedited Board** action that specified the following category/categories under 63FR 60364 dated November 9, 1998:

☒ (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

☒ *This study was approved on November 1, 2007 and may be initiated now that you are in receipt of Final Approval documents.*
- IF YOU ARE CONDUCTING YOUR RESEARCH AT ONE OF THE LOCAL HOSPITALS, YOU MUST RECEIVE THE APPROPRIATE APPROVALS FROM THAT HOSPITAL BEFORE INITIATING YOUR STUDY.
- IF YOU ARE CONDUCTING YOUR RESEARCH AT A SITE OTHER THAN EVMS, YOU ARE RESPONSIBLE FOR OBTAINING ANY LOCAL REVIEW NECESSARY FOR THE CONDUCT OF THIS RESEARCH.

☐ Special consideration was given to the inclusion of members of a vulnerable population in your study. The Board determined that you have incorporated proper protection of your subjects through local IRB review and community support.

☒ *You have satisfied the Human Subjects Protection Training requirements.*
☒ *You have completed an Investigator Assurance.*

☒ **Your protocol expiration date is October 31, 2008. Continuing review reports are due 60 days prior to protocol expiration.**

☒ Please remember that prompt reporting to the IRB of proposed changes in a research activity (e.g., changes to the protocol, consent form(s), advertisements, or other study-related materials) is required. In addition, the changes must be reviewed and approved by an EVMS IRB before the changes can be initiated except when necessary to eliminate apparent immediate hazards to the subject.

Eastern Virginia Medical School (EVMS) has a Federalwide Assurance (FWA 00003956) from OHRP. The Human Research Review Boards (IRB 00000460 and IRB 00001345) are registered with OHRP and are in compliance with 45 CFR 46, 21 CFR 50, and 21 CFR 56.

Please reference the IRB number, principal investigator and study title in any correspondence regarding this protocol.

Thank you for your continued cooperation with the Institutional Review Board.

Sincerely,

Barbara D. Cypher, CIP
IRB Manager

BC/cwa

P.O. BOX 1980 NORFOLK, VA 23501-1980
TELEPHONE: (757) 446-8423 FAX: (757) 624-2275
IRB.INFO@EVMS.EDU

Appendix I

Demographic Questionnaire

1. What is your age?

2. What tribe are you from?

3. When did you first find out that you had breast cancer?

4. What type of cancer treatment did you receive? Location?

5. What kind of healthcare/medical insurance do you have?

6. Did your cancer treatment include traditional American Indian practices, such as, teas, herbs, poultice, smugging?

7. Is there a history of cancer in your family?

8. What are your sources of emotional support?

Appendix J

Art Directives and Interview Questions

Please review the following art tasks and questions. You will have a choice to complete one, two, or all three art tasks. You will also be asked to draw for 5 minutes in a circle at the beginning and ending of our interview. You will have 2 hours to complete and discuss these drawings.

Task 1:

15 Using lines, shapes, and colors, or using clay, please make a symbol that represents what it means to have breast cancer and undergo breast cancer treatment.

16 What can you tell me about this symbol?

17 If you could alter or change this symbol in any way, what would you do?

18 Please make those changes (if any) on your drawing or clay.

19 How is this reflective of your circumstances now?

Task 2:

20 Using lines, shapes, and colors, or using clay, please make another symbol that represents wellness.

21 If you could alter or change this symbol in any way, what would you do?

22 Please make those changes (if any) on your drawing or clay.

Task 3:

23 Create a symbol of your choice. What can you tell me about this image?

24 If you could alter or change this image in any way, what would you do?

25 Please make those changes (if any) on your drawing or clay.

Appendix K

Legend for Transcription

Pauses

Short pauses indicated by series of dots (...)

Two dots = less than half a second

Three dots = one second

Fours dots = one and a half seconds

Longer pauses of two to three second breaks = (pause)

Pauses of four or more seconds = (long pause)

Laughing, coughing, sighs etc.

Stated parenthetically, e.g., (cough), (sigh)

One person laughing = (laughing)

More than one person laughing = (laughter)

Interruptions

Denoted by use of hyphen (-) at breaking point in conversation

Overlapping speech

Hyphen (-) used to indicate the when the another person is overlapping

(overlapping)

Inaudible speech

Words that are decipherable but unclear are bracketed with a question mark on the end [clear?]

The use of x's denotes a passage of inaudible speech, e.g., xxx xx xxx

Appendix L

Color Key for Zoom Model

Macro-zoom

Dominant discourses

[redacted]

[redacted]

Meso-zoom

Narrative process

Narrative themes

Key phrases

Micro-zoom

Pauses

Emotions

Interactional-zoom

[redacted]

Reaction

Appendix M

Specification Memo

Selection:

Framing: (inclusions, exclusions, cut off's)

Featuring: (foreground, middle ground, background, present)

Viewpoint: (close-up, medium shot, long shot, low angle, high angle)

Light:

Color:

Focus/Depth of Field:

Presense/Absense:

Intended/Unintended Audience(s):

Composition:

Texture:

Scale and Format/Proportions:

Technical Elements:

Single or Multimedia:

Relationship to Other Work in Same Media:

References:

Remediations:

Situatedness:

Relations with Visual Culture(s)

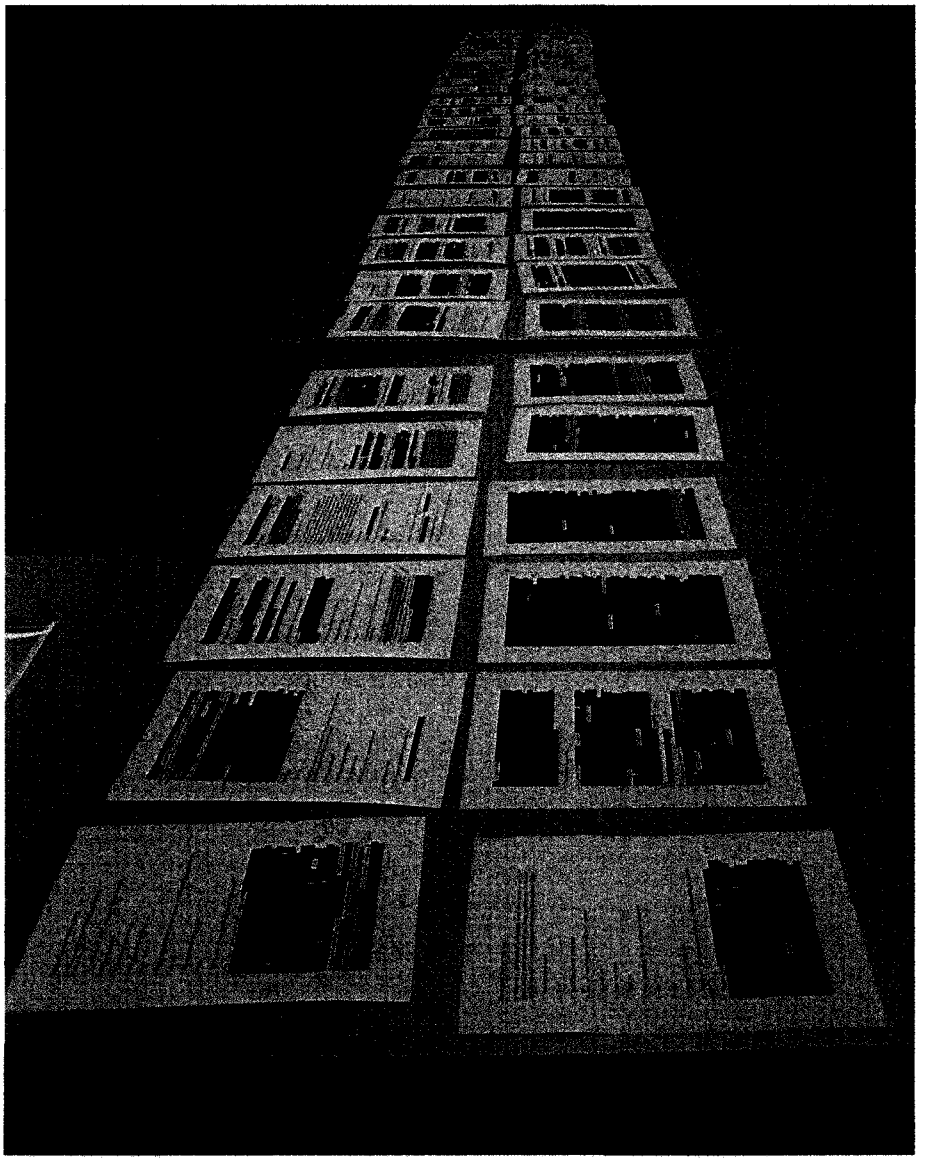
Commonness/Uniqueness:

Work of the Image:

Injunctions to Viewers

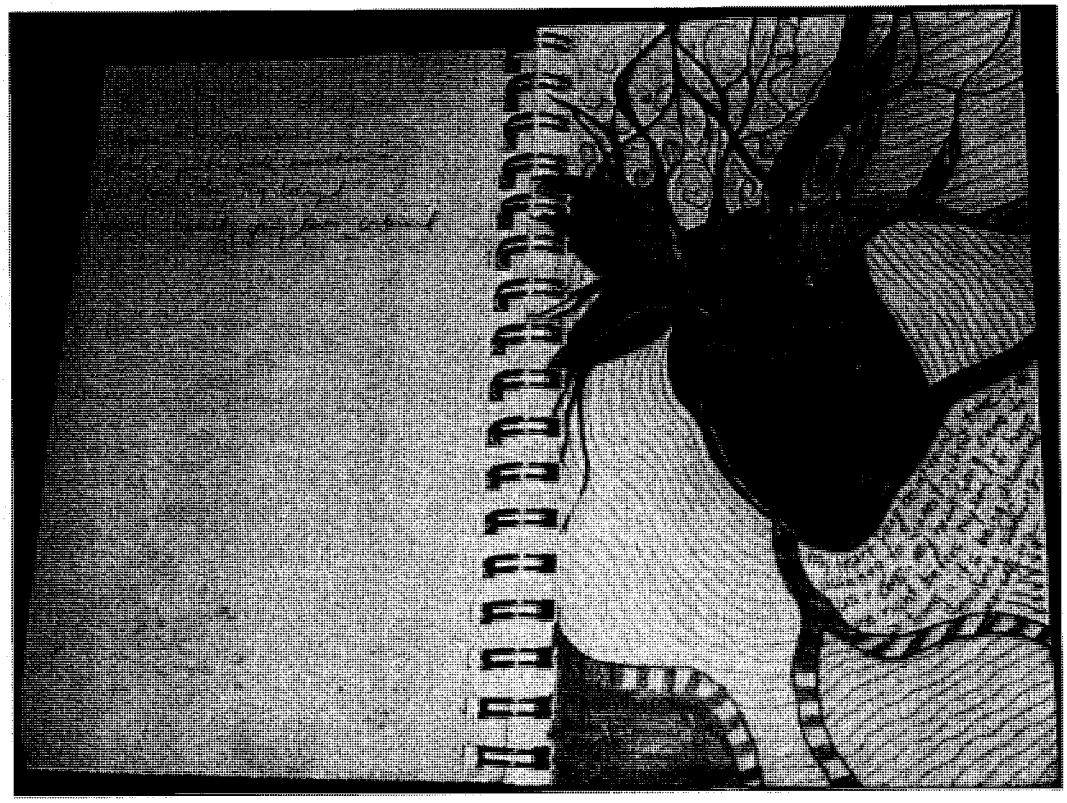
Appendix N

Illustration of Zoom Model analysis



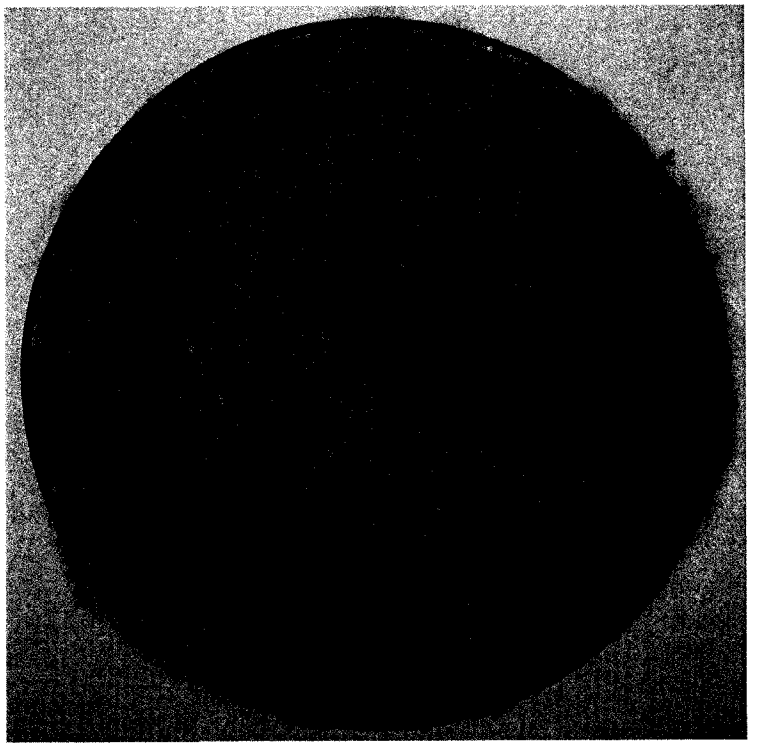
Appendix O

Personal Reflexivity



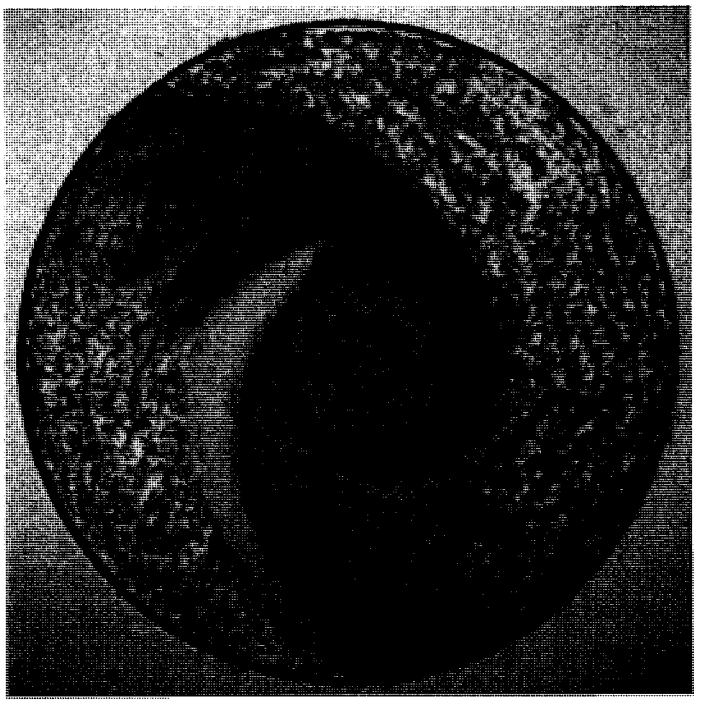
Appendix P

Positional Reflexivity



Appendix Q

Textual Reflexivity

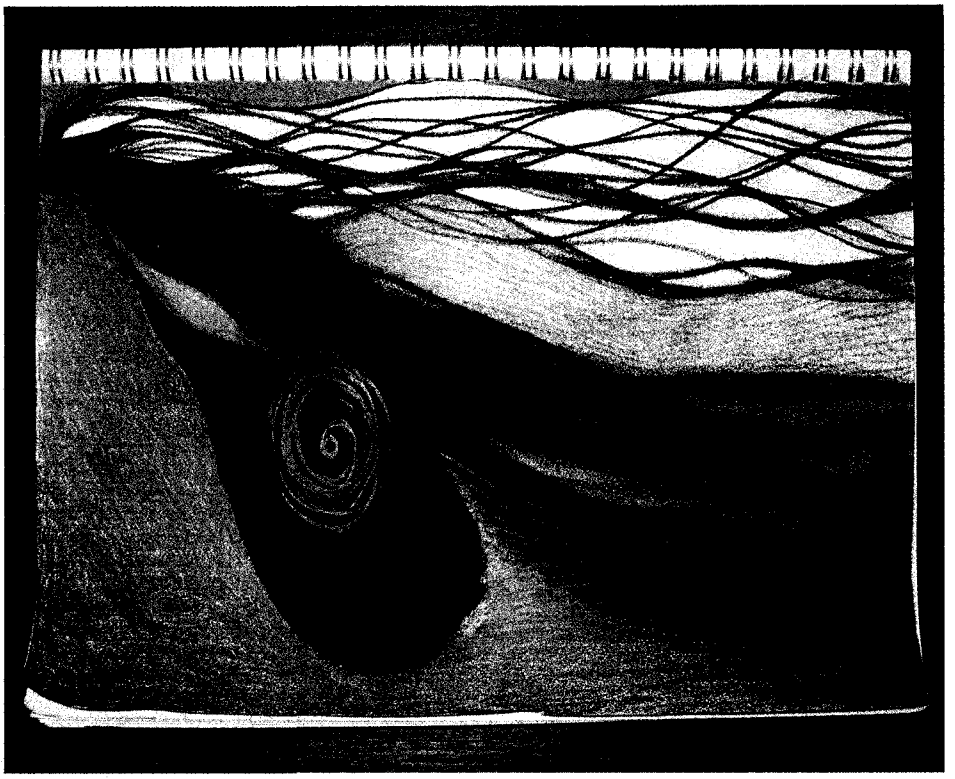


Appendix R

Epistemological Reflexivity

Appendix S

Introspective Reflexivity



Appendix T

Constitutive Reflexivity