

HUMANIZING THE INHUMANE: THE MEANING OF THE AMERICAN INDIAN  
PATIENT-CANCER CARE NURSE RELATIONSHIP

by

Natalie M. Pool

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SIGNED: Natalie M. Pool

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## DEDICATION

This dissertation is dedicated to all of the American Indian patients, families, and communities that have been impacted by cancer and to the hard-working nurses who care for them.

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## ABSTRACT

**Background:** Nurses comprise the majority of cancer care providers in the United States (U.S.) and play a pivotal role in patient experiences and outcomes. The establishment of caring relationships in order to provide high quality cancer care is particularly challenging for nurses who engage with ethnic minority populations as they contend with cultural and contextual influences different from those found in the majority population. American Indians (AI) represent an indigenous minority group in the U.S. facing a considerable cancer care inequity. Nurses who serve AI patients, families, and communities frequently encounter population-specific issues that impact the caring dynamic. Their experiences and the meaning they ascribe to them are largely unknown.

**Purpose:** This study described the unique relationships that develop while providing cancer care to AI populations and the underlying meaning that nurses ascribed to these experiences.

**Methods:** This was an interpretive phenomenological study with multiple data collections and analysis. Nine cancer care nurses with a minimum of three years of experience working with AI patients participated by engaging in 2-3 exploratory, open-ended, reflective interviews over a period of nine months. Thematic reduction was completed to explicate the fundamental structures of this particular relationship. I then engaged in extensive reflective writing resulting in a linguistic transformation illuminating the essential meaning for nurses within this patient-nurse phenomenon.

**Results:** Findings include individually-situated wholistic descriptions capturing the existential experiences of each of the participants. Reduction of individually-situated themes into seven shared meta-themes included: From Task to Connection; Unnerving Messaging; We Are One;

the Freedom of Unconditional Acceptance; Attuning and Opening; Atoning for the Past, One Moment at a Time; and Humanizing the Inhumane. Themes were explicated in a comprehensive general structural description followed by the reconstitution of the data and self-reflection into a deeply introspective essential description, suggesting the meaning embedded within this distinctive relationship.

**Implications:** Results are intended to contribute to the development of interventions designed to improve both the AI cancer care experience and the support and training of the nurses who serve this population. Further research into the AI patient's perspective of their relationships with cancer care nurses is called for.

## INTRODUCTION

Nurses comprise the majority of cancer care providers in the United States (U.S.) and play a pivotal role in patient experiences and outcomes (U.S. Department of Health and Human Services Health Resources and Services Administration, 2013; Hildebrandt, 2012; Raingruber & Robinson, 2010). Cancer care issues such as end-of-life considerations, multifaceted symptom management, and complex treatment trajectories create scenarios where nurses act in a prominent capacity as supporters and advocates for patients (Hildebrandt, 2012; Kelly & Minty, 2007; Potter et al., 2013; Raingruber & Robinson, 2010). The establishment of caring relationships in order to provide high quality cancer care is particularly challenging for nurses who engage with ethnic minority populations as they contend with cultural and contextual influences different from those found in the majority population (Baba 2012, 2013; Kelly & Minty, 2007; Murphy & Clark, 1993; Shahid, Finn, & Thompson, 2009). Nursing care of minority groups presents language and other types of communication challenges coupled with conflict surrounding treatment philosophies and discordant interpretations of wellness and disease (Alpers & Hansson, 2014; Kelly & Minty, 2007; Koithan & Farrell, 2010; Murphy & Clark, 1993; Shahid et al., 2009). These contextual considerations undoubtedly impact the development of authentic, effective, and fulfilling patient-nurse relationships during cancer care in many minority groups.

American Indians and Alaska Natives represent a racial and ethnic indigenous group in the U.S. comprising approximately 2% of the population (U.S. Department of Health and Human Service Office of Minority Health [OMH], 2015). This study pertained to nurses who provided cancer care to American Indians (AI) only, representing over 5 million people in the lower 48-

states region (OMH, 2015). The literature suggests that AIs experience significant health repercussions emanating from the historical trauma, marginalization, and systemic discrimination specific to this population (Institute of Medicine, 2013; Katz, O'Neal, Strickland & Doutrich, 2010; Keltner, Kelly, & Smith, 2004). For example, AIs bear a disproportionate cancer burden with malignant neoplasms as the leading cause of death for AI females and the second leading cause for AI males (Burwell, McSwain, Frazier, & Greenway, 2014). The AI cancer inequity is striking in that it is not the result of high disease incidence but rather increased mortality and morbidity (Cobb, Wingo, & Edwards, 2008; Guadagnolo et al., 2009; Vasilevska, Ross, Gesink, & Fisman, 2012; White et al., 2014). Other challenges impeding cancer care equity include

- Overall, AIs exhibit lower cancer screening rates, later stage diagnosis, and increased treatment complications (Burwell et al., 2014; Guadagnolo et al., 2009). This is particularly concerning when cancers are preventable or highly screenable such as colon, cervix, prostate, and breast (Guadagnolo et al., 2009; Nuno et al., 2012; Vasilevska et al., 2012). This evidence suggests that care providers, including nurses, may be failing to facilitate timely and effective cancer care among this population including the establishment of trusting relationships with AI patients and communities.
- Thus, a key feature of successful cancer care is an effective patient-provider relationship (Lamb et al., 2011). Yet the literature suggests that AIs describe significant issues related to providers such as ineffectual communication tactics, cultural insensitivity, perceived discrimination, and aggressive or dominating approaches to care delivery (Baba, 2012; Guadagnolo et al., 2009; Strickland, Squeoch & Chrisman,

1999; Vasilevska et al., 2012; Warne, Kaur & Perdue, 2012). As the largest group of direct cancer care providers, nurses potentially reside at the center of these relational and cultural safety issues.

- Cancer care inequity among AIs remains largely unchanged over the past 30 years despite significant improvement among other racial and ethnic groups in the U.S. (Espey, Paisano, & Cobb, 2005; Nuno et al., 2012; White et al., 2014). Nursing as a discipline has professed a commitment to raising the health status of the world's population through the promotion of equality, particularly among those that are underserved or marginalized (Falk-Rafael, 2005; Hall, 1999, 2004). However, nurses have been largely unable to impact the persistent AI cancer inequity despite our professional, moral, and ethical obligations *and* the disciplinary focus on caring relationships (Watson, 2006).

When viewed collectively, the literature suggests that systemic failures are taking place *during the provision of cancer care* for AIs contributing to cancer *care inequity*. As key cancer care providers and patient advocates, nurses have the potential to improve health equity in this particular arena due to our capacity and obligation to facilitate authentic, caring relationships that empower both patient and nurse within the wellness process and ultimately improve population health (Falk-Rafael, 2000; Watson, 2006). Yet nurses who care for AI patients, families, and communities frequently encounter population-specific issues that impact this dynamic (Aboriginal Nurses Association of Canada, 2009; Keltner et al., 2004; Murphy & Clark, 1993; Walsh et al., 2011). Therefore, this study explored and described the unique relationships that

develop while providing cancer care to AI populations and the underlying meaning that nurses ascribe to these experiences.

### **Significance**

This study contributes to the existing body of knowledge in several ways. First, illumination of the nuances of the essential AI patient-nurse relationship embedded in the cancer care process will contribute to the development of interventions designed to improve the patient experience. This may in turn promote earlier entry into cancer prevention and screening systems for AIs and enhance treatment partnerships, resulting in decreased mortality and morbidity.

Secondly, understanding the meaning of cancer care relationships for nurses working with AI patients and communities will assist in developing improved methods of support and training for nurses. Adequate support and training for nurses is associated with greater job retention, increased compassion, and the delivery of high quality and culturally safe care (Alpers & Hanssen, 2014; Bell & Breslin, 2008; Hildebrandt, 2012; Kelly & Minty, 2007; Raingruber & Robinson, 2010; Stone & Moskowitz, 2011).

Lastly, refinement of nursing praxis will ultimately result in improved outcomes for *both* nurses and AI patients, reflecting the inseparability of the two entities within the cancer care relationship. The complimentary and mutually dependent nature of the patient-nurse relationship implies that strengthening and improving support for one entity may in turn positively impact the other (Watson, 2006).

### **Purpose and Aims**

The establishment of a caring, authentic, and productive patient-nurse relationship is critical to improving the AI cancer care inequity (Lowe & Struthers, 2001; Keltner et al., 2004;

Watson, 2006). Although AIs' underutilization, distrust, and dissatisfaction with cancer care systems and providers is well-documented, there is a dearth of literature describing nurses' interpretations of the AI cancer care inequity or their perceptions regarding their relationships with these patients and communities (Guadagnolo et al., 2009; Strickland et al., 1999; Vasilevska et al., 2012). How the AI context impacts nurses and their ability to develop compassionate and effective cancer care relationships has not been previously investigated. Therefore, the purpose of this study was to describe the situated meaning of the AI patient-cancer care nurse relationship utilizing an interpretive phenomenological methodology. This study explored and described the interpersonal experiences of providing cancer care to AI patients and the underlying meaning for nurses at the most elemental level by reconnoitering and delineating this complex relationship-driven phenomenon (Crotty, 1996).

**Research Aim #1: Describe the immediate experiences of nurses that have engaged in cancer care relationships with AI patients.** Objectives included:

- Explore and describe the existential experiences and associated feelings of being in a cancer care relationship with AI patients, families, and communities using individual nurses' language.
- Examine the conflicts, rewards, and intricacies for individual nurses of this specific type of care relationship.
- Identify and describe where nurses situate themselves individually in relation to the AI cancer care disparity.

**Research Aim #2: Identify the underlying structures of the AI patient-cancer care nurse relationship as described by nurses.** Objectives addressing this aim were:

- Compare and contrast individual nurses' perceptions in order to elucidate the shared experience of being in a cancer care relationship with AI patients.
- Identify common themes and patterns related to this specific type of nursing relationship, creating a rich structural description of the phenomenon.

**Research Aim #3: Interpret the meaning of the patient-nurse relationship within the context of AI cancer.** Objectives included:

- Examine and describe the collective situated meaning of patient-nurse relationships within the overall AI cancer care inequity.
- Transform individual and shared interpersonal experiences into a comprehensive essential description of the relationship-centered cancer care phenomenon.

These research aims addressed the question, "What is the meaning of the AI patient-cancer care nurse relationship from the nurses' perspective"? Results from this investigation contribute to interventions designed to improve the AI cancer patient-nurse relationship and subsequent patient outcomes that may begin to address the inequities observed in cancer morbidity and mortality. Study results may also assist in the refinement of nursing praxis while giving voice to those who so often engage in the difficult task of providing cancer care to underserved minority populations in silence.

### **Paradigmatic and Worldview Congruency**

*What is known and how it is known* are important from a research perspective. Ontology represents the content and substance of knowledge including the topics of interest, applied

theories, and the search for what it means to *be within* and *in relation to* the world (Hart, 2010; Reed, 2011). Epistemology determines the methods used in the pursuit of “truth” and to what degree of certainty those means and findings are accepted by practitioners in a field of study (Rodgers, 2005). Epistemology and ontology combine to create a worldview. This study is conceived from the Unitary-Transformative worldview, a transcendental and holistic view of the world that is patient-centered and relationship-based (Newman, Smith, Pharris, & Jones, 2008)

My ontological worldview is informed by the structures of understanding and meaning that have been created by my experiences of providing care to a wide variety of underserved and multicultural patients, including in two different AI communities in the southwestern U.S. (van Manen, 1990). The focus for this study was not on what nurses who engage in cancer care with AIs *know* but rather how they *are* within-the-relationship. This perspective is in alignment with the chosen methodology utilized in this study as interpretive phenomenology attempts to uncover the situated meaning of *being* human rather than describing the characteristics of phenomena as they are consciously perceived (Lavery, 2003).

Regarding epistemology, I fundamentally believe in the centrality of context in relation to reality and reject any single truth as advanced by postmodernism (Prasad, 2005). Postmodernism demands that we consider and value the issue from every angle, paying close attention to the multiplicitous and tentative nature of assumptions and assertions (Mill, Allen, & Morrow, 2001; Rodgers, 2005). Nursing research can and should derive meaning from culture, language, and context while valuing sources of knowledge beyond the dominant framework (Reed, 2012; Rodgers, 2005; White, 2012). Postmodernism is congruent with both the topic of study and the ontological origins of interpretive phenomenology through the identification of the nurses’

highly individualized (and potentially repressed) immediate interpretations of their realities (Crotty, 1996). These reflections are then reconstituted through analysis to transcend subjectivity and create a collectively shared meaning as a method for creating knowledge (van Manen, 1990).

Lastly, Newman et al.'s (2008) Unitary-Transformative worldview emphasizes holism and is congruent with an investigation into a phenomenon as intangible and broad as a healing human-to-human relationship. The inability to separate the parts from the whole or to remove person from context are two central postulates of this paradigm that are in alignment with the hermeneutic circle utilized during interpretive phenomenological inquiries (Crotty, 1996; Koithan, 1997; Newman et al., 2008). The Unitary-Transformative worldview guides the pursuit of explicit and implicit patterns that influence health while recognizing the elusiveness of the human experience (Koithan, 1997; Newman et al., 2008; Reed, 2012). As both nurse and patient engage in the caring dynamic, each is transformed, either permanently or fleetingly, creating an experience ripe for exploration and the assignment of meaning (Falk-Rafael, 2000). This study seeks to name and assign meaning to that transformation so that we better understand our *lived-in* world as cancer care nurses serving AI populations.

### **Use of the *American Indian* Term**

It is important to acknowledge the use of the term *American Indian* in this study to describe the original and Indigenous inhabitants of the continental U.S. This label is often interchangeably used with others such as Native American, American Indian/Alaska Native, Indigenous, or Aboriginal in nursing research (Struthers et al., 2005). *Aboriginal* is commonly seen in regards to the indigenous peoples of Australia and Canada with the latter increasingly incorporating *First Nations* and *Metis* terminology to more accurately reflect political status and

racial composition (Aboriginal Nurses Association of Canada, 2009; Baba, 2012, 2013). Struthers et al. (2005) interviewed five AI nursing scholars and concluded that each individual, community, or tribe should be consulted regarding the preferred term. For the purpose of this study, the general terms *American Indian*, *Indigenous*, and *Native* was interchangeably used as is commonly found in the nursing and American Indian Studies literature. This was also a deliberate reflection of the geographical location of this study (the southwestern U.S.) where these labels are most often utilized and understood to represent the Indigenous inhabitants of the region and does not typically include Alaska Natives or other groups.

### **Historical Exploration of the AI Patient-Cancer Care Nurse Relationship**

There is a dearth of literature pertaining to the AI-cancer care nurse relationship specifically, but a comprehensive historical review of relevant literature begins to illuminate this mostly unknown phenomenon under study. A brief overview of cancer care and the patient-nurse relationships within this arena of care exemplifies both the standard and the ideal interpersonal interactions proposed by the nursing discipline.

Nearly 2,600 nurses and approximately 300-400 advanced practice nurses work within the federally-funded rural and urban health care systems that deliver care to AIs and Alaska Natives, representing a significant cohort of frontline direct-care providers engaged in cancer prevention and control, among other health conditions (Baba, 2012). Thousands of additional nurses provide cancer care to AIs in the public or private sector. Unfortunately, the literature indicates that AIs describe perceived discrimination and an absence of culturally safe care throughout the healthcare system, contributing to disengagement and under participation across various cancer care settings and conditions (Guadagnolo et al., 2012; Nuno et al., 2012;

Schumacher et al., 2008; Strickland et al., 1999; Vasilevska et al., 2012). And, at the very heart of this issue is the perceived lack of caring by healthcare providers, including nurses (Guadagnolo et al., 2008; Lowe & Struthers, 2003; Strickland et al., 1999). AI patient-cancer care nurse relationships are often strained, ineffectual, and a contributing factor to negative cancer care experiences and subsequent outcomes for this minority population (Baba, 2012; Lowe & Struthers, 2001; Vasilevska et al., 2012).

Although the literature clearly identifies that nurses working in cancer care experience high levels of compassion fatigue and psycho-emotional responses such as unresolved grief and moral distress (Henry, 2014; Hildebrandt, 2012; Katz et al., 2010; Keltner et al., 2004; Potter et al., 2013), there is a gap in our understanding about actual patient-nurse relationships and the meaning of providing care for these populations from nurses' perspectives. Therefore, to better comprehend the past experiences that each brings to the caring relationship, a retrospective review of the context of AI healthcare is warranted. In addition, an examination of the historical and sociopolitical background of AI healthcare structures and the subsequent impact on the contemporary AI patient-nurse relationship helps to situate this study by illuminating the often contentious yet emotionally fragile environment in which cancer care takes place. Several factors contribute to this relationship discord, including an overview of key historical and legislative events emphasizing AIs as a highly-politicized people; an exploration of ways that a particular brand of colonialism adopted in the U.S. continues to subjugate AI worldviews, particularly those concerning health; and the cumulative social consequences of these events on AI lifeways and health. How this multifaceted sociopolitical background potentially impacted the AI patient-cancer care nurse relationship is discussed.

## **The Nature of Cancer Care**

Cancer care encompasses a wide range of services requiring the coordination and collaboration of multilevel teams and systems across the continuum (Lamb et al., 2011; Potosky et al., 2011; Tapin et al., 2012). Cancer care includes prevention, screening, diagnostics, treatment (i.e., oncological, surgical, symptom management, etc.), palliative services, and hospice, among other services (Clauser et al., 2011; Shahid et al., 2009; Walsh et al., 2011). Cancer patients are often required to access unfamiliar systems and specialized providers in order to seek treatment, and cancer care is generally time-consuming, expensive, and emotionally draining for patients and families (Stanton, Rowland, & Ganz, 2015; Tapin et al., 2012). The patient trajectory varies considerably depending upon the individual and includes various transitions, interfaces, and multiple entry and exit points to the cancer care system (Tapin et al., 2012). During this process, the potential for system errors and provider miscommunication, misinformation, and contradictory recommendations to cancer patients and their families is significant (Lamb et al., 2011; Mazor et al., 2012; Potosky et al., 2011; Tapin et al., 2012). In one study, nearly a quarter of cancer patients felt that a preventable problematic event had occurred during their care; these events most often consisted of diagnostic and treatment delays and communication failures resulting in considerable physical, emotional, quality-of-life, or financial harm (Mazor et al., 2012).

During and following cancer treatment, patients often experience a profound change in their lifeways due to the complex nature of cancer care leading to an increased risk for compromised physical and psychological health (Stanton et al., 2015). Beyond the obvious somatic responses such as pain or fatigue, these alterations may include elevated anxiety and fear

or cognitive changes that can feel disorienting and alarming to patients and families (Stanton et al., 2015). Addressing the sequelae of cancer care and coordinating long-term management of cancer patients requires a fully interfaced and multidisciplinary approach that often fails to materialize in the U.S. despite our scientifically advanced and notoriously expensive healthcare systems (Potosky et al., 2011; Tapin et al., 2012). The literature suggests that when nursing personnel are excluded from decision-making and patient needs and desires go unnoticed, the quality of cancer care is greatly diminished (Lamb et al., 2011).

### **Nursing Care of Persons Affected by Cancer**

Nurses are integral to the provision of cancer care in the U.S., fulfilling a variety of roles that directly influence patient experiences and outcomes (Hildebrandt, 2012; Lamb et al., 2011; Potter et al., 2013). Cancer care implemented by nurses include symptom management, patient needs assessments, assistance with navigation through the healthcare system, coordination of complimentary and multidisciplinary services, communication with team members, support of family members, and education and information sharing (Clauser et al., 2011; Potter et al., 2013; Shahid et al., 2009; Walsh et al., 2011). Nurses serve cancer patients, families, and communities across all settings.

For many patients, nurses are the “face” and the “heart” of cancer care. More than any other type of provider, nurses spend time with patients and families engaging in extensive medical, psychosocial, and spiritual support (Corso, 2012). Due to the prolonged and complex nature of oncology treatment, close bonds develop between nurses and patients as systems are navigated, symptoms managed, and intense and multifaceted care is provided (Clauser et al., 2011; Hildebrandt, 2012; Potter et al., 2013; Walsh et al., 2011). Over time, many nurses come

to know cancer patients and their loved ones at a profound and insightful level, establishing caring relationships that are fundamental to the cancer care experience.

Yet, these relationships come at a cost. Cancer care routinely occurs in environments “replete with intensely emotional and often harrowing transactions where anguish, tears and fears, as well as relief, reassurance and even euphoria are all commonplace” (Henry, 2014, p. 10). Nurses caring for cancer patients within this emotionally volatile and potentially draining environment report a significant toll on their own wellbeing and resilience (Henry, 2014). Unsupported cancer care nurses exhibit elevated levels of burn out, compassion fatigue, unresolved grief, and staff turnover in comparison to nurses working in other areas of care (Corso, 2012; Hildebrandt, 2012; Potter et al., 2013). Nurses who are repeatedly exposed to ethically and emotionally distressing scenarios (e.g., cancer treatments that are highly aggressive or traumatic for patients) demonstrate greater job dissatisfaction and poor retention in the profession (Bell & Breslin, 2008; Hildebrandt, 2012; Raingruber & Robinson, 2010). The interconnectedness, familiarity, and emotional investment of nurses in their patients’ lives and wellbeing are both a hallmark and expectation of this type of care *and* a risk for nurse wellbeing.

### **The Context of American Indian Healthcare**

Comprehending the contemporary AI patient-cancer care nurse relationship requires an examination of the complex and often shifting provision of healthcare over time. A review of major historical, legislative, and political events suggests the deeply ambiguous and often confused social complex that Anglos often possess concerning North America’s original inhabitants (Baba, 2012; Getches, Wilkinson, Williams, & Fletcher, 2011; Hadjiioannou, 2001; Warne & Frizzell, 2014; Wolfe, 2013). While a comprehensive AI history is beyond the scope of

this review, an examination of selected major events especially pertinent to individual health and collective healthcare structures serves to highlight the level of devastation, violence, and subjugation AIs experienced following first contact with Anglo-Europeans (Institute of Medicine, 2013; Satter, Randall, & Arambula Solomon, 2013). These events shape the shared past, present moment, and future as experienced by AIs and nurses engaged in cancer care (Watson, 1985).

### **The Doctrine of Discovery**

Beginning in the late 15th century, Anglo-Europeans arriving in North America attempted complete physical, social, and cultural genocide of indigenous people under the guise of the ‘Doctrine of Discovery’ (Cobb et al., 2008; Getches et al., 2011; Viola, 1990). This canon, endorsed by colonizers all over the world, purported that Anglo-Christians could claim and seize already occupied territories inhabited by indigenous people, “who diverged from Christian-European cultural norms of religious beliefs and civilization” (Getches et al., 2011, p. 47). Paradigmatic differences essentially justified persecution, deprivation, and conquest through whatever means necessary, including violence and genocide. It is estimated that by the late 1800s, up to 90% of indigenous populations in North America had been decimated by European enslavement, disease, and warfare; entire tribes, languages, and cultures disappeared (Veracini, 2011; Viola, 1990).

Despite this widespread devastation, even the earliest relations between the Spanish Crown and AI tribes were considered to be formal nation-to-nation interactions according to medieval law (Getches et al., 2011). This designation continued with the French, British, and newly formed American governments, suggesting a certain level of inherent or natural

sovereignty among tribes that would prove to be critical over time (Hadjiioannou, 2001; Warne et al., 2012; Warne & Frizzell, 2014). The notion of nationhood is important to the structure of AI healthcare in that tribes are viewed collectively and individuals are largely powerless to receive any specialized benefits or pursue treatment outside of the allocated group system (Warne et al., 2012). The implications of this for AI cancer outcomes are particularly poignant considering the complexity of modern day disease management and the reality that the bulk of cancer care occurs outside of tribal communities and systems (Clauser et al., 2011; Walsh et al., 2011; Schumacher et al., 2008; Warne & Frizzell, 2014). This poses a considerable challenge for individuals requiring cancer care as it becomes difficult to access resources beyond those available to the tribe as a whole (Cobb et al., 2008; Warne et al., 2012).

### **The Marshall Trilogy**

AI nationhood and sovereignty were further reinforced in the early 19th century through a series of Supreme Court cases designated as “the Marshall Trilogy” (Getches et al., 2011; Hadjiioannou, 2001). This collection of cases presided over by Chief Justice John Marshall essentially determined the fundamental principles that continue to drive significant portions of AI life today (Getches et al., 2011; Hadjiioannou, 2001; Satter et al., 2014; Warne et al., 2012).

Of importance:

- Treaties are accepted contracts between the U.S. government and AI nations and create legally recognized benefits, rights, and conditions in exchange for millions of acres of ceded (or seized) AI lands.
- The sovereignty of AI nations is inherent but ultimately limited by the Doctrine of Discovery in that AIs are a “conquered people” subject to the federal laws of the U.S. as

the conquering nation. This creates a measure of dependency coexisting with a recognized autonomy.

- Lastly, the federal government has a responsibility to protect AI resources and provide essential services to AI people in exchange for seized land, including adequate healthcare. This dynamic is essentially considered a ‘guardian-and-ward’ relationship.

An additional outcome of the Marshall Trilogy is the assertion that the federal government has a duty and obligation to act in the best interest of tribes. For example, although the U.S. signed the last treaty in 1871 it must still honor the terms of all signed contracts per federal law and generally in favor of the tribe (Hadjiioannou, 2001). Beyond treaties, the federal responsibility to tribes is reinforced in the U.S. Constitution and is realized today in that the 566 federally-recognized AI and Alaska Native tribes are the only group in the country to have totally federally-funded healthcare services (Getches et al., 2011; IHS, 2014; Warne & Frizzell, 2014). However, this review of the historical record will demonstrate the challenges made to this guarantee due to an assortment of additional political, social, and cultural issues.

### **Settler Colonialism**

Emergent from this era of “discovery” and conquest and the delineation of state and tribal relations was a particular brand of imperialism that developed as Anglo-Americans increasingly moved west into AI territories in the 18th century (Veracini, 2011; Wolfe, 2013). Settler colonialism is defined as an ideology aimed at “taming” natural resources and extinguishing the original inhabitants through the systematic application of oppressive, permanent measures during expansion and relocation (Veracini, 2011). This unique form of colonialism is structured to eventually replace all existing systems and peoples; it does not cease until the indigenous people

are fully exterminated and the new arrivals have achieved complete control (Cattelino, 2012; Veracini, 2011). The finality of this particular brand of colonialism both distinguishes and perpetuates it, and the power imbalance between intruder and native becomes profound and omnipresent in all political and social systems (Wolfe, 2013).

Emerging scholarship suggests that the ramifications of settler colonialism are sensed in nearly every facet of AI life, including in healthcare. AI belief systems about disease and wellbeing were repressed to a significant extent by Anglo paradigms during relentless westward expansion in the U.S. in the 19th and early 20th centuries (Deloria, 2006; Johnston, 2002). This occurred through various exploitive mechanisms such as the 1887 Dawes Act in which AIs were forbidden from practicing traditional medicine despite its demonstrated effectiveness and cultural relevance (Hollow, 1999). However, due to the resilience, organization, and perseverance of AIs, settler colonialism in the Americas has not completely succeeded and many core philosophies concerning health persist, often quite subversively as a form of resistance and survival (Avila, 1999; Cattelino, 2013; Hollow, 1999; Gonzales, 2012a). These beliefs remain relevant, dynamic, and essential to comprehending the complicated interactions between AIs and the systems and providers tasked with providing healthcare to them.

### **Significant Historical and Political Events**

There is constant tension between tribal sovereignty and federal dependency within AI healthcare ensuing from the Doctrine of Discovery ideology and the Marshall Trilogy edicts (Getches et al., 2011; Warne & Frizzell, 2014). Likewise, an often oppressive and debasing atmosphere is present in the contemporary AI healthcare environment emblematic of settler colonialism (Guadagnolo et al., 2012; Johnston, 2002; Vasilevska et al., 2012). These three

colonialist ideologies laid the foundation for several centuries of often tyrannical policy that continues to impact AI healthcare and patient-nurse relationships as they exist *within* this troubling system. An examination of the timeline of events leading to the creation of today's complex configuration of AI healthcare places nursing within the context of this historical record while illuminating some of the challenges faced by both patients and nurses as they interrelate and exchange with one another during caring encounters.

**Warfare and removal.** In the early 19th century Indian health services were established under the jurisdiction of the War Department, perhaps reflecting the tone and general perception of AI people at the time (Hadjiioannou, 2001; IHS, 2014). These services were staffed by poorly paid and inadequately trained military clinicians in forts and outposts that were impotent in their efforts to control the devastating effects of infectious disease such as measles, whooping cough, and influenza (Satter et al., 2014; Viola, 1990). In fact, disease was at times purposely spread by federal agents through the distribution of blankets contaminated with smallpox to tribes as systemic extermination efforts and land seizures continued (Satter et al., 2014). Other mechanisms impacting AI health during this era included targeted warfare, exclusion from resources such as water and hunting grounds, and banishment to increasingly isolated and ecologically inferior territory (Rodgers, 2012; Viola, 1990; Wolfe, 2013).

**Assimilation and allotment.** During the latter half of the 19th century, displacement and relocation to reservation lands occurred, often causing a complete disruption of the social and cultural complexes integral to the maintenance of AI wellbeing (Hollow, 1999; Horowitz, 2012). Exploitive mechanisms such as the 1887 Dawes Act were enacted in which communal AI lands were divided into individual holdings and an agrarian lifestyle was encouraged by the federal

government (Hollow, 1999). This systematic allotment eroded tribal sovereignty and significantly reduced tribal land holdings.

By 1849, the healthcare of AIs was transferred to the Department of the Interior with Indian hospitals built towards the end of the century to accompany boarding schools (IHS, 2014). Boarding schools proved to have devastating bio-psycho-social-spiritual effects on AIs and were often breeding grounds for disease and abuse of youth despite access to Western-based medical services (Satter et al., 2014). AIs were increasingly subjected to forced assimilation in the early 20th, century, which is largely considered a response to failed extermination efforts (Veracini, 2011). Assimilation sought to erase AI culture by forcing integration into Anglo society through the systematic degradation of AI lifeways (Viola, 1990). For example, during this era AIs were forbidden to speak their language or practice their spiritual and cultural beliefs, including traditional medicine (Gonzales, 2012a; Hollow, 1999; Johnston, 2002).

Despite the federal responsibility to protect and provide care, AI health services did not appear in the federal budget until 1911 (Getches et al., 2011). Actual funds for AI healthcare were not consistently appropriated by Congress until 1921 under the Snyder Act, but even then remained insufficient and poorly administered with much of the focus on providing minimal, Western-based medical services to the complete exclusion of AI epistemologies and ontologies (Hadjioannou, 2001; Hollow, 1999; Warne & Frizzell, 2014).

**The Meriam Report.** In 1928, *The Meriam Report* uncovered the dismal condition of AI healthcare and education and called for significant reform as delineated in treaties, the Constitution, and legal precedents such as the Marshall Trilogy (Getches et al., 2011). This federally funded investigation made three recommendations pertaining to AI health: (a) care

should be delivered by actual health professionals instead of Bureau of Indian Affairs (BIA) staff; (b) the extensive development of social services on reservations was called for to facilitate AI self-sufficiency and alleviate abhorrent living conditions; and (c) the boarding school system and associated healthcare facilities should be immediately closed (Baba, 2012; Getches et al., 2011; Satter et al., 2014). The *Report* succeeded in drawing attention to a plethora of concerning socioeconomic and health issues in AI communities and marked a substantial change in policy and approach at the federal level; however, due to the overall racial, economic, and cultural climate of the Great Depression era, progress was limited and major health and socioeconomic inequities persisted (Getches et al., 2011).

**Early tribal autonomy.** In the post-World War II period, the Transfer Act (1954) finally moved AI health services from the BIA to the U.S. Public Health Service, which later became the U.S. Department of Health and Human Services overseeing the Indian Health Service (Baba, 2012; Hadjiioannou, 2001; IHS, 2014). The Transfer Act attempted to increase tribal sovereignty in regards to health policy decision making and some improvements in AI sanitation and health occurred during this period, largely in response to outcries from private humanitarian and religious groups (Warne & Frizzell, 2014). Yet, underfunding, discrimination, and widespread poverty in tribal communities continued, marking over four centuries of oppressions and marginalization since the arrival of Anglo-Europeans (Institute of Medicine, 2013).

**Increasing tribal autonomy.** Following the social upheaval of the 1960s and 1970s in the U.S., Public Law 93-638 (Indian Self-Determination and Education Assistance Act [ISDEAA]) was passed in 1975 (Hadjiioannou, 2001; Viola, 1990). The ISDEAA is perhaps the single most important piece of legislation for AIs, enabling tribes to administer portions of their

own healthcare by allowing the option of staffing and managing their own IHS programs using federal funding (Satter et al., 2014; Warne & Frizzell, 2014). Over 60% of the federally recognized tribes in the U.S. have assumed all or partial self-governance over their healthcare services under the ISDEAA creating a complex reimbursement, referral, compact, and contract system (Baba, 2012; IHS, 2014; Satter et al., 2014). The ISDEAA includes the requirement that IHS and/or its tribal partners attempt to provide healthcare to urban AI populations that may be removed from their rural reservations, resulting in more than 30 urban Indian healthcare centers today (Baba, 2012). It should be noted that both AI and non-AI providers work within these healthcare facilities, regardless of location or administrative variations.

In 1976, the Indian Health Care Improvement Act succeeded in further enhancing tribal autonomy over healthcare services by allowing IHS and tribally-owned health partners to bill Medicaid, Medicare, and the Children's Health Insurance Program, among other expansions (Warne & Frizzell, 2014). The Tribal Consultation and Participation Policy (TCPP), enacted in 1994, attempts to ensure that AI voices are heard regarding federal and regional decisions, including those concerning healthcare (Baba, 2012; IHS, 2014). The success of the TCPP is debatable based upon widespread reports of continued AI exclusion from decision-making and a serious lack of culturally appropriate care and adequately trained providers (Baba, 2012; Rodgers, 2012; Schumacher et al., 2008; Struthers, 2001; Vasilevska et al., 2012).

**The contemporary AI healthcare environment.** Despite the plethora of enacted policy and legislation described above, of the 5.2 million people currently classified as AI or Alaska Native in the U.S. fewer than 50% are eligible to receive federal health care services (Burwell et al., 2014; OMH, 2015). Many “fall through the cracks” if they are not registered members of a

federally-recognized tribe, do not reside near the assigned facility, or are otherwise alienated from federal or tribal health services (Satter et al., 2014). IHS is not an insurance plan or an entitlement program such as those guaranteed to veterans or the elderly, and tribal councils control which members are eligible for healthcare within the federal guidelines (Burwell et al., 2014; IHS, 2014; Satter et al., 2014). For example, councils may set requirements such as blood quantum or residency within so many miles of a reservation healthcare facility when determining which members qualify for services (Satter et al., 2014).

As of 2012, nearly 25% of AIs lacked health insurance, a key indicator for overall poor health outcomes (OMI, 2015; Shi & Stevens, 2010). Recent revisions of the Affordable Care Act have met with only marginal success in alleviating the AI health and insurance crisis and the majority of funds allotted for healthcare must still be annually appropriated from Congress with consistent and predictable shortfalls (IHS, 2014; Warne et al., 2012; Warne & Frizzell, 2014). As Warne et al. (2012) report, per capita funding for IHS is just \$2690 as opposed to over \$6800 for non-AI individuals eligible for federal health benefits. This means that a non-AI citizen eligible for federal healthcare is allotted nearly two and a half times more funding than an AI citizen.

In addition to the cancer care inequity of focus for this study, present-day health consequences experienced by AIs include exceptionally elevated rates of diabetes, infant mortality, tuberculosis, suicide incidence, traumatic injuries, stroke, heart disease, and HIV/AIDS (Baba, 2012; Burwell et al., 2014; OMH, 2015). The average life expectancy for an AI born today is nearly five years less than the U.S. all races population (IHS, 2014). Health inequities are often interpreted by AIs to be the result of both past and current government policies, a conceptualization that may be foreign to non-AI providers (Horowitz, 2012; Rodgers,

2012). It would appear that the federal duty to provide essential healthcare to AIs as set forth in the Marshall Trilogy, U.S. Constitution, and this wide assemblage of policy has been largely unable to overcome the lingering detriments of early colonial doctrine.

### **Significance of Historical and Political Events to AI Patient-Cancer Care Nurse**

#### **Relationships**

The ramifications of these causal elements on the patient-nurse relationship should not be underestimated. Nurses provide care within a constantly evolving sociopolitical context, yet we often misjudge the impact of both our patients' and our own histories on our lives and interactions with one another (Hall, 1999). History is particularly relevant to an interpretive phenomenological endeavor seeking to explore the influence of context on the structuring and sustenance of the patient-nurse relationship (Wojnar & Swanson, 2007).

Many nurses lack awareness of the depth of this inherently oppressive and exclusionary series of events due to the settler colonial ideology embedded in the social order and collective consciousness of modern-day American culture (Struthers, 2001; Veracini, 2011; Wolfe, 2013). Settler colonialism encourages non-AIs to “forget” some events and legitimize others as a way of justifying our status as the dominant group. Nursing originates from a largely Eurocentric, colonialist paradigm that often fails to acknowledge deeply embedded unequal power structures and our own complicity in perpetuating the marginalization of minority patient groups or at minimal, in maintaining the status quo (Hall, 1999; Falk-Rafael, 2005; Szreter & Woolcock, 2004). While some nurses possess an awareness of this situation, they often lack the skills, capacity, or proclivity to recognize how these underlying historical and political issues entrenched in healthcare impact their everyday work and relationships with AI patients; they are

subsequently unable to mount appropriate counter responses required to improve the relationship (Keltner et al., 2004; Struthers, 2001; Struthers & Lowe, 2003). This leads to both disciplinary as well as highly personal inaction, rooted in the suppressed historical and political record. A failure to reconcile this painful past has resulted in a dysfunctional relationship dynamic that is made all the more complicated by the addition of cancer care with all of its complexities. Likewise, various social consequences emanating from the historical and political context further influence the AI patient-cancer care nurse relationship with dire repercussions for both parties.

### **Social Consequences of AI Historical and Political Context Impacting Cancer Care**

Profound social repercussions of the repressive historical-political timeline are apparent in contemporary AI patient-cancer care nurse relationships. An examination of the prevalent issues of historical trauma, systemic poverty, and the often marginalizing reservation system reveals the contextual difficulties experienced by AIs and encountered by nurses who care for these populations (Brockie, Heinzemann & Gill, 2013; Keltner et al., 2004; Struthers & Lowe, 2003). Furthermore, the influence of these social consequences on cancer care and the patient-nurse relationship within that specific area of care are explored.

### **Historical Trauma**

The influence of historical trauma on present-day AI health and wellbeing should not be minimized despite its relatively new designation as a disease-causing entity (Brown-Rice, 2013; Struthers & Lowe, 2003). For many AIs, the loss of lands and cultural identity and the complete disruption of life systems following Anglo-European colonization remain acutely felt; this historical loss is consequently manifested in a variety of distressing bio-psycho-social-spiritual outcomes (Hollow, 1999; Horowitz, 2012). Historical trauma is described as an acute reaction to

colonization that manifests in a cumulative and complex set of symptoms exhibited across generations, regardless of direct exposure to traumatic events; these symptoms may include depression, unresolved grief, a sense of indifference or disconnect, and violence against oneself or others (Begay, 2012; Gonzales, 2012b; Lowe & Struthers, 2001; Struthers & Lowe, 2003).

Emerging research suggests that exposure to historical trauma may be associated with biological and physiological changes in the human brain leading to long-lasting negative behaviors (Begay, 2012; Gonzales, 2012b). Health behaviors related to historical trauma may include an aversion to physical touch, non-adherence to treatment regimens, or open hostility and distrusts of healthcare providers (Avila, 1999; Gonzales, 2012b; Strickland et al., 1999). For nurses unfamiliar with historical trauma, these behaviors appear confusing, counterproductive, and challenging to address within the caring relationship (Gonzales, 2012b; Struthers & Lowe, 2001). Additional research points to the epigenetic impacts of historical trauma (Brown-Rice, 2013). For example, AI children report experiencing historical loss, race-based discrimination, and exposure to traumatic events such as assault and neglect at much higher levels than non-AI children (Brockie et al., 2013). Consequently, AI children are at an increased risk for significant methylation changes in the genes responsible for the regulation of stress hormones (Brockie et al., 2013). This genetic response to the social environment may lead to a variety of adverse psychological and physiological health outcomes over time stemming from the inability to regulate the 'fight or flight' response (Brockie et al., 2013; Brown-Rice, 2013; Gonzales, 2012b). It is important to note that for many AIs historical trauma is powerful and enduring while others may not have experienced it at all; there is great variation in experience, intensity, and reaction (Brockie et al., 2013; Brown-Rice, 2013). Despite the name, historical trauma is not something

that occurs in the past but instead remains present and an active manifestation in contemporary AI lifeways, health, and relationships, including nurse-patient relationships (Struthers & Lowe, 2003).

### **Systemic Poverty**

Perhaps even more prevalent than historical trauma among the AI population is enduring and severe poverty (Rodgers, 2012). Nearly 25% of AIs live at or below the federal poverty index, twice the rate of all other races in the U.S. (Burwell et al., 2014; OMH, 2015).

Concentrated poverty among AIs is linked with high crime rates, elevated substance abuse, underperforming schools, and inadequate housing (Brockie et al., 2013). AIs living in rural areas are at an even higher risk of being impoverished and subsequently marginalized from healthcare resources (OMH, 2015; Rodgers, 2012). This is amplified by an acute shortage of nurses and other primary care providers in rural communities (Bushy, 2006). Despite the recent AI migration (or exodus, depending upon your interpretation) to urban areas, poverty statistics for urban AIs remain equally concerning (Cobb et al., 2008; OMH, 2015). As an example of the dismal conditions in AI communities, the U.S. Office of Minority Health (2015) considers “inadequate sewage disposal” as being a major factor in poor health outcomes among this population.

As the previously described overview of AI healthcare structures reveals, only about 50% of the populace are able to access federal health services and nearly 25% are uninsured (Burwell et al., 2014; OMH, 2015). The connections between poverty, limited access to care, and poor insurance coverage to negative health outcomes are extensively supported in the literature (Baba, 2012; Hall, 1999; Keltner et al., 2004; Shi & Stevens, 2010; Rodgers, 2012; Warne & Frizzell,

2014). AI poverty is tacitly linked to the historical and political milieu including protracted economic inequity enabled by race-based governmental policy, making these populations unusually vulnerable to health disparities (Burwell et al., 2014; Cobb et al., 2008; Keltner et al., 2004; OMH, 2015; Warne et al., 2012). Cancer incidence patterns among AIs are distinctly linked to impoverished communities: as poverty intensifies, cancer rates and mortality increase (Warne et al., 2012).

### **Marginalizing Reservations**

Poverty is particularly concentrated on AI reservations. For example, five out of ten of the poorest counties in the U.S. include AI reservations (Brockie et al., 2013). Reservations are legally designated areas managed by federally-recognized tribes under the jurisdiction of the U.S. Bureau of Indian Affairs (Getches et al., 2011). They are considered semi-sovereign nations with a complicated system of providing essential services to resident citizens. The creation of reservations in the late 19th century was very much in alignment with the settler colonial objectives of banishment and exclusion of indigenous people in the name of “progress and development” as defined by Anglo values (Wolfe, 2013). As White settlers moved westward, they often claimed the most fruitful and profitable lands, consequently relegating AIs to inferior territories (Cattelino, 2013; Cobb et al., 2008). Although there are a few exceptions where AIs remain on their ancestral lands (e.g., White Mountain Apache Tribe in eastern Arizona), for the most part, reservations were created to keep the problematic AI population “out of sight” and “largely invisible in their own land” (Wolfe et al., 2013, p. 4).

Reservations are often comprised of isolated homes and communities with stifled economic opportunity (OMH, 2015; Rodgers, 2012). Unemployment rates on many reservations

approach 40% for adult AI males and health outcomes among this mostly rural population tend to be alarmingly poor (Brockie et al., 2013; Rodgers, 2012). For example, reservation-dwelling AIs are more frequently exposed to elevated levels of environmental contaminants, particularly in traditional food and water sources, which may contribute to an increased risk for developing cancer (Cobb et al., 2008). Considering that most AIs will be required to leave the reservation to seek specialized cancer care, this system significantly limits access to services and likely influences overall experiences and outcomes (Warne et al., 2012).

### **Impact of Social Context on the AI Patient-Cancer Care Nurse Relationship**

It is reasonable to suggest that the striking historical, sociopolitical, and cultural oppression experienced by AIs as a group and the related persistent health inequities likely impact and challenge AI patient-nurse interactions in profound and perhaps unseen ways (Cobb et al., 2008; Lowe & Struthers, 2001; Warne & Frizzell, 2014). These three domains have a profound influence on patient-nurse relations and the AI proclivity for engaging in cancer care *in partnership* with their nurse providers.

**Historical impact.** The literature suggests a significant lack of understanding among non-AI nurses of the implications of historical and intergenerational trauma on AI health behavior and outcomes (Gonzales, 2012b; IOM, 2013; Struthers & Lowe, 2003; Struthers et al., 2005). The vast majority of non-AI health practitioners have not received any kind of training on the subject (Aboriginal Nurses Association of Canada, 2009; Gonzales, 2012b; Struthers & Lowe, 2003). For example, I received no training about historical trauma in my undergraduate clinical nursing program or later when I began working as a nurse in two distinct AI communities, both with traumatic historical pasts. My experience confirms Lowe and Struther's

(2001) claim that the lack of a nursing framework for understanding the specialized nursing care of AIs, including the implications of historical trauma, adversely affects the AI patient-nurse relationship and contributes to negative health outcomes. Nurses lacking the knowledge and skills to traverse this complex and often unfamiliar condition may be ineffective in their care at best and even harmful or counterproductive at worst (Aboriginal Nurses Association of Canada, 2009; Gonzales, 2012b; Lowe & Struthers, 2001; Struthers & Lowe, 2003).

AIs that distrust or have a negative perception of healthcare providers and systems are less likely to engage in any form of cancer care, contributing to elevated morbidity and mortality rates (Guadagnolo et al., 2008; Schumacher et al., 2008; Vasilevska et al., 2012). Cancer patients who are also incidentally experiencing historical trauma may exhibit behaviors or symptoms that appear confusing, atypical, or incongruent with treatment plans from the non-Native nursing perspective. In general, nurses lack the skills to comprehend and support the AI historical trauma illness manifestation, creating a formidable obstacle in the establishment of an authentic, caring patient-nurse relationship.

**Sociopolitical impact.** Like historical trauma, the impact of poverty on cancer care is palpable and is likely a major factor in the AI patient-nurse dynamic. Impoverished AIs are significantly less likely to obtain initial cancer screenings or to follow-up on abnormal results (Schumacher et al., 2008). AIs report poverty-related barriers such as a lack of transportation to urban or semi-urban facilities as being a significant factor in accessing cancer care with improved outcomes once mobile clinics are deployed (Nuno et al., 2012; Schumacher et al., 2008; Warne et al., 2012; White et al., 2014). Nursing staff may at times be oblivious to these barriers or perhaps lack the sensitivity or resources to address them even when made aware.

Moreover, a substantial power differential is observable when healthcare providers emanating from relatively advantaged systems are tasked with caring for economically disadvantaged communities (Szreter & Woolcock, 2004; Vasilevska et al., 2012). The gap between AI patient and cancer care nurse likely widens when poverty is present for only one person in the relationship; this divide may be even more acutely felt when the provider (i.e., the nurse) is viewed as being part of the political system perpetuating and enforcing poverty. Likewise, the inability to “transcend the [inequitable] system” in order to adequately provide care for AI patients may feel especially frustrating and stressful to nurses, contributing to high rates of turnover (Katz et al., 2010, p. 393).

High turnover among nurses is particularly pronounced on reservations, further intensifying the existing rural nurse shortage (Bushy, 2006; Department of Health and Human Resources, 2013; Keltner et al., 2004). This poor retention phenomenon is linked to cultural and geographical isolation and feelings of despair related to widespread health inequities encountered among AI patients (Keltner et al., 2004). While reservations provide AIs with a tangible representation of political sovereignty, they have often resulted in environments rife with significant health problems, including elevated cancer incidence and mortality (Cobb et al., 2008). Living on a reservation intensifies the AI cancer inequity by creating specific geographic and environmental barriers to care (Nuno et al., 2012; Schumacher et al., 2008; Warne et al., 2012). For example, AI women living in the rural southwest (predominantly on reservations) have particularly depressed breast and cervical cancer screening uptake (Nuno et al., 2012). This suggests a failure to engage many reservation-dwelling AIs, a primary task of cancer care nurses. If nurses don't live and work in AI communities for a sufficient time period their ability to

establish trustworthy and impactful caring relationships is likely diminished, yet the challenges of reservation life and its associated systems may drive some nurses away.

**Cultural impact.** These population-specific stressors are compounded by the already significant emotional burden of engaging in cancer care and by the lack of AI-specific information in cultural safety training for nursing (Baba, 2012; Corso, 2012; Gallagher, 2011; Hildebrandt, 2010). An examination of AI-specific cultural safety training offered to the nursing profession in the U.S. indicates serious deficiencies that negatively impact both patient satisfaction and population health (Baba, 2012, 2013; Gallagher, 2011; Struthers & Lowe, 2003). This insufficiency in training and support likely contributes to high levels of compassion fatigue and poor retention among nurses working with AI populations, which in turn perpetuates the cycle of distrust and suspicion among AI patients (Katz et al., 2010; Keltner et al., 2004).

While AI groups and individuals are hugely diverse, multiplicitous, and itinerant it is useful to acknowledge several core themes found across the literature that illustrate cultural representations of health and wellbeing, including those describing cancer (Cajete, 2000; Hollow, 1999; Gonzales, 2012a). Ancient AI concepts of holism, balance and harmony, and spirituality within health remain highly relevant and at times oppositional to Western systems and providers (Deloria, 2006; Hollow, 1999; Horowitz, 2012; Lowe & Struthers, 2001). Holism is viewed as a complete integration between self and the world; the comprehensive bio-psycho-social-spiritual nature of human beings is revealed in our relationships with self, others (animate and inanimate), the environment, and the universe (Avila, 1999; Deloria, 2006; Gonzales, 2012a; Koithan & Farrell, 2010; Stoffle et al., 2008; Swentzell, 1993; Wildcat, 2013). As a result, a sense of harmony and balance with all of these constituents is required to achieve wellbeing

(Avila, 1999; Koithan & Farrell, 2010). For many AIs, maintaining and restoring balance and harmony in regards to health requires ceremony with common examples being prayer, song, use of a sweat lodge, engaging with the natural elements, and the burning of sage or other medicinal plants for cleansing and renewal purposes (Avila, 1999; Hollow, 1999; Gonzales, 2012a; Koithan & Farrell, 2010). These activities may seem unfamiliar, unfounded, or perplexing to some allopathic providers, contributing to an already strained patient-provider relationship (Horowitz, 2012). Lastly, many AI beliefs about health reside in the spiritual realm, which is particularly divergent from contemporary biomedical views and systems (Deloria, 2006). AI interpretations of the source or cause of disease may appear “supernatural” to non-AIs, which can be a source of conflict and confusion between patient and nurse (Avila, 1999; Johnston, 2002). Cancer serves as a prime example with some AI cultures viewing the illness as a foreign, post-colonial, “Anglo disease” emanating from spiritual dislocation or disharmony (Deloria, 2006; Johnston, 2002; Strickland et al., 1999; Williams, 2012).

Core AI cultural values include reciprocity, responsibility, and sensitivity regarding the impact one has on constituents beyond self (Deloria, 2006; Stoffle et al., 2008; Swentzell, 1993; Wildcat, 2013). These altruistic concepts correlate with an overall sense of wellbeing and ease within the world, including the development of relationships defined by trust and mutuality (Hollow, 1999; Lowe & Struthers, 2001; Swentzell, 1993). Thus, the presence of mindful, respectful, and egalitarian relationships are crucial to nearly all AI worldviews and play a substantial role in the act of caring, particularly from a nursing standpoint (Lowe & Struthers, 2001).

## Summary

While cancer care is taxing for patients, families, and providers across the U.S., population-specific contextual factors often contribute to a remarkably difficult experience for many AIs. The social, cultural, historical, political, and economic components unique to this enduring and resilient Indigenous group create scenarios and actualities within cancer care that impede individuals and tribal groups in their efforts to leverage this devastating disease. Barriers experienced by many AIs may be clearly observable to outsiders such as geographic isolation from cancer care services or linguistically and culturally inadequate education materials, or they may be subtler in the form of deeply held past negative experiences with allopathic health care providers passed down from generation to generation that influence cancer care decision-making and treatment adherence in often carefully concealed ways. In either regard, AI cancer care experiences are too often fraught with behaviors, emotions, and interactions on the part of both patients and cancer care nurses that are the direct result of these historical, contextual, and causal factors. The many external and internal mechanisms comprising contemporary AI lifeways and healthcare often remain clandestine to nurses, further contributing to the dissonance and alienation between patient and nurse and negatively impacting cancer outcomes.

A complex interplay exists between perceptions of relationships, cultural discordance, and caregiving roles that negatively impact the AI cancer care experience and the patient-nurse relationship in this context. From one perspective, the literature suggests that cancer care nurses are at a high risk for experiencing adverse psycho-social-spiritual responses related to the distress of providing this type of care (Corso, 2012; Henry, 2014). Nurses suffering from these consequences may deliver insensitive and sub-par care, contributing to decreased patient

satisfaction (Potter et al., 2013; Raingruber & Robinson, 2010). From another perspective, AIs face a plethora of historical, sociopolitical, and conflicting cultural issues negatively impacting their cancer care experiences in today's existing allopathic systems (Cobb et al., 2008). When these two manifestations interact, it creates a "perfect storm" for a dysfunctional patient-nurse relationship despite the caring and moral ideals sought by the profession and expected by the patient (Falk-Rafael, 2000; Lowe & Struthers, 2001; Watson, 2006). As a result, the AI patient-cancer care nurse relationship is potentially fraught with high levels of tension, miscommunication, disconnect, disappointment, frustration, distrust, confusion, and a significant lack of cultural safety adversely impacting the patient's willingness to participate in cancer care.

At the very core of these experiences is perception of relationship and the meaning that is created within that relationship for both patient and provider. And, while there is a significant body of literature reporting on the negative issues within the AI experience of patient-provider relationships and cancer care, little is known about nurses' experiences within that dynamic and environment (Baba, 2012; Guadagnolo et al., 2008; Vasilevska et al., 2012). Therefore, this study addressed this identified gap by exploring the meaning of the AI patient-nurse relationship within the context of the cancer care experience from the nurses' perspectives. How this relationship feels for nurses and what it means to them on an existential level is described in the next chapter.

### **Manuscript Option for Dissertation**

At my dissertation proposal defense, my committee approved my proposal to complete the manuscript option for my dissertation. My role along with those of my co-authors for each of

the manuscripts is described in detail here. Prior to my final defense, three publishable manuscripts have been completed.

The first manuscript is a co-authored methodological article entitled, “Looking Inward: A Guide for Phenomenological Self-Reflection” (Appendix A). This manuscript was submitted to *Qualitative Health Research* in October of 2016 and is currently undergoing peer review. My dissertation Chair provided subject matter expertise, peer review, and editorial assistance with this manuscript.

The second manuscript is a co-authored analytical review of the sociopolitical context and patterns influencing the American Indian/Alaska Native patient-cancer care nurse relationship as viewed through the concept of Watson’s (1985) causal past (Appendix B). It is entitled, “Living with the Causal Past: American Indian/Alaska Native Patient-Nurse Relationships in Contemporary Cancer Care” and was submitted to the *Journal of Transcultural Nursing* in November of 2016 where it is currently undergoing peer review. My co-author provided significant reorganization and editorial assistance with this manuscript and my dissertation Chair served as a peer reviewer and provided final edits.

The third manuscript explicates the research findings of this study and is entitled, “Cultivating Relationships with American Indian Patients in the Cancer Care Setting” (Appendix C). It is single authored and was submitted to *Cancer Nursing* in December of 2016. My dissertation Chair provided peer review and minor editorial assistance with this manuscript.

## PRESENT STUDY

This chapter summarizes the methods, results and conclusions of the research with the complete findings fully presented in the appendices. This chapter includes a summary of the most important findings from the study.

### Study Design and Methods Overview

This was an interpretive phenomenological study involving multiple data collections and analysis following the hermeneutical process. Interpretive phenomenology, also referred to as hermeneutical phenomenology, uses radical reflection followed by interpretation as a method of human science inquiry into the meaning of Being (van Manen, 2011). This study focused on deriving the essential meaning of being *within* a particular phenomenon of interest, in this case the complex, dynamic, and largely unexplored American Indian (AI) patient-cancer care nurse relationship. Thus, the meaning of the AI patient-cancer care nurse relationship was apprehended in an effort to grasp what it is like to be a nurse in relation to AI cancer patients. *Being* for the participating nurses was explored in the most fundamentally human sense of the word (Crotty, 1996).

Throughout this research endeavor, I remained close to the phenomenological goal of returning “to the things themselves” – the “things” being the authentic phenomenon of the AI patient-cancer care nurse relationship as opposed to my assumptions, the nurses’ descriptions, or the nurses as individuals (Crotty, 1996; van Manen, 1990). Thus, the nurses’ descriptions of their experiences were not end points but rather the means for understanding the larger phenomenon. Utilizing “hermeneutic [interpretive] phenomenology as a vehicle for exploring the experience of

nurses caring for people with whom they have a dual relationship” is in alignment with the research objectives of this study (McConnell-Henry, Chapman, & Francis, 2009, p. 2).

### **Pre-Data Collection Self-Reflection**

Self-reflection played a principal role in the chosen methodology for this study as an integral piece of the hermeneutic circle (Reiners, 2012; van Manen, 1990). Self-reflection was performed rigorously throughout all of the phenomenological endeavors in the form of reflexive journaling and memos. It is essential for the co-creation of interpreted phenomena as we are all interpretive beings, including myself as the researcher (Crotty, 1996; Wojnar & Swanson, 2007). Hermeneutics actually *requires* the acknowledgment and integration of personal awareness with the reflective investigator moving beyond simple understanding and delving into actual meaning (Reiners, 2012). This placed me *within* the research from the very beginning and contrasts with the requirement in descriptive phenomenology that a suspension of belief in the form of bracketing must occur in order to separate the researcher from the phenomenon (Crotty, 1996; van Manen, 1990; Wojnar & Swanson, 2007).

An initial, in-depth, written self-reflection was designed to facilitate understanding of the historicity of my experiences and the inevitable presence of preunderstanding prior to embarking upon this interpretive phenomenological inquiry (Colaizzi, 1966; Koch, 1995; van Manen, 1990, 2011). During this process, I focused on accessing my own immediate experiences of *being* a nurse and establishing patient-nurse relationships while caring for AI patients, families, and communities. While many of my experiences involved cancer care, some did not; I did not limit or confine my reflections as long as they appeared significant and contributed to the

research process. The results of this self-reflection can be found in Appendix D and are explicated further in the first manuscript of this dissertation (Appendix A).

### **Setting**

The setting for the data collection research was a private location of the participant's choosing, such as their home, private office, or in a private meeting room at the University of Arizona's College of Nursing. All initial interviews and some follow-up interviews were conducted in-person, depending upon participant location and preference. Some follow-up interviewing was conducted via telephone. Although an option for interviewing using an internet service (Skype or FaceTime) was presented, none of the participants chose this method.

### **Sample**

The convenience sample for this study consisted of nurses who had experienced the phenomenon of interest: engaging in a cancer care relationship with AI patients and communities. Nurses could be of any gender, cultural, racial, and ethnic affiliation. The purpose of this broad sampling criterion was to keep the study focused on the essential AI patient-nurse relationship while reducing the influence of specific demographic factors (Bryczynski & Benner, 2010). Nurses could have experience providing cancer care in any capacity for this project including but not limited to: home health, community outreach, primary care, case management, inpatient or outpatient oncology (medical and surgical), or hospice. Sample diversity was determined in close collaboration with the dissertation Chair to ensure that the phenomenon was fully represented.

## Sample Size

This sample for this study consisted of nine nurses meeting the inclusion criteria described above. Although 10 nurses originally enrolled in the study, one participant was lost to follow-up and discontinued participation after the first interview was completed. This relatively small sample size is typical of the chosen methodology, interpretive phenomenology, as this process entails complex, in-depth renderings of an essential experience via repeated interviews (Creswell, 2013; Crotty, 1996; van Manen, 1990). The small sample reflects the methodological focus on rich descriptions of individual experiences that reveal the universal human nature of a phenomenon (Parse et al., 1985).

TABLE 1. *Sample Demographics*

<b>(n = 9) % Sample</b>		
Age	Reported Age Range (in years) 25-71	Mean Age (in years) 45
Gender	Male	0
	Female	9 100%
Self-described race and/or ethnicity	White (non-Hispanic)	6 66%
	African-American or Black	0
	Hispanic or Latina/Latino	0
	Asian	0
	Native Hawaiian or Pacific Islander	1 11%
	American Indian or Alaska Native	2 22%
Total years in nursing	(years)	2 22%
	3-5	1 11%
	6-10	1 11%
	11-15	0
	16-20	3 33%
	21-25	2 22%
	26 or more	
Types of cancer care nursing with regular contact with AI patients (select all that apply)	Medical-Surgical Oncology (inpatient)	4
	Medical-Surgical Oncology (outpatient)	4
	Case Management/Care Coordination	3
Combined years of cancer care nursing with regular contact with AI patients	(years)	3 33%
	3-5	3 33%
	6-10	1 11%
	11-15	0
	16-20	1 11%
	21-25	1 11%
26 or more		

**Inclusion/Exclusion Criteria**

Registered nurses with at least three years of experience in providing cancer care to AI patients and communities within the past decade; can read and speak English fluently; willingness and capacity to engage in repeated interview sessions over a prolonged (6-7 months) period; and access to a working telephone were eligible to participate in this study. Nurses who were terminated from their work with AI patients and communities for any reason or under the age of 21 were excluded from participation.

The rationale for targeting nurses that had adequate experience was to encourage the retrospective discussion required of interpretive phenomenology (Bryczynski & Benner, 2010). Nurses that have had a minimum of three years to engage in cancer care with AI populations were more likely to have had sufficient time to develop and reflect on their relationships and immediate experiences thus providing rich descriptions appropriate for analysis (Creswell, 2013; van Manen, 1990).

**Recruitment**

After receiving study approval from the University of Arizona institutional review board (Appendix E), nurses with experience caring for AI cancer patients in rural, semi-rural, and urban areas were recruited via email or word-of-mouth using academic and professional networks (Appendix F). Professional networks included the Partnership for Native American Cancer Prevention; Native American Research and Training Center; Arizona Tribal Collaborative; and known past and current nursing colleagues who care or have cared for AI cancer patients in the southwestern U.S. Colleagues and contacts at these organizations were provided a networking script to assist with study recruitment (Appendix G). With my dissertation

Chair, I created a list of potential participants based on existing relationships and recommendations; the list was kept in a confidential, encrypted Word document. Potential participants only received written recruitment one time (via email) in order to minimize coercion. The first batch of recruitment emails were issued to the most promising candidates in terms of experience, anticipated availability, and diversity. This decision was made in close collaboration with my dissertation Chair and eight participants were enrolled from this initial recruitment attempt. A second batch of recruitment material was issued to additional candidates after the initial responses and enrollment rates were considered, and an additional two participants meeting the inclusion criteria joined the study.

It should be noted that although the ‘American Indian’ term is used throughout this study in congruence with the vast majority of the health sciences literature, the term ‘Native American’ was alternately used in various study materials (e.g., Networking Script, Written Recruitment, etc.) or during interviewing as it may have been more familiar or appropriate for the nurse participants. In general, I used whichever term arose naturally in conversation with the potential participant.

### **Informed Consent**

Nurse-participants interested in participating in the study contacted me via email or telephone. They provided their telephone number upon initial contact and I responded with a telephone call in order to determine study eligibility (Appendix H). No data were recorded during this initial screening call.

If the interested participant met all of the sampling criteria and continued to express an interest in participating, written informed consent was obtained at the start of the first data

collection session, which was always in-person regardless of participant location (Appendix I). Two identical signed copies of the written consent form were provided; one for me and one for the participant to retain. The written informed consent form included wording about the likelihood of subsequent/repeated interviews being necessary (either in-person or via telephone or internet), negating the need for repeated consent.

Coercion and undue influence were minimized through the generalized nature of the recruitment email. Beyond recruitment, contact with me was initiated by the potential participant via email or telephone. Details about the monetary incentive were minimized in the recruitment and informed consent material; however, the amount approximated the minimum hourly pay rate of Registered Nurses in the U.S. in the form of a \$25 Visa gift card provided upon completion of each data collection session. The written informed consent form included wording about discontinuing participation in the study at any time; this option was also emphasized during initial contact with potential participants and during data collection sessions.

### **Data Collection and Analysis Procedures**

It is crucial to acknowledge the non-linear, back-and-forth action that occurred continuously during data collection and analysis in this study in alignment with the interpretive phenomenological methodology (Reiners, 2012; van Manen, 1990). This process reflects the hermeneutic circle of data collection-reflection-analysis-meaning making that is central to the phenomenological approach and philosophy (Crotty, 1996; Reiners, 2012). For this reason, data collection and analysis procedures for this study have considerable overlap and are described concurrently in the sections below.

### **Interview Process for the Study**

Data collection for this study was an iterative process enacted through a series of interviews intended to encourage increasingly deeper retrospective reflections (Parse et al., 1985). In alignment with the methodology, participants in this study engaged in 2-3 exploratory and open-ended interviews lasting approximately one hour that I facilitated. Phenomenological questioning throughout the interview series was based on the four lifeworlds (van Manen, 1990, 2014; Appendix J). While interviews were largely participant-directed, the integration of the lifeworlds into thought-provoking lines of questioning, prompting, and probing facilitated the co-creation of meaning at the existential level (Crotty, 1996; van Manen, 1990, 2014).

Interviews were conducted in chronological order for each individual participant and not for the sample as a whole; thus, one participant may have completed their second or third interview while a different participant was just beginning their first. This was both logistically convenient and in alignment with the interpretive phenomenological method of keeping interviews focused on the *individual experience* during the first phase of data collection (van Manen, 1990). Cross-comparison for the purpose of meaning-making did not occur until after the entire interview data had been collected (van Manen, 1990).

**The first interview.** A total of 10 first interviews were completed. At the start of the initial in-person interview, demographic information consisting of age, self-identified gender, self-identified race or ethnicity, and relevant background concerning nursing care of AI cancer patients was collected from the participant (Appendix J). The Demographics Form (Appendix K) was immediately numbered and participant data de-identified so that it could not be linked to any forms or the recorded interview. Participants were informed that any identifying information

emerging during the interview such as patient names, patient diagnoses, tribal communities, or place names would be redacted or significantly altered (in order to be unrecognizable) by me during transcription. This technique assisted in protecting confidentiality and privacy.

Following completion of the demographics form, the password protected digital audio recorder was turned on. The initial interview began with ‘what was it like’ for participants providing care to AI patients with cancer in order to begin grasping the basic features of this particular relationship. ‘Grand tour’ questioning was utilized to elicit memories, sensations, and experiential accounts (Appendix J). As participants shared their experiences during the interview, I guided the reflective process using lifeworld-based questioning. I wrote reflective notations/memos during and immediately after the interview noting phrases and descriptions that seemed to call for more elaboration or exploration as well as my initial impressions.

At the conclusion of the interview, I prompted each participant with a specific stimulating question or statement to contemplate during the interval between interviews (e.g., “Before our next interview, I would like for you to think more deeply about...”). This prompt emerged from the immediate data collection session and was intended to stimulate the reflective process and encourage thoughtfulness on the part of the participant (van Manen, 1990).

Also at the conclusion of this interview, participants were verbally reminded by me of the available crisis hotline for emotional support and the option to discontinue study participation at any time as detailed in the written informed consent. Participants were provided a \$25 Visa gift card. Participants were told that they would be contacted by me via email within 1-2 months for scheduling of the second interview. The schedule/calendar for the next set of interviews was

encoded using the participant numbering scheme to protect anonymity in an encrypted document on a password protected computer.

The digital audio recording was sent to a fully encrypted online transcription service, Landmark Associates, Inc. Within five business days, the transcribed document was returned and downloaded onto a password protected computer, where it remained encrypted. I redacted or altered any identifying information in the transcribed document before uploading it into Atlas.ti qualitative software on a password protected computer. Original audio recordings were erased from the digital recording device after transcription was completed, but a copy of the audio recording was retained in my password protected account with Landmark Associates, Inc. per the company's protocol. Written informed consents and demographic forms were stored in a locked filing cabinet at the College of Nursing (Room 103) for the duration of the study.

The contemplative dwelling process then commenced with repeated exposure to the transcribed interviews and the creation of reflective memos using the qualitative software that attempted to unearth potential or tentative structures buried within the text (Parse et al., 1985; van Manen, 1990, 2014). This prolonged engagement with the data resulted in tentative open (emic) coding utilizing van Manen's wholistic/sententious, selective, and detailed approaches and as guided by the phenomenological lifeworlds (Wojnar & Swanson, 2007). Each interview was subjected to each of the three analytical approaches.

Next, debriefing with the dissertation Chair occurred in order to address tentative coding patterns of significant statements, and assumptions, bias, and premature closure on my part (van Manen, 1990). Based on these debriefing sessions, additional "dwelling" and reflective writing took place, including maintenance of the reflective journal. Following this period of reflection

and debriefing, the next line of questioning for individual participant was prepared. An individualized guide for the second interview was prepared for each participant beginning with the reflective prompt and using the preliminary open coding from the first interview. Two examples of this type of individualized guide can be found in Appendix L.

**The second interview.** A total of nine second interviews were completed. The second interview was either in-person or via telephone depending upon the participant's location and preference. This interview revisited what was recounted previously in an attempt to confirm and encourage elaboration on the points of interest from the first interview that suggested implicit meaning (Crotty, 1996; van Manen, 1990). This process was akin to peeling back the layers of an onion in order to gain access to the concealed core. Appropriate probing and re-directing was necessary to "tease out" potentially buried feelings surrounding the topic of interest as I attempted to go "deeper" with the participant into the phenomenon of interest using the four lifeworlds; however, it was essential that the interview remain open-ended and largely directed by the participant (Patton, 2002).

Upon completion of the second interview, the previously described procedures for immediate transcription and uploading into Atlas.ti were repeated. In-person participants were again provided a \$25 Visa gift card; remote (telephone) participants verbally provided their address after the recording device was turned off and had their card mailed in an envelope using the U.S. Postal Service.

Again, a period of dwelling, reflective writing, open coding, and debriefing with the dissertation Chair occurred during the interval between the second and third interviews. van Manen's (1990) three analysis approaches were again applied to this second wave of data as

described above. Data from the first and second interviews were compiled into a level-one matrix for each participant, and utilizing the hermeneutical process, tentative themes and essences were formulated followed by participant-specific thematic descriptions (Appendix M). This process required significant debriefing with the dissertation Chair with multiple, iterative drafts and periods of reflection. Using the level-one matrices, the next round of questioning was prepared for interview three and transitioned from the concrete to the abstract using the tentative themes, essences, and thematic description for each individual (Parse et al., 1985). Preparations were made to move beyond what had been previously said in the first two interviews in an attempt to explore what remained unspoken. Each level-one matrix served as the interview guide for the third and final interview.

**The third interview.** A total of seven third interviews were completed; two of the nine remaining participants were lost to follow-up in between the second and third interviews due to extenuating life circumstances. The third interview delved more deeply into the participant's previously described experiences and allowed for discussion, confirmation, refinement, and elaboration on the tentative themes that had developed during this circular data collection and analysis process (Parse et al., 1985; van Manen, 1990). Individually-situated themes and essences from the level-one matrices were presented to each participant with the opportunity for them to clarify, deny, or claim its level of resonance with their individual experience (Creswell, 1990; van Manen, 1990). This approach encouraged probing of the individual variations within the phenomenon with each participant, allowing for a creative and open method of exploring consciousness and understanding (Parse et al., 1985). While cues about the possible situated meaning across the nurse-participants were gleaned from the interpretive analysis process

occurring in between interviews, the focus continued to remain on the deeply personal, individual experience of each participant (Creswell, 2013; van Manen, 1990). During this final interview, participants were encouraged to intensely reflect on the meaning of providing cancer care to AI patients, families, and communities for themselves as nurses and human beings.

Upon completion of the third interview immediate transcription, uploading into Atlas.ti, prolonged engagement, open coding, and debriefing procedures were repeated. Participants were once again provided with a \$25 Visa card either in-person or via postal mail. Based on the participant's confirmatory and positive responses regarding the presented themes and thematic description, I determined that the interview process was complete in collaboration with the dissertation Chair during extensive debriefing sessions. At this point the majority of the themes and coding patterns among participants appeared repetitive and saturated.

### **Analysis and Data Reduction**

Data analysis occurred during, in between, and after data collection sessions in this study (Parse et al., 1985). As participants described their experiences, my immediate impressions were recorded in written notations during the interview, which were viewed as part of both data collection and analysis (Creswell, 1990). After transcription of each interview was complete, I underwent a period of prolonged engagement with the data, also referred to as "contemplative dwelling," by repeatedly listening to and re-reading the interviews (Parse et al., 1985; Patton, 2002; van Manen, 1990; Wojnar & Swanson, 2007). This essential process encouraged reflection on my part as well as assisted in directing subsequent lines of questioning, facilitating the co-construction of understanding between participant and me (van Manen, 1990; Wojnar & Swanson, 200; Appendix F). Contemplative dwelling occurred after each and every interview.

Data analysis for this study utilized van Manen's (1990, 2014) three-tiered phenomenological method and was documented in Atlas.ti and in the various matrices and written drafts exchanged between myself and the dissertation Chair:

- *Detailed approach:* Every data piece (sentence or sentence cluster) was equally evaluated and open coded for importance. I weighed each one equally and made note of what it might describe and reveal in reflective memos in Atlas.ti. Data pieces that were the most evocative and powerful when kept intact or conjoined were identified and coded as exemplary stories or anecdotal accounts.
- *Selective/highlighting approach:* I isolated essential parts from each interview by listening and/or reading through the text repeatedly (i.e., dwelling) while literally circling/underlining/highlighting or otherwise noting evocative statements that stood out using Atlas.ti. This approach assisted in revealing repeated or embodied themes that were set aside as potentially important data pieces that later contributed to the whole phenomenological text.
- *Wholistic/sententious approach:* Each transcript was viewed as a whole and then transformed into a critical summative phrase termed a 'sententious formulation.' The entire text was examined in an effort to capture the major significance. This technique contributed to the final product by providing an inclusive and fundamental overview of how each participant contributed to the comprehension of the larger phenomenon.

### **Post-Interview Analytical Procedures**

**Research aim #1.** Following debriefing with the dissertation Chair at the end of the interviewing process, an intense period of contemplative dwelling and reflective writing

commenced (van Manen, 1990, 2014). Final adjustments were made to the level-one matrices that began in between the second and third interviews. Then, each participant's experience was viewed as a whole and captured in a wholistic/sententious description followed by a sententious formulation suggesting how this individual's lived experience contributed to the overall phenomenon (Appendix M). It should be noted that no amount of coding or thematic abstraction alone can produce phenomenological understanding; meaning occurs during the co-creation and transformation of text and is reflected in phenomenological "attitude" and "presence" throughout the study, especially during reflective writing (van Manen, 2014). Thus, numerous drafts of the level-one matrices and wholistic/sententious descriptions were required to reach this level of thoughtful, contemplative text surrounding individual participant's experiences.

During the post-data collection writing period considerable alteration of the text occurred; for this reason, van Manen (1990, 2011) recommends against returning to participants for further confirmation or clarification beyond this point. Comprehensive drafts were instead confirmed with the dissertation Chair as the interpreted text appeared significantly different than the verbatim participant narratives once themes, thematic essences, and the sententious descriptions and formulations were fully explicated (Reiners, 2012; van Manen, 1990, 2011).

**Research aim #2.** Analytical procedures for the second research aim entailed looking across the individual participants in order to compare and contrast the experience of being in a cancer care relationship with AI patients. This was accomplished by creating a level-two matrix comparing the themes and essences emerging from the nine individual level-one matrices (Appendix N). This process of cross-comparison enabled a visual means of reducing a total of 36-individual themes into a set of seven thematic descriptions capturing common themes and

patterns seen across the sample. Each thematic description began with “Relationship is...” to reflect the unique attributes of the object of inquiry. The thematic descriptions were further distilled into seven accompanying meta-themes from which a general structural description was constructed. This general structural description delved into the shared experiences across the sample at the experiential level. While meaning occasionally subtly emerged, I refrained from infusing any of my own interpretations into this textual document during this phase of the study in order to accurately and authentically represent the participants’ shared experiences.

**Research aim #3.** The results of this interpretive analysis were “phenomenologically sensitive” paragraphs connecting the themes and structures, referred to as an “essential description” (van Manen, 1990; Wojnar & Swanson, 2007). Yet, reflective writing continued until the essential experience was fully described and meaning began to emerge. The ‘why’ and ‘what’ of the meaning behind the AI patient-cancer care nurse relationship began to take shape; it appeared increasingly comprehensive and resonated with the reader (Creswell, 2013; van Manen, 1990). Ultimately, a complete interpretation of the meaning of providing cancer care to AI patients and communities from the nurses’ perspectives was created in textual form, helping to illuminate the foundations of this mostly unexplored phenomenon. The final linguistic transformation provided understanding into what Being is like and what it means for nurses engaged in this unique caring relationship.

### **Rigor**

Assuring rigor in this interpretive phenomenology required that the interpretive process was conducted in a vigilant, thorough, and deliberate manner (Crotty, 1996; Lavery, 2003). The various stages of interpretation facilitated within the repeated and inductive interviews allowed

for patterns to emerge that were both coherent and logical (Laverty, 2003). Infusion of meaning on my part was performed using the stringent reflective procedures described (van Manen, 1990). Rigor was further strengthened in this study through implementation of the following procedures addressing trustworthiness, reflexivity, credibility, dependability, and transferability.

### **Trustworthiness**

Trustworthiness for this interpretive phenomenological study was established by thoroughly answering the research question and aims with a constant returning to them throughout the project (Crist, 2005). There was an obvious sense of coherence between the aims and the findings with verbatim recordings, transcription, and emic quotes to support the analysis, reflections, and tentative conclusions (Crist, 2005; Koch & Harrington, 1988; van Manen, 1990). An easily traceable paper and decision trail was maintained using the reflective journal, debriefing notes, and Atlas.ti software.

### **Reflexivity**

Continuous and transparent reflexivity was maintained to ensure authenticity while allowing me as the researcher to be part of the phenomenon (Reiners, 2012; van Manen, 1990). The reflexive journal and memos were key as well as regular debriefings with my dissertation Chair, further contributing to the avoidance of premature closure and minimizing bias (Crist, 2005; Koch & Harrington, 1988).

### **Credibility**

Prolonged engagement and triangulation of data (interviews and reflective writing) assisted in establishing credibility; all of the recorded and transcribed interviews and all other materials concerning the data collection and analysis processes (i.e., matrices, coding schemes,

etc.) were documented in Atlas.ti (Crist, 2005). Both typical and atypical findings were acknowledged and integrated into the findings.

### **Dependability**

Findings appeared consistent and dependable with the ability to easily trace my decision trail. This was facilitated by the qualitative software, debriefing notes, and reflective writings.

### **Transferability**

The results from this study are transferable in the sense that the thick linguistic description of the phenomenon resonated with readers and appeared valid, useful, and meaningful (van Manen, 1990, 2014). Findings are not intended to be generalizable in interpretive phenomenological research (Creswell, 2013).

## **Findings**

Findings for this study are explicated in the following sections, in the appendices as indicated, and in the publishable manuscripts associated with this dissertation.

### **Research Aim #1 Results**

The goal of the first research aim was to describe the immediate experiences of nurses that have engaged in cancer care relationships with AI patients. What follows is a brief summary of each participant's lived experience in the form of individually-situated structural descriptions. More detailed findings with verbatim (emic) support are presented in level-one matrices and wholistic/sententious descriptions for each participant in Appendix M.

### **Participant #1**

As the youngest nurse in the sample, Participant #1 has spent her entire three-year career as an RN working on an inpatient medical-oncology unit in a large city in the southwestern U.S.

She appears to be sincere and somewhat careful, but as a White nurse she has found her relationships with AIs sent to her facility to often be challenging, strained, and frustrating. She imagines herself entering the cancer care relationship with AI patients with complete benevolence and even some level of maternal authority. When the patients fail to recognize or respond to this approach as wholly trusting recipients of care, she is bewildered and discouraged; her altruistic deeds have gone unrecognized, causing her to question her impact and purpose as a nurse. She finds many of her AI patients to be vexing, especially in regards to subdued bodily messaging and erratic communication patterns. She is nameless and faceless to them, dashing her expectations and leaving her disoriented, disappointed, and feeling invisible. It is only after the patient engages in an act of *opening up* to her that she feels they have connected. This often occurs during moments of extreme vulnerability, but at no time does she reveal what she gives the patient in return other than *learning to adjust* her care tactics and expectations over time. The irony is that she is describing her very own *opening up*, the very action that she has so far exclusively demanded from her patients.

## **Participant #2**

As one of two AI nurses in the study, this nurse's extensive clinical background makes her lived experience distinctive. She currently works at an outpatient medical-oncology facility in a mid-sized town serving a large number of AI patients, the bulk from the same tribe as her own. She is a *guardian* of her people, ensuring the protection of and reverence for their language, shared (often painful) history, and communal identity. She is beholden to them, finding this sense of belonging to be full of great meaning and purpose. Unafraid to look her patients in the eyes or to touch them gently, she uses these acts as symbolic messages that

convey a deeper meaning. In this familiar relationship she experiences instant recognition and trust, and assurance that her skills and wisdom are deeply appreciated. She is an intermediary who inherently grasps the complicated context in which her patients receive cancer care and live their lives, and this acumen is both a burden and a gift as she listens deeply to their stories. Her sacred and ancient role in this community of cancer patients is fraught with tensions between tradition and modern medicine; personal fulfillment and emotional exhaustion; patient and physician; exasperation and joy. Yet there is an inescapable thread that binds her to the community and to these particular patients. When she experiences a powerful patient encounter in which she has made a positive difference, or when she retreats deep into tribal lands to replenish her soul, it *tethers her in place* and sustains her ability to carry on.

### **Participant #3**

As the sole retired participant in the study, this nurse brings a tone of reflection and wistfulness to the interviews. Her close connection to the AI community she worked in for six years as a cancer care coordinator has recently been heightened by her own cancer diagnosis. Her own Pacific Islander heritage colors her lived experience with the AI community, and she feels *at ease* and finds a fundamental compatibility between her patient's worlds and her own despite their individual differences. She is confident in their *sameness*, resulting in a sensation of being *indivisible* from her patients on an existential level. This enmeshment is seen by her as completely organic and utterly ordinary despite its depth and implications. Through the act of physically looking into their eyes, she sees herself mirrored (and vis a vis). Thus, she proceeds with reverence during the provision of care knowing that *whatever she does to her patient, she also does to herself* since they are one and the same. Within the space of her own illness, her

patients and their families return to her the “gifts” of compassion, empathy, and support. She embraces *this role reversal*, finding great solace and security in their concern and solidifying her feelings of belonging. She allows them *into her world* through the porous borders between them; perhaps we are all united by illness in the end. This sense of mutuality reinforces the impact that her own care has had on this community; it is the essence of karma and yet another sign that she has had a greater meaning and purpose as a nurse and as a human being.

#### **Participant #4**

As a Clinical Nurse Specialist with over two decades of experience in the inpatient surgical-oncology field in a southwestern city, this middle-aged White participant comes across as soft-spoken yet firm in her commitment to the nursing ideals she holds dear. Morally compelled and personally driven to provide *complete* care to her AI patients, she is faced with impossibly frustrating obstacles and contextual barriers unique to this population, yet strives to prevent their intrusion into the caring relationship. She cherishes the specific bond that develops between nurse and patient, allowing her to *reach* patients in a way that causes them to invite and include her in the most *sacred aspects* of their lives. She is astutely aware of the rarity and fragility of this invitation (it could be rescinded at any moment), and she protects and honors it accordingly. Caring for AIs requires significantly *more time* and an appreciation for the *power of silence*, exemplifying true *presence* within a caring nurse-patient relationship. Over the years, she has learned to transcend her discomfort with (and even to appreciate) these two interventions in an effort to achieve the depth of relationship that her vocation calls for.

**Participant #5**

Middle-aged and with an air of frank seriousness, this participant has spent her entire adult life working as a nurse with the last decade on an inpatient hematology-oncology unit. She claims that her encounters with AI patients seeking cancer treatment are “rare” but is easily able to describe in detail various patients and experiences during the interviewing process. She finds that restrained and minimalistic communications from AI patients leads to a sense of alienation for her. It creates a sense of otherness and perpetuates a *foreboding sense of dread* when she knows she will have an AI patient. She enters relationships with hesitancy and trepidation, hoping to establish connection but finding it impossible to do so. She is unable to find the pleasure and fulfillment that is so essential for keeping her engaged in her work. They seem *foreign* to her, and not even the passage of time can foster familiarity. Within this insurmountable void, her efforts to deliver essential information fall flat and unreceived. In the stillness and silence, she wonders if they are in fact conveying their respect and trust in her authority as a nurse. Despite the emotional disconnect, they are undemanding and agreeable, easing her physical workload. The outcome of this dichotomy is that she focuses on her tasks instead of the emotional relationship, and *time moves strangely and slowly* during these moments of care. Her AI patients are undeniably present, inhabiting a time and space that is unfamiliar yet intriguing. Occasionally, the smallest of convivial gestures is made on the part of the patient or family member and she seizes it desperately, holding on for sustenance and validation.

**Participant #6**

In her mid-thirties and a RN for over a decade, this participant has spent the bulk of her career in outpatient oncology, where she both delivers and coordinates care. She feels strongly

that cancer care is where she is “meant to be” and encounters a large number of AI patients referred to her facility for chemotherapy from both local and distant communities. Relationships with AI patients teach her that the painful legacy of history and the unjustness of the present world are very much a part of the caring encounter. The most tangible inequality is represented by the *banishment and isolation* of her patients to remote lands where cancer care is inadequate and she has no means of reaching them, leaving her adrift in the helplessness of it all. These are inescapable realities that create distrust and leeriness on the patient’s part while simultaneously placing her in a position of power as a member of the “dominant” system. Yet she feels compelled to adjust her expectations as much as possible, to find a middle ground where they can bond together and create a healing trajectory. She is morally compelled to provide the most just care that she can, and this allows her to view her patients for what they authentically are: what she sees is strength, resiliency, and perhaps an innate wisdom and presence that is lacking in both her personal and professional worlds. She takes a step back, a deep breath, and appreciates the lessons that her patients provide in the form of slowed time, welcome silence, and unequivocal acceptance of the world in all of its mystery.

### **Participant #7**

Effervescent and outgoing, this young nurse works in outpatient medical-oncology in a diverse mid-sized town and claims that “80%” of her cancer patients are of AI affiliation. Being White, her racial discordance with the bulk of her patients is a major factor in her lived experience. Her *otherness* is inescapable and unavoidable, and even if she understands its ancient origins, she still attempts to assuage her AI patient’s fear through exceptional kindness and demonstrations of care. This tactic initially fails to dislodge their distrust and suspicion, forcing

her to accept the inevitable reality of interminable distance and to *adjust her expectations* of what it means to provide authentic nursing care. Eventually, she confronts her own bias and *relinquishes judgement*. This freeing act leads to increasing moments of connection that permit her to reach her patients deeply, which is hugely fulfilling and personally transformative. She watches with admiration as her AI nursing colleague moves with ease among the AI cancer population, unearthing feelings of *insecurity and inferiority* as she is forced to *constantly prove* that she can also be trusted. Every encounter feels like a test, and she finds herself *withdrawing and letting go*, relinquishing her best intentions while masking her disappointment with professional courtesy. Equally maddening is the never-ending cyclical pattern of caring for people in a dysfunctional system. The frustration leaves her hollow inside, and she forces herself to *emotionally detach as a desperate act of self-preservation*.

### **Participant #8**

As the second AI nurse in the study, Participant #8 began her career as a social worker but transitioned to nursing where she now coordinates cancer care in an AI community, among other duties at an outpatient clinic. Although from a different tribe than the one she serves, she is deeply connected to her patients and their families, thoughtfully conveying her experiences in the interviews in the hope of improving cancer care and outcomes for AI populations as a whole even further. She *belongs* to the People, and she is beholden to them. She *transcends doubt* and past abandonments to foster relationship. The rewards for her persistence provide her a *home* in which to authentically be a nurse through human connection. Within the relationship, she bears the burden of *caring to the point of personal depletion*, but her cries of exhaustion are answered by incredibly fulfilling moments that sustain and reaffirm meaning for her while *restoring*

*wholeness* so that she can carry forward this essential work. It is a challenging yet anticipated pattern, one she has learned to cope with over time in order to support her patients in thriving against the odds.

### **Participant #9**

With over three decades of experience working in inpatient and outpatient medical-oncology, this highly experienced White nurse is nearing retirement but reports that she has cared for a variety of AIs from various regions of the country. In her current position in a large southwestern city, she regularly provides care to AIs from both urban and rural areas. At times, her relationships are fraught with contradictions and mixed messages. Striving to convey her respect for and understanding of her patient's painful collective history, she carefully applies deferential touch to convey her healing intentions. Yet this approach does not come without disappointment as she finds that touch alone cannot completely transcend the scars of the past nor personify the sterile cancer care environment. She is left stymied and bereft, but finds fulfilling purpose in her role as buffer and guide as together they navigate cancer care. Remaining open allows her to experience the powerful lessons her AI patients' have to offer about life's mysteries and our own minuscule roles in them. She finds comfort and connection in their spiritual explorations, affirming for her that no one –not nurse, patient, physician, or system –is in control. This relinquishment attunes her to the subtle but meaningful messages that are all around if we pause long enough to listen during the acts of nursing *and* living.

### **Research Aim #1 Conclusions**

As these individually situated structural descriptions illustrate, the lived experience for cancer care nurses engaging in relationship with AI patients, families, and communities are

multifaceted, contextual, and often contradictory. Participants described the joys and sorrows; rewards and burdens; successes and frustrations; and vitality and exhaustion of these relationships. Heidegger proposed that the lifeworlds are inseparable from our Being, and the participant's embodied descriptions clearly convey the complex enmeshment between our constructed past, present, personalities, and perceived environment during caring encounters (van Manen, 1990). With little to no prompting, all nine participants acknowledged an awareness of the AI cancer care inequity and situated it within a larger and more structural marginalization from resources across healthcare in general and the entire U.S. infrastructure as a whole. How each participant viewed their role in this care inequity varied considerably across individuals, yet there was an undercurrent of desire for improving this trajectory among most, with an implicit understanding of the nurse-patient relationship being a powerful and salient tool for doing so.

### **Research Aim #2 Results**

The goal of the second research aim was to identify the underlying structures of the AI patient-cancer care nurse relationship by describing shared themes seen across the group as a whole, as represented in a general structural description. The outcome was a rich structural description of the phenomenon of being in a nursing relationship with AI patients within the context of cancer care. Cross-participant analysis of the individually situated themes and essences resulted in a total of seven meta-themes with descriptions representing repeated patterns related to the AI patient-cancer care nurse relationship. Organization of these meta-themes was facilitated by creating a level-two matrix that sorted situated themes and essences by lifeworld, revealing the considerable overlap between lifeworlds in lived human experience (Appendix N).

## General Structural Description

The following general structural description is organized by shared meta-theme. Each meta-theme begins with a thematic description explicating what this relationship is from the nurses' standpoint. Emic quotes are attributed to each participant, interview, and transcript section as organized by Atlas.ti (e.g., P6-1, 237; meaning participant #6, interview #1, section 237).

**From task to connection.** Relationship is paramount for nurses to transform nursing *care* into authentic *caring*. Relationship is not necessary for engaging in the work of nursing, but it is deeply desired by cancer care nurses in order to feel a sense of fulfillment and purpose. When nurses are able to establish an open, comforting, and compassionate relationship with AI patients, they feel as if they are being virtuous and ideal nurses. Once you “start the relationship, then I think they start trusting you, and then the relationship just grows,” illustrating the inter-reliance between trust and relationship, which then creates space for caring to take place (P4-3, 139). AI nurses inherently understand the centrality of relationship, and also express a feeling of being appreciated within their relationship with AI patients: “I think they've [AI cancer patients] learned to appreciate the relationship we have...they'll let me know, ‘Thank you’” (P8-2, 583).

Without relationship, nurses are relegated to engaging in surface-level conversation and only the slightest, most necessary touch. Their work as nurses has no meaning and is simply an unfulfilling “task” to be performed wherein the nurse feels like a “robot” (P5-3, 230). It is degrading, draining, and unsustainable. When relationship does not occur, nurses “feel frustrated and then sorry at the same time,” and pangs of regret and failure cling to them long after the

patient has gone (P6-2, 76). It represents a missed opportunity for caring, regardless of whether the impetus to do so was professional, personal, or both.

**Unnerving messaging.** Relationship is thwarted by an inability to read verbal and nonverbal cues expressed by AI patients. When nurses are unable to interpret AI patients' often subtle messaging, it causes nurses to feel disconnected from the patient and to doubt their clinical competence:

“I feel more distant from the [AI] patient. It's harder for me to relate to them. I feel that when it's harder for me to relate and connect to them, it's harder to read their symptoms and do my job to help keep them comfortable” (P1-3, 144).

The formation of relationships partially relies on the ability to “read” the patient, but when this ability is inhibited by the patient's muted or unexpected signals, it is unsettling and often vexing for the nurse. “If you do try talking, you're met with silence....I go in with a shut-down expectation... and “I just don't seem to have any sort of way of making that connection, that spark” (P5-2, 171). When nurses encounter AI patients exhibiting “blank stares and sometimes not even acknowledging that I had spoken,” they find themselves lost in a sea of uncertainty and confusion, struggling to make sense of the situation and to regain meaning and purpose in order to reconnect with what drives them to continue caring (P1-1, 36).

For AI nurses, the messaging is familiar and decipherable. They use both verbal and nonverbal tactics to facilitate connection, hope, and partnership, and do not need to spend precious time breaking the code between patient and nurse. By “taking their hands... right away, they feel, as a group, you're connected” (P2-3, 169). Their relationships with AI patients are

imbued with both spoken and unspoken meaning that is understood at an almost instantaneous and intrinsic level.

**We are one.** Relationship is deepened by recognizing self in the other (and other in self) regardless of contextual differences. When a nurse looks into her AI patient's eyes and sees herself, she is able to transcend any barriers and differences between them. This act gives rise to a primordial recognition permeated with meaning as boundaries are erased in order to enact altruistic caring based in humanistic love. When nurses allow it, relationship becomes a way to honor our sacred connection to one another. Nurses imagine that patients also see themselves in their eyes, creating a sense of reciprocity, indivisibility, and exchange: "They're looking at themselves in my eyes when we look at each other...What's the difference? It's nothing" (P3-2, 862). This sense of oneness also creates an obligation to provide care in a manner that nurses would like to be cared for, should they ever require it. For AI nurses, recognition is immediate and infused with understanding; there is an ancient and deep connection between AI people. When they look at their AI patients, there is a distinct sense of being in the right place, at the right time, doing the right work. Recognition contributes to the patient feeling comfortable as "they feel safe with their own people," illustrating the powerful sense of mutuality experienced by those sharing heritage and identity (P8-1, 433).

When AI patients feel unrecognizable to nurses, it creates alienation and *othering*, as if "you're taking care of someone from a different country" (P5-1, 108). There "is a wall in between me and them that you can't really - of course you can't see, but you can't even figure out really sometimes how to break it down" (P5-3, 3). This hyper focus on separateness impedes

the relationship and perpetuates a sensation of coolness between patient and nurse, twisting the meaning of the relationship into something unrewarding and estranging.

**The freedom of unconditional acceptance.** Relationship is facilitated by removing bias, assumption, and judgement and finding neutral ground for caring to take place. Relinquishing these obstructions caused one nurse to reflect, “I noticed that I had a few judgments of my own when I first started working with the Native American population...I understand that now. It’s just definitely opened my mind to see my blindness” (P7-3, 12). This transformation takes time, self-awareness, and a commitment to change from nurses, but the rewards are realized in a palpable strengthening of relationships. Relationships also become exponentially more fulfilling and even freeing as inhibitions are stripped away in favor of unrestrained acceptance of the patient by the nurse. However, an inability by nurses to release assumption or bias creates stunted relationships with the potential for fallacy:

“When you know you’re going to have a Native American patient I think that you have an idea or an image that forms in your mind, like a preexisting idea of how this person is going to be... whether or not that’s true” (P5-1, 112).

The nurse enters into the relationship anticipating disappointment and irritation, and any chance for “meeting in the middle respectfully” is dashed (P6-2, 146). Nurse and patient are closed off and isolated from one another in this scenario, like two ships passing in the night.

**Attuning and opening.** Relationship is a process of attuning to the AI patient in every dimension and becoming receptive to a new way of being. Attuning to patients requires speaking less and listening more; mirroring the patient’s preferred (and often slower) pace instead of marching forward at their own speed; and, relinquishing their own expectations in favor of

honoring the patient's preferences. These practices often came quite easily to the AI nurses, but for non-AI nurses a unique attunement is required with AI patients due to cultural variations, calling for a heightened sensitivity and a willingness to learn. Attunement is fundamentally embedded in the ability of nurses to respond authentically and benevolently to AI patients despite their own preconceptions. This requires a conscious act of relinquishing control over both the patient and the situation, a difficult task within the often urgent and regimented cancer care world:

“[AIs] don't expect things to happen quickly, or they don't expect immediate results... [They are] culturally different, and so that urgency isn't in them. They'll come maybe, and they'll get treated, but all in their own time, which is okay—I think something that I've learned is that it is okay” (P6-2, 142).

Being attuned to AI patients gives the relationship great meaning for nurses by creating a sense of collaboration and synchronicity. Feeling out of tune with AI patients fosters a dichotomous and superficial approach to care as if, “you're coming from this direction, they're coming from that direction” and like “you're taking care of somebody on the surface...you're taking care of their needs, or their problems, in that exact moment, but you haven't really made a connection or an impact” (P6-2, 145 & 127). This feels radically unsatisfying for nurses, yet they know that attunement often takes time and attention: “I think in my listening, my ability to care for her at several different times... we [eventually] connected because of my openness in wanting to learn, and then wanting to care for her however she wanted to be cared for” (P9-2, 63). There is an element of deference in this type of caregiving that stands out.

**Atoning for the past, one moment at a time.** Relationship is a means for honoring the struggles of AI peoples through the easing of suffering, even if only momentarily. The verb ‘honor’ is derived from the Latin *honorem*, meaning to show respect or reverence. Essentially, approaching the relationship from this perspective creates opportunities for nurses to facilitate both personal (immediate) and collective (historical) healing. “A lot of patients don’t realize that they are strong,” yet nurses are in a position to increase cognizance of this resiliency and to support it wholly (P8-2, 413). They are acutely aware of the substantial barriers and systemic complexities their AI patients’ encounter while seeking cancer care: “When you realize whatever it took to get down here [for treatment] or what they’ve been through before, it’s humbling” (P6-3, 121). Threaded throughout many of the relationships is a strong sense of past injustices committed by non-AIs against AIs; these historical violations infiltrate the present in subtle yet insidious ways. “It’s difficult to touch someone in an atmosphere of distrust,” and this may also mean that “you’re trying to make up for things that have happened in the past” during present-day cancer care (P9-1, 1005; P6-3, 5). While the past is unchangeable, many nurses felt compelled to use the present time to promote reconciliation and restore trust between AI patients and cancer care systems and providers. For AI nurses, the past is implicit between themselves and their AI patients: “You understand each other and the history and your roots... I think most Natives have that deep understanding... I think that deepens the connection [between us], knowing the history” (P2-3, 31).

When relationships fall short, “it makes me sad because especially in the cancer business by the time it is figured out, it’s a lot farther than it [should] have been” (P6-1, 63). Thus, relationships have an adherence component in that patients may be “resentful” when they don’t

feel respected, which in turn “clouds their judgement” about continuing care and perpetuates the historical pattern of disengagement from healthcare services and providers (P4-3, 187). Nurses use relationship as an implement for reducing the cancer care inequity, one patient at a time; a relationship comprised of respect and parity may literally save a patient’s life. Relationships are the most salient tool nurses have to counter four centuries of inequity within AI healthcare.

**Humanizing the inhumane.** Relationship is a mediator between the biomedical cancer care and AI worlds. It serves as a conduit between “crisp, clean and regimented” allopathic care and more nuanced, complex AI patterns of health and wellbeing (P9-2, 1029). As humans, we are always within our bodies, and nurses become the human image of cancer care through their “caring eyes” “positive” touch, and simple presence (P6-1, 239; P9-1, 1033). They often act as “the mediator, the middle person” between patients and families, physicians, and systems (P8-2, 461). Uniquely, AI nurses *reside within* their patients’ worlds, permitting them both a distinctive vantage point and attenuating the taken-for-granted nature of perception: “You think about these patients who come from the reservation and they come to the cancer center and it’s a whole new environment” and “It helps me in that I understand both worlds and I don’t take anything for granted” (P8-1, 433 & 489). The enclosed sterility of the cancer care world is potentially harmful to AI patients’ healing: “It’s not good for their spirit or their emotions, just to focus on only their physical” and AIs “need to touch ground, and they’re not touching the ground” in the biomedical setting (P9-1, 749 & 757). Connecting with nature is another basic feature of being human, and nurses recognize this even within their own process of healing following the loss of a patient: “I kept looking outside and I wanted to see the sun... It feels so dark inside of you” (P2-2, 27).

When nurses feel nameless and faceless to their patients within the cancer care world, it is dehumanizing. The sheer amount of time and persistence it takes to earn the trust of AI patients and to reach a point of familiarity and ease is exhausting for many nurses, and some never get there. It is disappointing and calls into question their bearing and purpose as nurses:

“I thought maybe she would even recognize my face, [but] when I have spent a significant amount of time with somebody for them to not even have facial recognition...I mean if they don't remember my name that's one thing, but that she didn't even recognize my face was surprising. After all that time we spent together in comparison to other interactions with other patients who not only remember my face but know my name...” (P1-3, 73).

To be human is to have a name and to be recognized upon sight by other humans. When this fails to happen, it has implications for the meaning of the relationship between AI patient and cancer care nurse as it casts shadows of doubt on the depth of their shared connection at the most fundamental level.

### **Research Aim #2 Conclusions**

The general structural description conveys the rich experiences of nine cancer care nurses serving AI patients. Through the examination of shared themes and patterns, the underlying structures of this relationship phenomenon were elucidated. What we learn is that as fundamental as relationship is to caring for AI cancer patients, it is not without tribulation and frustration for many nurses as well as deep satisfaction and gratification. Each of the participants deeply desired a relationship with their AI patient. It was seen as essential to caring and transformed what would have otherwise simply been work into something meaningful and valuable.

Relationship did not always occur naturally or quickly for all of the nurses, initially leaving them bereft and disillusioned. Over time, many adjusted their way of being as a nurse through a process of attunement and found much greater success with a more flexible and open-minded approach to care; others were unable to transcend their own inhibitions and remained inert and frustrated.

For the AI nurses, relationship came easily and was utilized to improve the patient's experience as well as to solidify the nurse's purpose. Although the establishment of relationship may have come more easily to AI nurses, all of the participants shared a striking awareness that caring for AI people within cancer care was a unique experience colored by both the traumatic historical past and persistent present-day inequities. They sensed that they were the human face of an often inhuman system, and they utilized relationship to soften the edges of an otherwise painful and all too often unjust situation.

### **Research Aim #3 Results**

The goal of the final research aim was to interpret the meaning of the AI patient-cancer care nurse relationship by examining and describing the collective situated meaning within the observed care inequity. The result was an embodied essential meaning followed by a comprehensive essential description of this relationship-centered cancer care phenomenon.

#### **Essential Meaning**

The meaning of the AI patient-cancer care nurse relationship from the nurses' perspectives is expressed in contradictory yet simultaneous patterns of joy and sorrow; ease and difficulty; obligation and vocation. It is challenging, often vexing, and sometimes heart wrenching; yet it is also rewarding, inspiring, and humbling. From one moment to the next,

nurses seek synchronicity with their patient as they dance to a life rhythm that reveals and conceals; enables and limits; connects and separates. *Being in* relationship gives nurses great purpose within the universal human context of caring.

I do it for the joy it brings...

Because the world owes me nothing

And we owe each other the world

I do it because it's the least I can do

(DiFranco, 1996, track 11)

### **Essential Description**

Meaning is not only contradictorily patterned, but also existential. The phenomenological lifeworlds providing a guide for traversing the nuances of the lived human experience within lived body, lived space, lived time, and lived communality.

**The embodied relationship.** Caring for AI patients, families, and communities encountering cancer instigates a number of corporeal sensations for nurses. “When we meet another person in his or her landscape or world we meet that person first and foremost through his or her body” (van Manen, 1990, p. 103). For many non-AI nurses, a vexing inability to read their AI patients’ cues results in being feeling unnerved, disoriented, and inept. They are immobilized by doubt and ambiguity, and the formation of relationship is either delayed or perpetually stalled. They are plagued with uncertainty about touch, personal space, and spoken and unspoken messages. Moving beyond this inertia requires complete sensory attunement on the nurses’ part as the patient knows of no other way to be. She must adapt the way she approaches the physical body, adopting a softer and lighter touch compared to what she is

accustomed to with non-AI patients. She uses fewer and more carefully chosen words, giving the patient time and space to respond. There is less doing and more *being within* the body.

For AI nurses, this embodiment is familiar and comfortable, for they share the same form as their AI patients. The patient's body and messages are as recognizable as their own. Their lives are enmeshed and intertwined in a sensed way, and they use this physical connection to collaborate with the patient and convey their caring intentions. The body represents a receptive object where relationship can be enacted, yet the body is also accessed through relationship.

**The spatial relationship.** The lived space where the meaning of the AI patient-cancer care nurse relationship resides varies depending upon personal experience, but coexists with the shared landscapes of nursing and humankind. Essentially, how nurses perceive this felt space is both individually and collectively determined based on personal, cultural, and professional norms. Some cancer care nurses feel *at home* with AI patients and communities, finding an overarching sense of belonging and comfort from *being in* the AI world. Being at home in this environment is as effortless and natural as breathing air; at other times, it arises from a purposeful and conscientious integration of the nurse's world with that of her patient.

Often, the nurse is a conduit between two worlds, creating a relationship comprised of mediation, compromise, and advocacy. The relationship itself can be a bridge between the strikingly different cancer care and AI worlds with the nurse navigating with either ease or difficulty. Those that have the advantage of speaking an AI language use it to interpret between worlds. They are aware that the healthcare space in general and cancer care specifically, is often cold, isolating, and depersonalized. Cancer care nurses seek to alter this impersonal space, to make it more human and hospitable to AI patients.

Yet for so many non-AI nurses the AI world remains a mystery, an unexplored landscape where they find the patient unreachable; this barrier encumbers and twists the relationship into something tenuous and unsteady. They are unable to transcend the void between worlds, leaving them stranded on the other side and waiting (sometimes in vain) for the patient to reappear or extend forth. This experience is isolating and constricting for the nurse, as captured by the poet Rainer Maria Rilke (1984, p. 55):

“Why not then continue to look upon it all as a child would, as if you were looking at something unfamiliar, out of the depths of your own world...? Why should you want to give up a child’s wise not-understanding in exchange for defensiveness and scorn, since not understanding is, after all, a way of being alone...?” (Rilke, 1984, p. 55)

Yet those that allow themselves to see the AI world are awed by its spiritual undertones as well as its inequity; this compels the nurse to foster a relationship that honors these actualities, changing the space between them into one of both reverence and atonement. The environment is transformed from a narrow, sterile, and inhospitable place into one inhabited by living, breathing humans who honor and cherish one another in spite of all of their idiosyncrasies. Together they create a “middle ground” where their worlds can peacefully coexist, a place where both nurse and patient can be their authentic selves and the relationship can flourish.

**The temporal relationship.** Parse (2014, p. 47) writes of “the continuous change of the emerging now,” a fitting descriptor for the transient yet incipient nature of this particular relationship dynamic. Its meaning is constantly evolving, shifting, and transforming with time dictating the tempo as patient and nurse are intertwined in the dance of cancer care. Many nurses

must learn to dance at a much slower pace than what they are accustomed to; this is both disconcerting as well as enlightening and represents yet another example of the necessary attunement of the relationship. While this deceleration emanates from both the AI world and the complicated structures controlling the pace of care, it permits a level of *presence* for the nurse that is otherwise impossible. Urgency wanes in favor of the here and now, creating a relationship that is deeply attentive and aware. For some, adjusting the pace of care is irksome as it conflicts with the demands of the biomedical cancer care world; they feel the urge to press upon their AI patients, to goad them into action, and to rail against the burdensome system impeding the progression of care. Others reach acceptance and embrace it as a rare opportunity for reflection and stillness. For AI nurses, this is a known tempo, as familiar as a favorite song. It arises from their shared identity and results in a present moment that is conducive to the formation of a deep and abiding relationship.

The AI patient-cancer care nurse relationship can also be caught in a cycle, an endless and futile pattern of miscommunication and diminishing hope. When the AI patient feels elusive and distant from the nurse, each moment is strained and never-ending. The nurse finds herself wishing for the time to pass and for an end to come to this protracted state of disjointedness and disillusion. She longs to escape and dreads the moments in which she must face her own failure to establish the kind of relationship with the patient that she so desperately desires and knows to be true. Breaking this cycle requires the release of frustration and expectation on the nurse's part, a proverbial "hitting of the re-set button" between them. She stops and considers the situation with new eyes, seeing the patient for perhaps the first time, and comes to terms with how little control we *all* have over the rhythms of both cancer and life. She and the patient are equally at

the mercy of this world, and there is solidarity in this knowledge that encourages a more synchronous relationship.

**The communal relationship.** What is shared between an AI patient and cancer care nurse within the permeable and shifting borders of relationship is often profound. It is a sacred space where two people unite and separate; support and withdraw; disclose and obscure. At the heart of it lies the nurse's desire to alleviate the patient's suffering in whatever manner possible. Yet the suffering of AI patients is unique, for they carry a burden that is four-centuries old yet makes its presence known in the extant moment. How nurses choose to confront this invisible yet tangible "beast" in the room varies. Some ignore it, professing ignorance and discomfort, and absolving themselves of any ownership or participation in the failure of this ancient, festering wound to heal. Others acknowledge it, albeit from somewhat of a distance, and endeavor to honor it through the creation of a relationship built on atonement and compassion. It is possible to make amends for transgressions you have not personally committed, and what better place to do this as a nurse than in a single, caring moment? For the AI nurses, this burden has always been theirs to bear. It is acknowledged when they look into their AI patient's eyes and see themselves, and nothing else need transpire in order to convey their healing intentions to the patient within the present relationship. This mutual understanding is a given and relationship has purpose for the AI nurse in this sense, perhaps even the same purpose as those of traditional healers and medicine people from the beginning of time.

However, regardless of whether the nurse is AI or non-AI, all are capable of seeing our shared humanity when they look into their AI patients' eyes. When this occurs there is a dissolving of our separateness and everything from the traumatic historical past to contemporary

suffering becomes shared within the relationship. It is neither mine nor his, but *ours*. Suddenly the role of the nurse shifts from one of *benevolent doer* to *fellow sojourner*. We are not so different after all, and this burgeoning relationship reinforces the nurses' vulnerabilities in a way that is terrifying yet empowering. After all, "staying vulnerable is a risk we have to take if we want to experience connection," the very foundation of relationship (Brown, 2016, n.p.). It is not only the patient that must acquiesce, but also the nurse. There may be a temporary loss of self during this process, a period of becoming nameless and faceless, but it resolves when the nurse comes to terms with unadulterated acceptance of both self and patient. The need to be named and seen gives way to what is simply *felt*. This is especially poignant in lieu of patterns of discrimination, judgement, and subjugation of AI peoples and our own complicity as people and a profession in their perpetuation. Suddenly, cancer care nurses see strength within AI patients where before there had only been loss and difficulties. It is the patient-nurse relationship that makes this new vision possible.

### **Research Aim #3 Conclusions**

Meaning for cancer care nurses serving AI patients, families, and communities was expressed as opposing yet coexisting experiences. These paradoxical sensations were aligned with Parse's (2014) human becoming paradigm in which human rhythmicity allows two people to continuously move with and apart from one another over time. In many ways, the meaning for nurses in this study was located somewhere along this continuum and within these enigmas, palpable yet elusive.

## Conclusion

As nurses fulfill their many roles within cancer care, they form significant and influential bonds with patients. These relationships likely impact AI patient experiences with cancer care, including satisfaction with services and overall outcomes, yet this study is limited in its exploration from only the nurses' perspectives. However, nurses clearly articulate in this study that there are unique challenges to the formation of effective and caring relationships with AI patients as well as profound professional and personal rewards and satisfaction in serving this population.

What these relationships mean to nurses is revealed in the “imaging and valuing” of their language (Parse, 2014, p. 37). Their words form descriptions that expose the multifarious, fluctuating nature of engaging in a deeply personal relationship with AI patients, families, and communities who feel familiar and unknown, receptive and impervious, predictable and volatile. In some ways, these contradictions may be a universal experience of nursing, part and parcel of the unpredictability of human beings that is so often amplified during times of intense interfacing. The typically prolonged nature of cancer care adds yet another element to this nursing experience as relationships have the opportunity to become enduring yet undulating.

Yet, AI patients with cancer pose a challenge for many nurses in that their very way of being within the world feels distinctly different than the biomedical-allopathic (and mostly White) paradigm that nurses and nursing emanate from (Hall, 1999). Regardless of shared heritage or identity, a nurse's ability to seize upon similarities while embracing differences between herself and the AI patient seems to be deeply connected to her overall fulfillment and sense of purpose within the relationship. Those nurses that were unable to envision any piece of

themselves in their patients found the relationship reduced to one of task-performance and superficial interactions that left them emotionally fatigued and longing for more.

Patient-nurse relationships are comprised of continuous two-way exchanges and certainly the experiences of AI patients within this dynamic is equally worthy of inquiry. However, considering my own experience as a nurse caring for this population, I made a conscious decision to explore both what was underrepresented in the literature as well as what was most familiar to me as a nurse-researcher. The philosophy and practice of interpretive phenomenology suggests that what appears the most familiar to us is often the most elusive (Crotty, 1996; van Manen, 1990). I found certain similarities between my own experiences and that of the study participants, most namely a deeply sensed unpreparedness for working with this distinctive group despite my many years of training and experience as a nurse and my geographic proximity to dense AI populations. The complete absence of AI perspectives and experiences in my undergraduate nurses training was intensified by the tangible presence of a painful historical past lingering within everyday patient-nurse encounters that I often felt powerless to impact. Like many of the participants, I sought to soften and humanize my approach out of respect for the unique AI context, including the systemic present-day inequities that were so obvious in my patients' lives. I could also identify with the need to adjust and attune my patterns of clinical practice to reflect the patient's unfamiliar (to me) verbal and bodily messaging. Like many of the nurses in this study, I became more adept at this over time and gradually came to appreciate a slower, quieter, and deeply respectful approach to providing care.

There were other portions of the data that were less familiar to me, most significantly the experiences of the AI nurses and the additional minority nurse, all of whom were able to readily

identify and name the experience of being in relationship with a fellow person of color. There was a sensed solidarity present in their recounting that myself and the other White nurses found difficult to imagine, even if we could respect it from a distance. I also never had the sensation of an AI patient being “foreign” as if from another country; on the contrary, perhaps because I lived and worked within tribal lands for the bulk of my experience caring for these populations and therefore felt more like a guest (and sometimes an interloper) rather than a host, I found myself more intrigued about our cultural variations than alienated by them. After all, when we become nurses we implicitly understand that we will encounter endless varieties of people, practices, customs, values, and ways of being within the world. Why some of these convolutions are more perplexing and taxing than others perhaps says something about the persistent dominance of Anglo and Western neo-colonial structures in nursing practice, education, and research and our failure as a nation to reconcile our uncomfortable shared histories with AI peoples (Mohammed, 2006; Wolfe, 2013).

### **Implications for Practice**

This study has several implications for cancer care nursing practice. First, illumination of the nuances of the essential AI patient-nurse relationship embedded in the cancer care process will contribute to the development of interventions designed to improve the patient experience. This may in turn promote earlier entry into cancer prevention and screening systems for AIs and enhance treatment partnerships, resulting in decreased mortality and morbidity and reducing the cancer care inequity.

Secondly, understanding the meaning of cancer care relationships for nurses working with AI patients and communities may assist in developing improved methods of support and

training for nurses, including targeted and tailored cultural safety training. Adequate support and training for nurses is associated with greater job retention, increased compassion, and the delivery of high quality and culturally safe care (Alpers & Hanssen, 2014; Bell & Breslin, 2008; Hildebrandt, 2012; Kelly & Minty, 2007; Raingruber & Robinson, 2010; Stone & Moskowitz, 2011). The responsibility for supporting nurses' in their endeavors to provide this type of highly compassionate and versatile care resides in nursing educators and leaders throughout the United States and particularly within regions with significant AI populations, such as the southwest.

Lastly, refinement of nursing praxis will ultimately result in improved outcomes for *both* nurses and AI patients, reflecting the inseparability of the two entities within the cancer care relationship. The complimentary and mutually dependent nature of the patient-nurse relationship implies that strengthening and improving support for one entity may in turn positively impact the other (Watson, 2006).

### **Implications for Research**

Interpretive phenomenological studies are highly suitable for initial forays into human phenomena that we know very little about (van Manen, 1990). This study typifies this methodological characteristic as further inquiry is called for in several areas.

First, it would be prudent to explore if the experiences of nurses who reside within AI communities are different than those who live and work in areas dominated by non-AI populations, as all but one of the participants in this study did. It is possible that AI community-dwelling cancer care nurses may have significantly different perceptions, feelings, and experiences due to a radical shift in not only racial and ethnic demographics but also in the sociocultural systems unique to Indigenous communities. For many non-AI nurses, living or

working in an AI community may entail being a ‘minority’ for the first time in their life and exploring how this juxtaposition shifts the meaning they ascribe to their relationships is intriguing.

Secondly, the experiences of the other half of the nurse-patient relationship of focus for this study, AI cancer patients, are needed specifically related to nurses. The bulk of the extant literature is focused on the AI patient-cancer care physician relationship despite the centrality of nursing as a profession within cancer care. It is plausible that AI patients feel very differently about cancer care nurses, including possessing altered expectations for what an effective patient-nurse relationship looks like as opposed to an effective patient-physician relationship. Further research into the experiences, hopes, and desires of AI patients concerning cancer care nurses is called for.

Ultimately, this study represents the first step in a program of research aimed at fully illuminating the AI patient-cancer care nurse relationship in an effort to improve outcomes for both underserved yet resilient AI populations and the complex, often highly dedicated nurses who care for them.

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APPENDIX A:

LOOKING INWARD: A GUIDE FOR PHENOMENOLOGICAL SELF-REFLECTION

Looking Inward: A Guide for Phenomenological Self-Reflection

Natalie M. Pool, BSN, RN, PhD Candidate

College of Nursing

The University of Arizona

Mary Koithan, PhD, CNS-BC, FAAN

Associate Dean, Professional and Community Engagement

Ann Furrow Endowed Professor

College of Nursing

The University of Arizona

Correspondence concerning this article should be addressed to:

Natalie M. Pool, College of Nursing, PO Box 210203, Tucson, Arizona, 85721 USA

nataliepool@email.arizona.edu

1 (520) 621-1981

Abstract

Engaging in early and ongoing self-reflection during interpretive phenomenological research is critical to ensure rigor. However, the lack of procedural guidelines and clarity about the role of self-reflection in this methodology creates both theoretical and procedural confusion. The purpose of this article is to suggest a set of procedural guidelines to facilitate reflexivity by

detailing the philosophical underpinnings, rationale, processes, and benefits of engaging in self-reflection during interpretive phenomenological investigation. The characteristics of high-quality self-reflection are detailed using illustrative excerpts from an ongoing interpretive phenomenological study. These guidelines are intended to be particularly beneficial for novice researchers who may find self-reflective procedures and the necessary style of writing to be daunting and unclear. Increasing its utility and application will strengthen both the interpretive phenomenological body of work as well as that of all qualitative research.

*Keywords:* interpretive phenomenological methods; Heidegger; self-reflection; rigor

### Looking Inward: A Guide for Phenomenological Self-Reflection

Engaging in early and ongoing self-reflection during interpretive phenomenological research is critical to ensure rigor. Self-reflection during interpretive phenomenological investigation (a) recognizes the “researcher as instrument”, including the fallible and transient nature of individual interpretation; (b) confronts and helps to mitigate the inevitability and complexity of researcher bias; (c) promotes a deeper sense of openness and receptivity to the often hidden dimensions of human phenomena while expanding our understanding of self and world; and, (d) contributes to shared meaning making, the sought after outcome of interpretive phenomenological inquiry (Creswell, 2013; Crotty, 1996; Munhall, 2012; van Manen, 1990, 2011). However, the lack of procedural guidelines and clarity about the role of self-reflection in interpretive phenomenological research creates both theoretical and procedural confusion surrounding reflexivity in general and self-reflection in particular (Crotty, 1996; de Witt & Ploeg, 2006; Gearing, 2004; Jootun et al., 2009; Koch & Harrington, 1996; Tuohy, Cooney, Dowling, Murphy & Sixmith, 2013).

In response, the purpose of this article is to suggest a set of procedural guidelines to facilitate reflexivity by detailing the rationale, processes, and benefits of engaging in self-reflection during interpretive phenomenological investigation. These guidelines are intended to be particularly beneficial for novice researchers who may find self-reflection daunting and unclear. To further illustrate the practical application of self-reflection, a set of exemplar reflective statements from an interpretive phenomenological study about the meaning of the relationship between cancer care nurses and American Indian patients are provided. This article features not only the procedures associated with self-reflection during this study, but also

proposes the long-term impact of this process on the quality and authenticity of interpretive phenomenological research as a whole.

### **Overview of Interpretive Phenomenology**

To fully appreciate the role of self-reflection in interpretive phenomenology it might be useful to briefly review the development of this scientific method. Our current phenomenological philosophical and methodical approaches emerged in the late 19<sup>th</sup> century in response to the positivist paradigm of the previous era in which logical thought and Kant's bifurcating distinction between perception and reality dominated science (Rodgers, 2005). While positivists were consumed with locating truth using empirical means, the ancient Greeks had originally focused on searching for wisdom (Creswell, 2013). Edmund Husserl, a German theoretical mathematician, returned to the classical Greek teachings of Plato by acknowledging the influence of subjective and idiosyncratic interpretations of reality (Parse et al., 1985). Directly responding to the positivist traditions, Husserl suggested that there was in fact no mind-body dualism and that phenomena occur within experience as perceived through conscious awareness (Koch, 1995; Lavery, 2003).

In the early 20<sup>th</sup> century Husserl's student, Martin Heidegger (1997/2006), questioned if reality or truth could ever be grasped in an unbiased manner. He challenged Husserl by altering the way meaning was uncovered through a hermeneutical approach (Rodgers, 2005; van Manen, 2011). A former theology student, Heidegger transformed the Husserlian phenomenological orientation of epistemology into a deeply ontological orientation by studying the science of Being, or *Dasein* (Reiners, 2012). Thus, interpretive phenomenology focuses on the way we are rather than on what we know.

Yet Being and our ability to understand “the way we are” tends to be “vague”, “obscured”, and limited by our ability to view our own immediate and past experiences (Crotty, 1996, p. 79). By integrating existentialism and ontology with phenomenology, Heidegger encouraged researchers to concentrate on the situated meaning of being human rather than describing characteristics of phenomena as they are consciously perceived (Koch, 1995; Laverty, 2003; Rodgers, 2005;). Moving beyond description and into meaning requires an interpretive process, and interpretation is inherently reflective.

### **Self-Reflection as a Cornerstone of Interpretive Phenomenology**

The best way to address our own preunderstanding and assumptions about phenomena is through extensive and focused self-reflection; thus, this process is foundational to the methodology (Heidegger, 1997/2006). However, performing authentic self-reflection is a challenging task. Like all humans, researchers are constantly and subliminally engaged in interpretation of the world, yet this particular methodology asks that we consciously bring these revelations to the surface and critically examine their influence on the perceived phenomenon under study (van Manen, 1990). Furthermore, self-reflection:

**Hones the research instrument.** The researcher acts as the instrument during interpretive phenomenological research. However, our inability to separate ourselves from our own background layers and context plays a significant role in how we interpret human phenomena (Johnson, 2000; van Manen, 1990). As human beings within-the-world, phenomenological researchers benefit from deep introspection as a way of fine-tuning and adjusting the “instrument” of use. Yet according to Heidegger, conscious perception is transient, imperfect, and highly subjective (Crotty, 1996). Self-reflection illuminates this muddled personal context in

order to create conscious awareness about the present phenomenon. Thoughtful engagement in self-reflection helps to grasp the elusive essence of a phenomenon as it exists in one moment of time as seen through the interpreter's lens, an activity similar to data collection using a fully calibrated tool in other forms of research.

**Confronts and mitigates bias.** Self-reflection encourages researchers to directly confront our own bias and to recognize the extent that past experiences influence present interpretation and subsequent meaning making. "We are always selective in our perception of situations", becoming hyper focused or oblivious to certain aspects of phenomena depending upon their relevance to our own history and way of being (Crotty, 1996, p. 160). The potential to contaminate research findings is particularly increased during interpretive phenomenological inquiry because of the highly iterative nature of the hermeneutic circle used to guide data collection and analysis; during the back-and-forth action occurring during this process it can become challenging to maintain distance between self and phenomenon (de Witt & Ploeg, 2006; Lavery, 2003; Reiners, 2012). Disciplined and persistent self-reflection encourages the tempering of bias by forcing us to closely examine our previous thoughts and feelings about a phenomenon, making them explicit, and exploring their origins and relevance to the investigation at hand (Crotty, 1996; Parse et al., 1985). These preconceptions are then held at abeyance to the fullest extent possible while the phenomenon is examined in a new light (Bevan, 2014; Gearing, 2004).

**Facilitates openness and receptivity.** Self-reflection creates a sense of unknowing/unseeing as well as a clearer grasp of the phenomenon under study at a particular moment of time (Creswell, 2013; Munhall, 2012). According to Heidegger, the goal is to set

reason aside and surrender, contemplate, and listen to what the phenomenon has to offer (Crotty, 1996). Adoption of this perspective strengthens qualitative research by allowing the researcher to become more receptive and sensitive to the subtleties and often obscured nature of human idiosyncrasies. Strategic self-reflection encourages researchers to fully engage with our own immediate perceptions and to apprehend the phenomenon of interest as it is authentically and fully lived (Lavery, 2003; Munhall, 2012). In addition, self-reflection promotes personal knowing, cultivating a deeper appreciation of human lived experiences and their meaning (Carper, 1978/2012; Munhall, 2012; Quinn, 2014; van Manen, 1990). As a keystone of nursing inquiry, personal knowing is primarily achieved through self-reflection, a form of knowledge generation that contributes to both nursing praxis and the overall scholarly body of qualitative literature (Carper, 1978/2012; Quinn, 2014).

**Contributes to shared meaning making.** Self-reflection facilitates the co-creation (between participant and researcher) of meaning by illuminating shared albeit tentative understanding of phenomena arising from data (Crotty, 1996; Lavery, 2003; van Manen, 1990). Meaning is “always in the context of something –one’s humanity, one’s culture, [and] one’s personal situation” (Johnson, 2000, p. 135). When self-reflections are reconstituted with the *emic*, and often profound, elicitations of study participants in the search for meaning, the subjective become increasingly objective. Objectivity is a key component of a collective understanding that resonates across humanity and fosters shared meaning. Self-reflection both counters and authenticates study participants’ perceptions, and from the subsequent reconstitution, meaning is uncovered as a reflection of the universal human experience (Gearing, 2004; van Manen, 1990). It is essentially a process of recognizing self in other, and other in self.

### **Characteristics of Quality Self-Reflection**

The word 'reflection' comes from the Latin *reflexionem*, meaning "a bending back" or a "turning back one's thought on some subject" (Merriam-Webster Dictionary, 2009, p. 1046). In contemporary literature, reflection is "something that shows the effect, existence, or character of something else" (Merriam-Webster Dictionary, 2009, p. 1046). The etymological origin suggests that self-reflection is a conscious act of bending/modifying how you look at or consider an object in relation to self. The object of reflection can consist of anything as long as it existed in the past, thus permitting a person to "turn back" and appraise its unique qualities and characteristics through individual perspective and the passage of time. The term 'reflection' assumes a degree of distortion, further compounded by the unreliability of human memory and perception (Crotty, 1996). Reflection that minimizes distortion occurs over time, is deeply contemplative, and is grounded in lived experience.

Self-reflection is not a simplistic or chronological recounting of events, nor is it a story or allegorical narration. In order to make the intangible more perceptible and to uphold the methodological foundations of interpretive phenomenology, self-reflection requires a thoughtful, mentored, and well-organized process that strives for authenticity and depth. It is not a random, untethered formality; rather, it is a focused and structured method based on the same principles that guide data collection with study participants during phenomenological inquiry (Bevan, 2014; Clancy, 2013; van Manen, 1990). One must move far beyond memory recall into the often uncharted territory of the repressed psyche, a process best supported by experienced guidance and a serious commitment from the investigator.

So, how does one engage in self-reflection during interpretive phenomenological research? What does this process entail on a pragmatic level? What does truly reflective writing look like? Consider the following guidelines and best practices as informed by van Manen's (1990) approach for eliciting lived-experience descriptions (including those from self) and reconstituting their meaning. I have provided excerpts from my own unpublished self-reflection completed prior to beginning a study examining the meaning of the American Indian patient-cancer care nurse relationship. The excerpts are intended to illustrate each of the following hallmarks, and examples of targeted feedback from my research mentor are included to demonstrate the depth of guidance and iterative pattern required to elicit truly reflective text.

### **Focus on the Phenomenon**

Maintaining focus on the phenomenon of interest helps the researcher avoid contamination of the rest of the study by superficial preconceptions or unrelated forays (Clancy, 2013; Tuohy et al., 2013). Constant refocusing allows for deeper comprehension, and surface-level assumptions are made explicit so that the phenomenon can be viewed with a more penetrating gaze (Crotty, 1996; van Manen, 1990). As phenomenologists endeavor to be overt about their own understanding through the process of reflexivity, focusing on the phenomenon itself is crucial. Despite Heidegger's warnings, phenomenologists often find themselves with a shallow or murky grasp of the phenomenon of interest. This occurs because it is often difficult to recognize your own perspective or point of view; meaning originating with others may actually be interwoven with your own perception as various accounts of human experience emerge during data collection (Bevan, 2014; Johnson, 2000; Koch, 1995; Lavery, 2003; van Manen, 1990, 2011).

Maintaining focus is more challenging than it initially appears. It is easy to become distracted or to introduce seemingly related topics that are actually subconscious attempts at avoidance, deflection, or even dishonesty. This initial journal entry from my own self-reflection completed at the start of an ongoing interpretive phenomenological study provides an example of writing that is fairly insipid, even when attempting to recount a specific patient experience:

*There is some fundamental tone of openness and respect that is so quickly sensed by patients. Cancer in particular calls for respect –of the journey people are undergoing, of the fear and immensity felt, the gravity of the situation, the connotations behind the very word ‘cancer’. I stayed consistent with her and her family, always listening more than I spoke, staying calm and respectful. We ended up building a beautiful nurse-patient relationship that brought forth a lot of thoughts and questions for me. (p. 2, lines 39-45)*

This passage reveals very little about the phenomenon of focus, i.e. *the lived experience* of her relationship as a cancer care nurse with an American Indian patient. In the course of three sentences the text moves from what patients might sense about a nurse, to the implications of the word ‘cancer’, to a vague insinuation about a female patient. This ambiguous and unfocused ramble fails to shed any light on the phenomenon. We gain little insight into how the experience of relationship feels and are left wondering what “thoughts and questions” emerged, and what significance they might hold. What is meant by “a beautiful nurse-patient relationship” in this context? Although the passage alludes to some behaviors, how does the nurse determine a relationship is “beautiful” and how do those behaviors exemplify that beauty? What does any of this mean to her?

In response to these initial and unfocused passages, my mentor encouraged me to “stop thinking and analyzing” and to instead “start *feeling* the relationship”. She encouraged me to “reflect on my own lived experience rather than trying to make the situation better”. Carefully examining each word, she asked me to “sit with” particular terms or phrases in order to instigate a more thoughtful and contemplative approach to writing. This technique also helped me to maintain focus by forcing me to pause and consider both semantics and why I chose to recall the particular patients and instances that I did. It became apparent that some of my inability to focus was related to my own hesitation; I was choosing to focus on emotionally safe topics while avoiding the complex and sometimes uncomfortable nuances of my past relationships with American Indian patients, contributing to an overall sense of generality and depersonalization in my writing. After further exploration and a certain amount of re-focusing, a more focused reflective writing emerged:

*She required very complicated wound care several times each shift and we would often pass the time by talking. I think it was a form of distraction for her from the physical and mental discomfort of the situation, and many of these conversations evolved into stories about our families or Indian Country. She really appreciated that I could relate to a small part of her world. I think she felt very alone in the hospital, and these casual conversations helped me to understand her isolation and fear. We began to appreciate where each of us came from, and it helped us to connect with each dressing change. (p. 26, lines 588-596)*

In this passage we gain some initial insight into how a clinical task evolved into a connecting moment. It is detailed, more personal, and hints at the underlying structures of

this particular nurse-patient relationship. When performed correctly, focused self-reflective writing provokes questions and exposes gaps in our understanding of a specific and easily identifiable object, such as this excerpt does (Clancy, 2013; van Manen, 1990).

### **Access the Lifeworlds**

Originally proposed by Husserl, Heidegger ascertained that lifeworlds are reflected across humanity and are composed of four domains essential for interpretation of self-within-world: corporeality, experienced as physical responses and embodied sensations; spatiality, represented by emotional and spiritual reactions to place, space, and the environment; temporality, or when sensations and impressions occur and descriptions of change over time; and relationality, the characteristics of human connection during these bio-psycho-social-spiritual processes (van Manen, 1990). During self-reflection, repeatedly returning to the lifeworlds serves as a means of remaining close to the foundations and origins of the complex and often subconscious nature of human experience (Crotty, 1996). Examples of lifeworld-based descriptions of caring for American Indian patients include: *“I felt under attack and very uncertain about my place, unable to resist the urge to physically escape the patient’s room”* (corporeality; p. 19, line 429); *“It made my job seem impossible as I was caught between wanting to provide complete, detailed care while respecting her personal and cultural space”* (spatiality; p. 30, lines 675-676); *“it felt like time had been suspended because that traumatic history was so present in the moment”* (temporality; p. 11, line 242); *“Providing nursing care for her felt like a substantial responsibility, as well as sacred; I did not want to take anything for granted about our interactions”* (relationality; p. 25, lines 564-565).

As these brief examples demonstrate, accessing the lifeworlds results in writing that is markedly different than typical journaling. It requires significant practice and revision that calls for a specific type of probing applied during and after the creation of self-reflection drafts, often precipitated by a mentor who facilitates a more objective and keen perspective of the described experiences (Clancy, 2013; Johns, 1995). Typically, the first-draft tends to be narrative and observational in nature:

*From nearly the beginning she was “pegged” as being difficult to care for by the physicians and the nursing staff. This was not based on her clinical state, but on her perceived behavior and attitude. I found her to be quiet and observant; I can see how this might have been seen as being withdrawn and sullen. She and her husband expressed their distrust of the nursing staff and residents very early on. Somehow I persisted with them. I spoke about my time and experiences in two previous Native communities –this seemed to build a small amount of trust as we could relate to familiar place names and even some people. Would I have been able to build this bridge as a nurse without previous experience in these communities? I don’t know, but I do believe that there is something in a nurse’s approach that can transcend that common ground. (p. 2, lines 28-39)*

To move beyond the observational, lifeworld-based probes facilitate recognition and expression of suppressed sensations or previously unrecognized areas of significance in narratives (van Manen, 1990). Lifeworld probes are objective and pointed phenomenological queries, such as these from my mentor:

*What did it feel like when she was quiet, observant, withdrawn? What did that feel like inside of you? What did it feel like to persist despite her demeanor? What did being distrusted physically feel like? Take those sensations and ask yourself about time and timing... Again, what did persistence feel like in terms of timing? How did it affect the timing of other sensations?*

This exhaustive probing is aimed at accessing the authentic lifeworlds of the writer in order to truly facilitate understanding about abstract lived experiences (van Manen, 1990). After thoughtfully considering my mentor's feedback, a later reflection became far more embodied, enhancing my understanding and interpretation of a specific experience physically, mentally, spatially, and in relation to others:

*I walked into her room, and she immediately burst into tears. I began to tear up as well and felt that swelling sensation deep in my chest that arises when you are overwhelmed by a strange mix of love and sadness: I was happy to see her, but disheartened to see her readmitted. It was all we could do for a moment to embrace, and I felt honored. This was a woman who had been labeled "withdrawn" and "standoffish" and who openly admitted to not trusting most of our staff. I knew with every cell of my body that I had managed to truly and authentically nurse this person. I had touched her and I felt privileged that she had allowed me to do so. In that moment I also realized how much she had touched me. In our shared vulnerability we found familiarity, comfort, and connection. Words were not needed between us. (p. 4, lines 82-91)*

This excerpt essentially illustrates how an experience physically felt (“*swelling sensation deep in my chest*”); a triggered response when the nurse entered into a particular space (“*I walked into her room, and she immediately burst into tears*”); when a new awareness occurred (“*In that moment I also realized how much she had touched me*”); and the attributes of a specific relationship (“*familiarity, comfort, and connection*”). Originally described in the narrative as a somewhat generic observation, lifeworld-based questioning brings the experience into a deeply embodied sensation taking place during a transient moment of time. This would likely have been impossible without the deliberate direction provided by my mentor, particularly for a novice phenomenological researcher unaccustomed to such personified and lyrical writing.

### **Create Time and Space**

Lastly, self-reflection requires carefully allocated time and space. It is time consuming to generate extensive, thoughtful, and attentive writing (van Manen, 1990). There is no rote or formulaic procedure for producing truly reflective text, and this process must be individually tailored depending upon researcher proficiency and the study timeline (Clancy, 2013; Johns, 1995). Therefore, adequate time should be set aside for written self-reflection both at the beginning and recurrently throughout an interpretive phenomenological study.

Before beginning data collection in the study currently underway, I engaged in self-reflection for approximately 3-4 hours per day, 3-4 days per week, over a 15-week period. This was time exclusively devoted to attentive, disciplined writing and did not include additional intervals spent performing the phenomenological technique of “dwelling with”. Dwelling with refers to a period of prolonged engagement with all textual data (as much as 1-3 additional weeks), including with one’s own reflections about the phenomenon of focus (Wojnar &

Swanson, 2007). Reserving adequate time for prolonged engagement and writing slows the pace of self-reflection, which has been found to result in heightened awareness and greater insight into the lived experience (Creswell, 2013; van Manen, 1990).

Likewise, space should be set aside for self-reflection to occur. This refers to not only a quiet and comfortable physical environment, but also to the emotional and psychological “space” Heidegger claims is essential for critical contemplation (Crotty, 1996). I have found that deeper phenomenological reflection occurs when I am in a quiet yet public environment where anonymity is possible, such as a library. At home or work I encounter distractions and interruptions where it is difficult to focus on the task at hand. Mentally and emotionally, it may be uncomfortable to articulate a painful or unpleasant sensation, particularly when another person (e.g., a mentor) will read the account. Yet, learning to emotionally “trust the process” can allow more genuine and honest writing to emerge. At times, self-reflection feels like a solitary endeavor where the benefits and contributions to the larger research study are not immediately apparent (Clancy, 2013). Foremost among the benefits, phenomenological research findings are significantly strengthened when a researcher “acknowledges his or her suppositions and becomes consciously self-aware of their influence on the phenomenon under investigation” (Gearing, 2014, pp. 1449). In short, findings from self-reflection are a crucial piece of the greater whole during phenomenological data collection and analysis procedures.

### **The Case for Written Self-Reflection**

The literature recommends that self-reflection in interpretive phenomenology is written rather than oral as the act of writing creates a specific type of consciousness and mindfulness (Heidegger, 1997/2006; Koch & Harrington, 1998; van Manen, 1990). Writing forces the

researcher to proceed at a slower pace and to contemplate events in a more attentive manner. Through writing, researchers begin to unfold a deeper understanding of not only the phenomenon, but also of their own positionality. Additionally, self-reflection teaches a novice researcher how to produce truly reflective writing that is immediate, intense, and insightful; this style may be unfamiliar to many researchers in the social sciences who are more accustomed to a formal and depersonalized tone (van Manen, 1990). Reflective writing may feel invasive and out of place when viewed as data, but it is imperative that investigators report their process and findings, particularly with qualitative methodologies requiring a great deal of interpretation and transformation of text (Clancy, 2013; de Witt & Ploeg, 2006).

### **Procedural Guidelines for Self-Reflection**

The following guidelines are offered as a means to facilitate self-reflection in the novice phenomenologist. Much of the extant literature omits this process or describes it in vague, abstract terms that leave less experienced researchers uncertain of where to begin. Even when expert researchers such as van Manen (1990) or Parse, et al. (1985) emphasize the importance of self-reflection to the interpretive phenomenological process, locating clear and practical guidelines is challenging. As a result, the following steps are procedural and chronological in nature, and perhaps excessively prescriptive. My intention is that those with little to no experience in self-reflection will find them helpful as they plan and prepare for data collection. As with any procedural guidelines, they will require adjustment and tailoring depending upon the specific context of each study, researcher, and phenomenon under investigation. Examples and excerpts from my own ongoing interpretive phenomenological study are occasionally provided for illustrative purposes.

### **Ten Steps for Producing Self-Reflective Text**

1. *Make a plan.* Planning for an organized and prolonged period of self-reflection is essential. During an initial meeting with my mentor, we established the objectives and an anticipated timeline for my self-reflection. Because I had never engaged in detailed self-reflection before, we co-created several open-ended reflective prompts as a starting point such as, “Explore a specific time when I provided cancer care for an American Indian patient” and “What was it like to care for American Indian patients dealing with a cancer diagnosis as opposed to patients from different ethnic/cultural backgrounds? What made it unique?”
2. *Obtain materials, schedule time, and arrange the writing space.* I obtained a paper journal to facilitate handwritten reflections and set aside regular time several days a week over a period of approximately three months to thoroughly engage in the process. I first attempted to self-reflect at home or in my work office but found these places to be distracting, so I adjusted and found a more conducive environment for introspection. I viewed these writing periods as critical to the forthcoming study, which created a sense of self-discipline and commitment.
3. *Attempt a first draft.* I created an initial handwritten description of various experiences of caring for American Indian patients over several sessions, attempting to avoid causal explanations, generalizations, or premature interpretations with varying success. Feelings, moods, emotions, and embodied sensations were detailed in alignment with the reflective prompts as much as possible. I found it inevitable that experiences falling outside of the research focus naturally arose; these were not disregarded, but instead acknowledged and

“set aside” as much as possible. A conscious effort was made to continuously re-focus on cancer care relationships with American Indians specifically.

4. *Transcribe and continue reflecting.* I transcribed the initial draft into a Microsoft Word (2010) document. During transcription, new reflections and insights were incorporated into the draft as they arose. The fully transcribed and reflected first draft was then submitted to my mentor for review.
5. *Dwell with lifeworld-based feedback from the mentor.* My mentor responded with lifeworld-based probing surrounding particular passages that called for deeper elaboration. These directed queries were focused on eliciting more contemplative descriptions from me such as, “What do you mean when you say ‘frustrated’?”, “What does ‘being confused’ feel like physically and emotionally?”, and “In that moment, what were you feeling? How do you feel now looking back on it?” I then refrained from writing for approximately one-week unless a particularly pressing thought or sensation occurred; when this happened, I noted it but refrained from any analysis. For the most part, this was a period of “stepping back” and simply “sitting with” the text and feedback. I was eager to resume the reflective process and initially found this phase to be somewhat restrictive. However, over time I came to appreciate the value of stillness and restraint during phenomenological research as it greatly improved my understanding of self-in-relation to the greater phenomenon.
6. *Resume (more focused) writing.* After this period of “dwelling with” the first draft and feedback, additional writing commenced. Re-focusing on the lifeworlds allowed me to move beyond an unclear narrative and to instead access deeply held sensations, often for

the first time since the original experience had occurred. This was a sometimes unsettling experience but also triggered my memory in a highly productive manner. Constant attention was given to how my body felt as well as to other sensory responses, resulting in increasingly corporeal writing such as “*I literally felt the burden of her distrust weighing on my shoulders*” (p. 3, line 66) and “*my inability to answer those comments about race felt paralyzing*” (p. 7, lines 153-154). As with the first draft, this second self-reflection was handwritten in my journal, digitally transcribed, and submitted to my mentor.

7. *Embrace ongoing critique and probing questions...and dwell (again).* My mentor provided a second round of commentary designed to gently challenge, call into question, and even provoke me when necessary. For example:

*You are analyzing rather than feeling, experiencing, and living the experience... Stop trying to explain what happened. Instead, how does suspicion feel? What does it do to you? What does it feel like to be considered a colonizer? Did you want to hide your face? Or did you feel compelled to “do” something, i.e. spurred to action? If so, to do what?*

I was once more encouraged to “sit with” the existing draft for 1-2 weeks before embarking upon any further written reflections. I was challenged by the slowed pace and sometimes critical commentary from my mentor, but also found this second period of inactivity to be particularly insightful and stimulating. I became increasingly more comfortable with the personal vulnerability required by the self-reflective process and a

growing sense of trust and confidentiality with my mentor began to take shape. Once again, if a particularly pressing memory, sensation, or thought occurred during this period of dwelling, I noted it in my journal for later contemplation.

8. *Intensify your writing.* Following this second period of mentored feedback and dwelling, I began drafting a more intense and candid self-reflection. I found myself not only less hesitant to share increasingly poignant experiences, but I also began feeling compelled to explore their potential meaning. Recalling a particularly upsetting incident with a disgruntled family member, I was prompted to contemplate the role of race in my experience of being a White nurse on an American Indian reservation:

*He suddenly snapped and said, "I don't want a White nurse anymore!" I physically froze. I remember feeling terrified for a minute –the possibility that it could escalate from verbal into physical violence felt very real... I quickly exited the room feeling stunned, incredibly awkward, and uncomfortable. I wanted to get out of [the hospital room]. It was also fear. I had never been spoken to like that by a patient and the mere mention of my race being an issue felt humiliating in a way I had never experienced before...I had to tell myself repeatedly not to take it personally, but what could be more personal than the color of my own skin? (p. 18, lines 394-422)*

As I engaged with that particular memory (one I had not considered in years), I realized the value of revisiting such a distressing experience: *"Maybe now, I have the slightest*

*inkling of what it must feel like to be irrationally and aggressively shouted at because of the color of your skin, something so visible and inseparable from you”* (p. 19, lines 424-425). This provided a miniscule yet important insight into the experience of racial discrimination that my American Indian patients likely encountered on a regular basis in our hegemonic American society, yet was unusual in its isolation for me as a relatively privileged White person.

Writing about these experiences and insights often felt foreign or even unscholarly and required significant reassurance and encouragement from my mentor (Clancy, 2013; van Manen, 1990). Together, we strove to keep language and text as authentic as possible and to detail the ephemeral sensations that occurred during particular moments in time. This was no small task and required practice, a continued commitment to the time and space necessary for such an endeavor, and implicit trust in the novice researcher-mentor relationship.

9. *Evaluate and organize.* During and after transcription of the resulting third-draft, essential elements of my complex patient-nurse relationships began to emerge. These essential elements were identified in reflective notations and were illuminated by lifeworld-directed writing. I created a first-level matrix in order to draw attention to repeated patterns and to help make sense of my nearly 6,000 word self-reflection. The matrix consisted of verbatim excerpts that illustrated four tentative themes: conflicting expectations about the nurse-patient relationship; feeling emotionally fatigued; fear and uncertainty about cultural norms; and sensing a power imbalance. The revised third draft and accompanying matrix were submitted to my mentor for review, discussion, revision,

and approval. Writing ceased when we both agreed that a preliminary end-point had been achieved as demonstrated by the repetitive and well-supported themes.

10. *Suggest tentative meaning.* Finally, I created a summarizing interpretation attempting to capture the whole of my self-reflection. The summary suggested possible meaning, but clearly from my exclusive and somewhat limited standpoint. Eventually, my mentor and I co-created a more concise description that attempted to grasp the authentic meaning of my experiences of providing cancer care to American Indian patients, families, and communities:

*Often confused, exhausted, and paralyzed, longing for an anchor or guide as I traversed the complex relationships and expectations of my role, I found fulfillment and sustenance in the quiet moments of connecting, where trust was built and lives touched.*

This final step echoes the interpretive phenomenological process of co-creating a synopsis of the experienced phenomenon that appears balanced, open, genuine, and resonates with the reader (de Witt & Ploeg, 2006). Our attempt at capturing the essence of a personal experience sought to recognize the inseparability of emotion, thought, and language in the reconstitution of meaning (Crotty, 1996; Johnson, 2000; van Manen, 1990)

### **Conclusion**

The guidelines and processes described in this article represent only a small piece of the overall reflexive process. However, when aligned with Heideggerian philosophical

underpinnings, a systematic approach to self-reflection can improve reflexivity and rigor in a larger phenomenological study by:

- legitimizing and authenticating the role of the researcher as instrument from the very beginning of the study;
- minimizing premature judgement while the phenomenon is examined repeatedly and from every angle until an understanding of Being emerges;
- facilitating “genuine openness” to the phenomenon under study and stimulating a truly reflective gaze on the part of the researcher;
- contributing to the co-creation of meaning between researcher and participant, helping to uncover knowledge that resonates with humanity on a universal level;
- informing the lines of open-ended questioning that are later employed during data collection with study participants, resulting in less biased, more genuinely open inquiries about the phenomenon of interest;
- providing a foundational tether for the frequent reflections performed throughout the duration of the study and improving the overall consistency, depth, and quality of phenomenological writing.

Self-reflection maintains an essential position in qualitative nursing research, particularly in phenomenological studies where interpretation of highly abstract experiences and their associated meaning are sought (Lavery, 2003). Completion of the first turn of the hermeneutic circle through self-reflection contributes to our understanding of the phenomenon as a whole through appraisal of the many parts (Reiners, 2012). Ongoing self-reflection should continue to serve as a means of revealing the researcher’s continually evolving positioning and bias within

the phenomenon of interest (Clancy, 2013; Gearing, 2004). Increasing its utility and application will strengthen both the interpretive phenomenological body of work as well as that of all qualitative research.

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APPENDIX B:

LIVING WITH THE CAUSAL PAST: AMERICAN INDIAN/ALASKA NATIVE PATIENT-  
NURSE RELATIONSHIPS IN CONTEMPORARY CANCER CARE

Living with the Causal Past: American Indian/Alaska Native Patient-Nurse Relationships in  
Contemporary Cancer Care

Natalie M. Pool, BSN, RN\*

College of Nursing

The University of Arizona

1305 N. Martin Avenue

Tel: (520) 621-1981

Fax: (520) 626-6424

Email: nataliepool@email.arizona.edu

Tucson, Arizona 85721

Leah S. Stauber, PhD

Clinical Assistant Professor, College of Nursing

Affiliated Faculty, Institute for LGBT Studies

The University of Arizona

1305 N. Martin Avenue

Tel: (520) 626-1378

Fax: (520) 626-6424

Email: lstauber@email.arizona.edu

Tucson, Arizona 85721

Abstract

The American Indian/Alaska Native (AI/AN) cancer inequity is linked to systemic failures taking place during the provision of care. This care inequity is of concern to cancer care nurses as they utilize relationship to reduce fear, foster trust, and improve outcomes among highly diverse AI/AN populations. The emanation of the historical into interpersonal present is explored through the lens of the “causal past”. The traumatic pasts of AI/AN populations and the complicity of nursing in their continued suppression and subjugation are critically examined. Relationships are impacted by the preconceptions, histories, and intentions that both nurses and their patients bring to the present encounter. Cancer care is a forum in which improved partnership, cultural safety, and critical self-reflection are called for. The nursing discipline must come to terms with our individual and shared causal pasts order to transform our relationships with AI/AN peoples and reduce the existing cancer care inequity.

*Keywords:* American Indian/Alaska Native; Patient-nurse relationships; cancer care; historical research

Living with the Causal Past: American Indian/Alaska Native Patient-Nurse Relationships in  
Contemporary Cancer Care

Despite significant advancements in cancer prevention, screening, and treatment in the United States (U.S.) over the past 30 years, American Indians/Alaska Natives (AI/AN) continue to be disproportionately impacted by this disease when compared to non-Hispanic Whites (U.S. Department of Health and Human Services Office of Minority Health [OMH], 2015; White et al., 2014). Nationally, malignant neoplasms are the leading cause of death for AI/AN females and the second leading cause for AI/AN males (Burwell, McSwain, Frazier & Greenway, 2014). Cancer is among the many significant health repercussions emanating from the historical trauma, marginalization from resources, and systemic discrimination specific to AI/ANs (Institute of Medicine [IOM], 2013; Katz, O'Neal, Strickland & Doutrich, 2010; Keltner, Kelly, & Smith, 2004). However, unlike other disease processes, the AI/AN cancer inequity is striking in that it is not the result of high incidence but rather increased mortality and morbidity (Cobb, Wingo & Edwards, 2008; Guadagnolo et al., 2009; Vasilevska, Ross, Gesink & Fisman, 2012; White et al., 2014). Uniquely, the literature suggests that systemic failures are taking place during the provision of cancer care for AI/ANs, contributing to a care inequity as opposed to a biologically driven disease disparity.

While nurses have the potential to improve cancer care equity through caring-healing relationships that reduce fear, foster trust, and improve adherence to treatment and persistence in monitoring/surveillance during survivorship, these relationships are impacted by the preconceptions, histories, and intentions that both nurses and their patients bring to the present encounter (Falk-Rafael, 2000). Past experiences, rooted in the causal past, “intersect and interact,

creating an alchemical change that transforms both patient and nurse” during the provision of care (Gaydos, 2004, p. 16; Watson, 1985, 2006). The purpose of this article is to explore how current relationships between AI/AN patients and cancer care nurses within cancer care are impacted by the totality of their individual and shared political, cultural, and historical experiences. The emanation of past into interpersonal present is explored through the lens of the “causal past,” a concept defined as all past events in an individual’s life continuously culminating in each present moment (Gaydos, 2004).

### **Significance of the Causal Past in Patient-Nurse Relationships**

Human-to-human relationships are pivotal to the healing process and are foundational to nursing care. These relationships are conceptualized as a series of caring moments that occur as nurses and patient come together in awareness and action that are shaped by previous events, and segue into causal pasts in an ongoing spiral of ever-evolving futures (Watson, 2006). This dynamic process is similar to the Whiteheadian (1929/1979) notion of concrescence. “All past experiences are brought to bear on the present occasion and merge with it to form the current experience”, such as a shared, singular patient-nurse relationship (Watson, 1985, p. 55).

The cumulative and often overlooked phenomenal field of each AI/AN patient and cancer care nurse impacts their relationship in subtle yet significant ways. For example, various expectations and assumptions possessed by patients and nurses about one another and the cancer care system in general are influenced by the totality of their individual and broader social and historical experiences. Cancer care nurses often view themselves as benevolent caregivers and patient advocates dedicated to providing highly individualized care, even when it comes at a significant emotional cost to their own wellbeing (Corso, 2012; Newman, 2016). However,

AI/AN patients describe a very different experience with cancer care providers such as ineffectual communication patterns, cultural insensitivity, perceived discrimination, and aggressive or dominating approaches to care delivery (Baba, 2012; Guadagnolo et al., 2009; Strickland, Squeoch & Chrisman, 1999; Vasilevska et al., 2012; Warne, Kaur & Perdue, 2012). The explanation for this striking discordance may lie, in part, with the reality that approximately 80% of cancer care nurses in the U.S. identify as non-Hispanic White and less than 0.5% identify as AI/AN (U.S. Department of Health & Human Services [DHHS], 2013; OMH 2012). Therefore, the vast majority of AI/AN patients will be cared for by nurses from racial and cultural backgrounds different from their own and with potentially widely variant personal and communal experiences.

Neither AI/AN nor White cultures are static or one-dimensional and are instead comprised of multiplicitous ways of being that are continually evolving (Baba, 2012; Wolfe, 2013). However, epistemological and ontological assumptions associated with mostly White nurses in a (debatably) post-colonial moment in U.S. history inform their perspectives on relationships with patients, particularly in regards to caring for indigenous populations (Hall, 1999; Mohammed, 2006). These assumptions, emerging from a sociohistorical past dominated by Whites, include a focus on biomedical-allopathic cancer care models and the utilization of hierarchical methods of communication and information dissemination that may contradict with AI/AN patterns of health (Alpers & Hanssen, 2014; Stone & Moskowitz, 2011; Szreter & Woolcock, 2004). Calling forth the AI/AN past illuminates such conflicts and provides opportunities to redress the current cancer care disparities that result from it through the improvement of patient-nurse relationships.

### **Tracing the Causal Past of Contemporary AI/AN Healthcare Inequities**

An examination of the prevalent issues of historical trauma, systemic poverty, and marginalization via reservations reveals the ways in which settler colonialism and exploitation have become ingrained in contemporary care inequities for AI/ANs (Brockie, Heinzemann & Gill, 2013; Keltner et al., 2004; Struthers & Lowe, 2003). A brief review of major legislative and political events exposes the complex and deeply traumatic causal past from which contemporary AI/AN patient-nurse interactions have arisen (Getches, Wilkinson, Williams & Fletcher, 2011; Hadjiioannou, 2001; Warne & Frizzell, 2014; Wolfe, 2013). The violence and subjugation experienced by AI/AN populations in the centuries following first contact with Anglo-Europeans remains evident in widespread health inequities.

[Insert Table 1]

**Settler colonialism.** The legal and social contexts featured in Table 1 contributed to the development of a particular brand of imperialism in the U.S. termed settler colonialism, an ideology aimed at “taming” natural resources and extinguishing the original inhabitants of a colonized region through the systematic application of overt and covert structural violence during expansion and relocation (Veracini, 2011). This unique form of colonialism supplants all existing systems and peoples; it does not cease until the indigenous people are fully exterminated and new arrivals have achieved complete control (Cattelino, 2012; Veracini, 2011). The power imbalance between intruder and native inhabitant becomes profound and omnipresent in political and social systems, including in service structures such as health care (Wolfe, 2013).

Typifying the operation of settler colonial ideology, Anglo paradigms suppressed AI/AN belief systems about disease and wellbeing during colonizers’ relentless westward expansion between the 16<sup>th</sup> and 20<sup>th</sup> centuries (Deloria, 2006; Johnston, 2002). Some scholars argue that

settler colonialism continues to permeate every facet of indigenous/Anglo interactions today (Doyle, Redsteer & Eggers, 2013; Wolfe, 2013). This would include present-day AI/AN patient-cancer care nurse interactions as settler colonialism remains an integral part of our collective history as a predominantly White profession.

**Historical trauma.** The influence of historical trauma on present-day AI/AN health and wellbeing is profound, despite its relatively new designation as a disease-causing entity (Brown-Rice, 2013; Struthers & Lowe, 2003). For many AI/ANs, the loss of lands and cultural identity following Anglo-European colonization manifests in a variety of distressing outcomes (Doyle et al., 2013; Hollow, 1999; Horowitz, 2012). Historical trauma is described as an acute reaction to colonization that is a cumulative and complex set of symptoms exhibited across generations, regardless of direct exposure to traumatic events. These symptoms may include depression, unresolved grief, a sense of indifference or disconnect, and violence against oneself or others (Gonzales, 2012b; Lowe & Struthers, 2001; Struthers & Lowe, 2003).

Emerging research suggests that exposure to historical trauma may be associated with biological and physiological changes in the human brain, leading to long-lasting negative behaviors including an aversion to physical touch, non-adherence to treatment regimens, and distrust of or open hostility to healthcare providers (Avila, 1999; Gonzales, 2012b; Strickland et al., 1999). Additional research points to the epigenetic impacts of historical trauma in the form of methylation changes in the genes responsible for the regulation of stress hormones (Brockie et al., 2013; Brown-Rice, 2013). This genetic response to the social environment leads to a variety of adverse health outcomes over time stemming from the inability to regulate the ‘fight or flight’ response (Brockie et al., 2013; Brown-Rice, 2013; Gonzales, 2012b).

It is important to note that for many AI/ANs historical trauma is powerful and enduring while others may not have experienced it at all; there is great variation in prevalence, intensity, and reaction. The term itself is somewhat misleading as historical trauma is not something that occurred in the past but instead remains a present and active manifestation in contemporary AI lifeways (Struthers & Lowe, 2003).

**Systemic poverty.** Enduring and severe poverty characterizes contemporary AI/AN life (Rodgers, 2012). Nearly 25% of AI/ANs live at or below the federal poverty index, twice the rate of all other races in the U.S (OMH, 2015). Concentrated poverty among AI/ANs is linked with high crime rates, elevated substance abuse, underperforming schools, and inadequate housing (Brockie et al., 2013) – all linked to poor health outcomes (Baba, 2012; Hall, 1999; Keltner et al., 2004; Rodgers, 2012; Warne & Frizzell, 2014). Despite recent AI/AN migration to urban areas, poverty statistics between rural and urban AI/ANs remain comparable (Cobb et al., 2008; OMH, 2015). However, AI/ANs living in rural areas are at increased risk of being marginalized from healthcare resources (OMH, 2015; Rodgers, 2012); rural areas demonstrate an acute shortage of nurses and other primary care providers (Bushy, 2006). Less than 50% of the AI/AN population are able to access guaranteed federal health services and nearly 25% are uninsured (Burwell et al., 2014; OMH, 2015).

**Marginalizing reservations.** Reservations are endemically linked to AI/AN poverty. Five out of ten of the poorest counties in the U.S. include AI/AN reservations (Brockie et al., 2013). The creation of reservations in the 19<sup>th</sup> century was in alignment with the settler colonial objectives of banishment and exclusion of indigenous people (Wolfe, 2013). As settlers moved westward they often claimed the most fruitful and profitable lands, consequently relegating

AI/ANs to inferior territories (Cattelino, 2013; Cobb et al., 2008). Reservations were intentionally created to keep the problematic AI/AN population “out of sight” and “largely invisible in their own land” (Wolfe et al., 2013, p. 4).

Reservations are legally designated areas managed by tribes and are considered semi-sovereign nations with complicated system of essential-service provision (Getches et al., 2011). They often comprise isolated homes and communities with stifled economic opportunity. Unemployment rates on many reservations approach 40% or even higher for adult AI/AN males, and health outcomes among this mostly rural or semi-rural population are alarmingly poor (Brockie et al., 2013; Rodgers, 2012). Reservation-dwelling AI/ANs are more frequently exposed to elevated levels of environmental contaminants – particularly in traditional food and water sources – that contribute to increased cancer risk (Cobb et al., 2008; Schumacher et al., 2008). Considering that most AI/ANs must the reservation to seek specialized health services, the marginalization of reservations significantly influences overall cancer experiences and outcomes. Living on a reservation intensifies the AI/AN cancer inequity by creating specific geographic and environmental barriers to care (Nuno et al., 2012; Schumacher et al., 2008; Warne et al., 2012).

### **Relevance for Nurses Serving AI/AN Populations**

Historical trauma, systemic poverty, and the marginalization of AI/AN reservations contribute to a legacy of inequality and oppression for nurses serving AI/AN populations in both rural and urban contexts. For nurses unfamiliar with historical trauma, for instance, the resultant behaviors associated with this manifestation appear confusing, counterproductive, and challenging to address within the caring relationship (Struthers & Lowe, 2001). In addition,

exposure to intense poverty and resource-depleted reservations are integral components of many AI/AN people's causal pasts, regardless of whether or not they have personally experienced these actualities. This may be a difficult concept for non-AI healthcare providers to grasp as the Western/Anglo perspective is highly focused on the individual rather than the collective experience of the group (Avila, 1999). Nurses emanating from this paradigm may question the relevance of generational or historical events on a present-day AI/AN individual's life and may struggle to see where they fit into this scenario as representatives of a healthcare system complicit in the perpetuation of these inequities.

Moreover, a substantial power differential is created when healthcare providers from relatively advantaged systems, such as middle-class nurses, are tasked with serving economically disadvantaged communities, such as those in which many AI/AN patients reside (Szreter & Woolcock, 2004; Vasilevska et al., 2012). The inability to "transcend the [inequitable] system" in order to adequately provide care for AI/AN patients may feel especially frustrating and stressful to nurses and contribute to high rates of turnover (Katz et al., 2010, p. 393). Elevated rates of turnover are also linked to the geographical and cultural isolation of reservations, which can exacerbate nurses' feelings of despair concerning widespread health inequities encountered among AI/AN patients (Keltner et al., 2004). This attrition phenomenon further intensifies the existing rural nurse shortage (Bushy, 2006; DHHS, 2013). Additionally, if nurses live and work in AI/AN communities only briefly, their ability to establish trustworthy and impactful caring relationships is significantly diminished. When viewed collectively, these realities create a layered and deeply troubled causal past shared by AI/AN peoples and nurses in present-day cancer care regardless of whether they are cognizant of them or not. As the following section

will demonstrate, the contemporary AI/AN patient-cancer care nurse relationship continues to suffer from our failure to reconcile the past with the present.

### **Emanation of Causal Pasts into Contemporary Patient-Cancer Care Nurse Relationships**

Nearly 2,500 nurses and approximately 300-400 advanced practice nurses work within the federally funded rural and urban health care systems serving AI/ANs, representing a significant cohort of frontline direct-care providers engaged in cancer prevention and control among other services (Baba, 2012; Indian Health Service [IHS], 2014). Thousands of additional nurses provide cancer care in the private and public sector and have regular or intermittent contact with AI/AN patients and families.

Cancer care encompasses a wide range of services including prevention, screening, diagnostics, treatment, palliative care, and hospice, requiring the coordination and collaboration of multilevel teams and systems (Lamb et al., 2011; Shahid, Finn & Thompson, 2009; Taplin et al., 2012; Walsh et al., 2011). Nurses fulfill a variety of these roles, including symptom management, patient needs assessments, assistance with navigation through the healthcare system, coordination of complimentary and multidisciplinary services, communication with team members, support of family members, and education and information sharing (Hildebrandt, 2012; Lamb et al., 2011; Potter et al., 2013).

For many patients, nurses are the “face” and the “heart” of cancer care. Nurses spend time with patients and families engaging in extensive medical, psychosocial, and spiritual support, which facilitates close bonds between patient and nurse (Corso, 2012; Hildebrandt, 2012). Over time, many nurses come to know cancer patients and their loved ones at a profound and insightful level, establishing caring relationships that are fundamental to the cancer care

experience. Yet, the establishment of caring, high-quality relationships for the provision of cancer care is particularly challenging for nurses serving AI/AN populations, whose causal pasts are, at best, discordant with those of their largely White nurses. Such dissonances manifest as challenges to the establishment of the caring nurse-patient relationships that are so desperately needed.

Nurses have the potential to develop more equitable and effective care models for AI/AN populations by attending to several challenges fundamental to nurse-patient relations across the experiential divide: (1) differing values placed on the concept of relationship; and, (2) distrust by AI/ANs of biomedical cancer care systems and providers.

**Right relationship.** For many AI/ANs, relationships must be “right” for healing to take place, meaning that balance, honor, respect, and good-standing “with families, the community, the universe, and healers” is present (Horowitz, 2012, p. 25). The very notion of “relationship” is considered to be essential to the concept of caregiving for many AI/ANs, and is relevant to nearly all of the core health and wellness concepts found across AI/AN populations (Hollow, 1999; Koithan & Farrell, 2010; Lowe & Struthers, 2001). Many AI/AN worldviews posit that animate and inanimate (including spiritual) entities exist in relation to one another (Avila, 1999; Deloria, 2006; Gonzales, 2012a). This sense of interconnectivity and reciprocity is fundamental to relationships within healthcare settings and significantly impacts the development of trust, fidelity, and communication between AI/AN patients and providers (Hollow, 1999; Johnston, 2002; Lowe & Struthers, 2001). Nursing as a discipline also recognizes the centrality of relationship and has a long history of investigating the significance and physiognomies of relational phenomena (Newman, Smith, Pharris & Jones, 2012; Quinn, 1997; Watson, 2006).

However, caring relationships in biomedical-allopathic nursing models are distinguished by tending less toward reciprocity and interconnected worldviews (like the AI/AN model) and more toward an interpersonal dynamic within a single encounter (Watson, 1985).

**Distrust of biomedical cancer-care approaches.** Based on both individual and collective experiences, many AI/ANs have developed a noteworthy level of distrust and suspicion regarding biomedical-allopathic models of disease prevention and treatment and the providers associated with these modalities. This distrust is woven deeply into the social, historical, and cultural fabric of AI/AN people's lives (Avila, 1999; Gonzales, 2012b; Johnston, 2002; Strickland et al., 1999; Lowe & Struthers, 2001). Historical trauma, oppressive federal and local policy, resource exploitation, cultural insensitivity, and structural and targeted racism experienced by AI/AN people and communities contribute to widespread cynicism and underutilization of contemporary cancer care systems (Guadagnolo et al., 2009; Vasilevska et al., 2012; Schumacher et al., 2008). Disengagement from allopathic cancer care services and providers in turn contributes to later stage cancer diagnosis, increased risk for treatment complications, and elevated morbidity and mortality for AI/ANs (Guadagnolo et al., 2009; Warne et al., 2012).

Many AI/ANs turn first to traditional healthcare providers, including for cancer care, potentially generating conflict with allopathic providers who are ill-informed and unequipped for collaboration or partnership with their AI/AN counterparts (Hollow, 1999; Horowitz, 2012; Johnston, 2002; Koithan & Farrell, 2010). This is not to suggest that traditional AI/AN approaches to cancer prevention and care are less valuable, but rather that the two systems are often in opposition to one another, creating opportunities for miscommunication and an

environment of clandestineness. Nurses may be unaware of their AI/AN patients' preferences for and utilization of traditional health services and their patients' hesitation to share these sacred health practices for fear of disapproval or harsh judgement from providers (Avila, 1999; Gonzales, 2012a; Hollow, 1999; Horowitz, 2012; Johnston, 2002).

### **Transforming the Causal Past into an Efficacious Future**

The striking historical, sociopolitical, and cultural oppression experienced by AI/ANs impact and challenge patient-nurse interactions in profound and largely undiscussed ways. Nurses serving AI/AN populations work within an inherently inequitable system serving patients who are potentially among the most marginalized and traumatized in the country. Yet, opportunities exist for progress and improvements to take hold, particularly within cancer care where patient-nurse relationships are often enduring and can be directly impacted by nurses.

### **Reconsidering and Authentically Practicing Cultural Safety**

As influenced by settler colonial ideologies, the causal past creates systemic challenges and moral dilemmas encountered on a personal level by nurses who may or may not be equipped to address their own biases, assumptions, and collective histories. In the midst of making claims about proficiencies in delivering culturally safe and relationship-based care, nurses and the systems within which we work may be unwittingly contributing to the suppression and devaluation of AI/AN knowledge and health-seeking behaviors, negatively impacting patient experiences and outcomes. Redesigning the development and implementation of culturally safe care is an effective first step towards improving outcomes.

Cultural safety is defined as the provision of care in whatever realm and manner the consumer-patient prefers and functions best (Nursing Council of New Zealand, 2011). It is an

expansive term that recognizes the fluid nature of culture while promoting tailored approaches from caregivers (Aboriginal Nurses Association of Canada [ANAC], 2009; Baba, 2013). The goal of culturally safe nursing care is to allow the recipient of care to define the nature and parameters of the relationship. This method of care provision relocates control to the historical subaltern, of particular significance for countries with Indigenous peoples (Nursing Council of New Zealand, 2011). Features of culturally safe nursing care include recognition of power differentials, institutional discrimination, and the political nature of health inequities such as cancer (ANAC, 2009; Baba, 2013). Culturally safe care also recognizes that techniques that are effective for one AI/AN tribe, community, or individual may be less well-received by another. According to the U.S. government, there are over 5.2 million people classified as AI/AN alone or in combination with other races, yet they constitute a diversity of cultural traditions (OMH, 2015; Cobb et al., 2008).

Despite our failures to do so, the ideal of providing truly culturally safe care is integral to the nursing discipline and is deeply embedded in our moral and ethical onus (Struthers et al., 2005). This conflicts with the biomedical paradigm that rarely acknowledges or incorporates perspectives from outside the allopathic realm (Avila, 1999; Hall, 1999). Most cultural safety frameworks and training for nurses in the U.S. are highly generalized and exclude AI/AN ways of knowing and being with respect to wellness and disease manifestations (Baba, 2012; Doyle et al., 2013; Gallagher, 2011; Hall, 2004). Regardless of their own racial or cultural affiliations, the majority of nurses receive training based on this exclusionary paradigm. Reconciling biomedical-allopathic training with the traditional values of AI/AN communities presents a challenge even

for AI/AN nurses, resulting in high levels of stress and attrition for this crucial nursing demographic (Katz et al., 2010).

When hegemonic nursing paradigms collide with the principles and preferences of AI/AN patients and communities, the patient-nurse relationship suffers. Importantly, these cultural safety mishaps contribute to disengagement and under-participation across cancer care settings for AI/AN patients and erode the patient-provider relationship. On a hopeful note, some nursing programs and institutions are developing AI/AN-specific cultural safety trainings in order to increase awareness, alter attitudes, and address preconceptions about health and wellness paradigms (Baba, 2012; Gallagher, 2011). Improving critical self-reflection and cultural safety practices among nurses represents the first step in improving the relationship, yet the situation also requires a greater understanding of what it means to be in relationship with AI/AN peoples as nurses. Cancer care nurses in particular may be emotionally stressed and unable to deliver the high-quality, compassionate care required for optimal healing (Potter et al., 2013). While such factors negatively impact cancer care nurses' abilities to establish caring relationships with all patients, they may be especially devastating to AI/AN patients due to the centrality and cultural relevance of relationship to the AI/AN worldview.

### **Collaborating on Specialized Care**

Lowe & Struther (2001) claim that the lack of a nursing framework for understanding the specialized nursing care of AI/ANs adversely affects the patient-nurse relationship and contributes to negative health outcomes for AI/AN peoples. Nurses are confronted with the products of historical and social inequities in a profound and intimate way during the provision of present-day patient care. For example, nurses who lack the knowledge and skills to traverse

the complex terrain of historical trauma may be ineffective at best or harmful and counterproductive at worse. However, there are several possibilities for transformation of this dynamic and for increasing overall collaboration within the nurse-patient partnership.

First and foremost, nurses who serve AI/AN patients require additional training beyond cultural safety education because an authentic understanding of the historical and sociopolitical context of our patients will radically transform the way we think about and deliver care. Anglo-American/ European epistemology and settler colonialism in particular have not only fundamentally shaped healthcare but also nursing's most basic educational structures, including what is revealed and concealed in historical and sociological curricula (Wolfe, 2013). Nursing does not exist in a sociocultural vacuum and therefore must challenge and confront these ideologies across all research, education, and practice structures (Falk-Rafael, 2005; Mohammed, 2006). Importantly, failure to recognize and take ownership of our own oppressive causal past undermines the discipline's commitment to social justice within healthcare. Care of marginalized groups such as AI/ANs requires carefully negotiated approaches and communicative techniques in combination with a professional commitment to confronting the pervasive power imbalances that characterize provider-patient dynamics. This process begins with acknowledging how the causal past impacts contemporary care relationships and patient outcomes, and is best facilitated by transparent, critically reflective, and specialized professional training for nurses.

Increased diversity in the nursing workforce and enforcement of the Culturally and Linguistically Appropriate Services (CLAS) standards for all facilities receiving federal funds are also improving (Gallagher, 2011). Nurses should continue to demand that CLAS standards are consistently and adequately met within their institutions and facilities. Nursing educators and

mentors should also make coordinated and concerted efforts to recruit, retain, and support a wide representation of people into the profession, particularly in consideration of the underrepresentation of AI/AN nurses in both general and cancer care arenas.

### **Conclusion**

As key cancer care providers, nurses have the potential to contribute to health equity by becoming patient advocates through the facilitation of considerate, caring relationships (Falk-Rafael, 2000; Watson, 2006). Cancer care relationships are just one of numerous examples of the inequity and devaluation of traditional knowledge that AI/ANs are forced to contend with while interacting with healthcare systems and providers. This is a forum in which partnership, cultural humility, and critical self-reflection on both past and present events can make a positive impact. We must come to terms with our individual and shared causal pasts as nurses in order to transform our relationships with AI/AN peoples and challenge the existing cancer care inequity.

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Table 1

*Abbreviated Historical and Sociopolitical Events Impacting AI/AN Health and Wellbeing\**

<u>Date(s)</u>	<u>Era</u>	<u>Key Events</u>	<u>Implications for AI/AN Health and Wellbeing</u>
1492-18 <sup>th</sup> century	First Contact and the Doctrine of Discovery	<ul style="list-style-type: none"> <li>• Columbus arrives in North America</li> <li>• Widespread land seizures, warfare, starvation, and enslavement by Anglo-Europeans</li> <li>• Exploitation of natural resources begins</li> </ul>	<ul style="list-style-type: none"> <li>• Attempted physical, social, and cultural genocide of AI/AN peoples</li> <li>• Up to 90% of Indigenous populations in the Americas are decimated by 18<sup>th</sup> Century</li> <li>• Disease inadvertently and purposefully spread (through distribution of blankets contaminated with smallpox by Anglo-Europeans)</li> </ul>
1789-1871	Warfare and Removal: Federal-Tribal Treaty Relations <sup>1</sup>	<ul style="list-style-type: none"> <li>• French, British, and U.S. governments engage in treaty negotiations with AI peoples; treaties often broken and generally unfavorable to tribes</li> <li>• Land seizures and relocation to reservations continue</li> <li>• The Marshall Trilogy (1823-</li> </ul>	<ul style="list-style-type: none"> <li>• Relocation to inferior territories with limited food and water resources; malnutrition and disease rampant</li> <li>• Federal government obligated by treaties to provide essential services such as healthcare to federally-recognized tribes in</li> </ul>

	<p>1832): set of three U.S. Supreme Court decisions setting legal precedent for federal-tribal relations including recognition of tribal sovereignty, nation-to-nation relationship, government must act in best interest of tribes (as determined by the government), nature of relationship is “guardian to ward”</p> <ul style="list-style-type: none"> <li>• Bureau of Indian Affairs (BIA) assumes control of healthcare from War Department (1849)</li> </ul>	<p>exchange for land seizures; medical outposts generally poorly staffed by military clinicians under the War Department</p> <ul style="list-style-type: none"> <li>• Other health services delivered by missionary staff with some federal funding</li> <li>• Late 1800s: BIA facilities remain understaffed and poorly funded</li> <li>• Loophole in healthcare services created for AI/AN individuals and communities unaffiliated with a federal tribe or for tribes unrecognized by federal government</li> </ul>
1871-1928	Allotment and Assimilation	<ul style="list-style-type: none"> <li>• Shrinking of reservation land base</li> <li>• Indian boarding schools attempt to assimilate AI/AN youth</li> <li>• Dawes Act (1887): Indian lands divided into individual plots to weaken and destroy tribal</li> </ul> <ul style="list-style-type: none"> <li>• Increased density of population on smaller land bases encourages proliferation of communal diseases such as Tuberculosis</li> <li>• Transition to agriculture creates sedentary lifestyle, metabolic changes related to loss of</li> </ul>

		sovereignty, agriculture lifeway encouraged	traditional diet
		<ul style="list-style-type: none"> <li>• Snyder Act (1921): first formal authority for provision of funds towards AI/AN healthcare by Congress</li> <li>• <i>Meriam Report</i> (1928): draws public attention to dismal health, education, and economic conditions on reservations; encourages increased funds from Congress to alleviate health inequities</li> </ul>	<ul style="list-style-type: none"> <li>• Boarding schools rampant with epidemics, malnutrition, physical, emotional, and sexual abuse of youth</li> <li>• Traditional medicine and other cultural practices forbidden under Dawes Act; traditional healers sanctioned and subject to federal persecution</li> <li>• Federal budgeting for AI/AN healthcare remains inconsistent and insufficient despite legislation and <i>Report</i>, continued inequities</li> </ul>
1928-1961	Reorganization and Limited Tribal Autonomy	<ul style="list-style-type: none"> <li>• Johnson-O'Malley Act (1934): BIA is permitted to contract for essential services, including healthcare</li> <li>• Indian Reorganization Act (1934) attempts to restore some lands, increase tribal autonomy</li> <li>• Termination of federal-tribal</li> </ul>	<ul style="list-style-type: none"> <li>• Federal supervision over tribal healthcare continues but becomes fractured with contract services and elimination of federally-recognized tribes; thousands of individuals no longer qualify for guaranteed federal healthcare</li> <li>• Urban relocation intensifies health</li> </ul>

- relationship with 106 tribes between 1945-1961; state authority and taxation on terminated lands is allowed
- Reservation AI/ANs relocated to urban areas for vocational training through federal programs
  - Transfer Act (1954): responsibility for healthcare moved from BIA to Public Health Service (PHS)
  - Indian Health Service (IHS) established under PHS in 1955: access to and quality of healthcare improves but underfunding continues
  - Exploitation of AI/AN territories and surrounding state and federal lands contribute to environmental degradation through damming waterways; excess logging and fishing; and contamination of soil, water, and
- problems through further erosion of traditional diet, increased access to alcohol, and exposure to industrial pollution and other toxins
- Transfer Act encourages tribal health policy decision making; some improvements in sanitation and disease management
  - Cancer “clusters”, digestive, and respiratory diseases appear in AI/AN communities exposed to improper mining and manufacturing practices

		air from mining and industry	
1961- Present	Increasing Tribal Autonomy and Contemporary Issues	<ul style="list-style-type: none"> <li>• Indian Self-Determination and Education Assistance Act (1975): tribes permitted to plan, conduct, and administer programs using federal funding; may receive portions of the IHS budget through compact agreements</li> <li>• Indian Health Care Improvement Act (IHCA; 1976): aimed to narrow health inequities gap by increasing quality and quantity of services; improving participation of tribes in planning and administering healthcare; increasing access to care for urban AI/ANs</li> <li>• Tribal Consultation and Participation Policy (1994): attempt to increase tribal presence during policy making, including in healthcare</li> </ul>	<ul style="list-style-type: none"> <li>• Increased participation in health services, including influx of AI/AN healthcare professions obligated to work in AI/AN communities under federal scholarship program</li> <li>• By 2012, 60% of tribes have assumed all or partial governance over their healthcare services</li> <li>• Improved drinking water and sanitation in AI/AN communities, yet significant inequities continue (e.g. Navajo Nation water crisis)</li> <li>• Medicare, Medicaid, and Children’s Health Insurance Plan billing allowed under IHCA</li> <li>• Congressional funding appropriations to IHS are guaranteed each year, but insufficient for medical inflation and increasing AI/AN populations; widespread health inequities</li> </ul>

- An updated version of the IHCIA continue  
is made permanent under the  
Affordable Care Act in 2010,  
expanding coverage and choice in  
services but not increasing  
funding

<sup>1</sup>The political history of Alaska Natives (AN) is distinct from that of American Indians (AI) in several ways. Although the U.S. federal government acquired Alaska from Russia in 1867 and agreed to treat ANs the same as AIs legally and politically, treaties were never negotiated with ANs. Very few AN reservations were created and instead the federal relationship was with individual villages through the BIA. For the sake of continuity in this article, the AI/AN abbreviation is used throughout this table while recognizing these key differences.

(Sources: Getches et al., 2011; Hadjiioannou, 2001; IHS, 2014; IOM, 2013; Satter et al., 2013; Shelton, 2004; Warne & Frizzell, 2014).

APPENDIX C:  
NURSES' EXPERIENCES OF ESTABLISHING MEANINGFUL RELATIONSHIPS WITH  
AMERICAN INDIAN PATIENTS IN THE CANCER CARE SETTING

## INTRODUCTION

American Indians and Alaska Natives in the United States (U.S.) comprise a small but incredibly diverse minority population.<sup>1</sup> Approximately 5 million people identify as American Indian (AI) alone or with other races, mostly in the lower 48-states region.<sup>2</sup> AIs as a whole experience a cancer inequity primarily comprised of elevated morbidity and mortality despite an overall lower incidence rate compared to all other races combined.<sup>3</sup> Disproportionate cancer morbidity and mortality among AI populations are often attributed to lower screening uptake, later stage diagnosis, increased treatment complications, and worse overall outcomes.<sup>4-7</sup>

Successful cancer care requires effective patient-provider relationships, yet the literature suggests that AIs describe significant issues related to providers such as ineffectual communication tactics; cultural insensitivity; perceived discrimination; and aggressive or dominating approaches to care delivery.<sup>5,6,8-11</sup> The literature suggests that care providers, including nurses, may be failing to facilitate timely and culturally safe cancer care among AI populations and thus are unintentionally contributing to an ongoing cancer care inequity.<sup>8,12-15</sup> Although the underutilization, distrust, and dissatisfaction with cancer care systems and providers is well-documented for AIs, there is a dearth of literature describing nurses' interpretations or perceptions of caring for AI patients. Therefore, the purpose of this article is to describe the unique relationships that develop while providing cancer care to AI patients and the underlying meaning that nurses ascribed to these experiences.

Nurses play a pivotal role in cancer patient experiences and.<sup>16-18</sup> Cancer care creates scenarios where nurses act in a prominent capacity as supporters and advocates for patients.<sup>17,19</sup> However, the establishment of caring relationships in order to provide high quality cancer care is

particularly challenging for nurses who engage with ethnic minority populations as they contend with cultural and contextual influences different from those found in the majority population.<sup>8,20-23</sup> Nursing care of minority groups presents language and other types of nonverbal communication challenges coupled with conflict surrounding treatment philosophies and discordant interpretations of wellness and disease.<sup>21-25</sup> These contextual considerations undoubtedly impact the development of authentic, effective, and mutually beneficial patient-nurse relationships during the care of minority patients.

### **Research Question and Aims**

The present study explored and described the unique relationships that developed while providing cancer care to AI patients and the situated meaning that nurses ascribed to these experiences utilizing the research question “what is the meaning of the AI patient-cancer care nurse relationship from nurses’ perspectives?” The study addressed three aims: (1) describe the immediate experiences of nurses that have engaged in cancer care relationships with AI patients; (2) identify the underlying structures of the AI patient-cancer care nurse relationship as described by nurses, and (3) interpret the meaning of the patient-nurse relationship within the context of AI cancer experiences.

## **METHODS**

### **Study Design and Sample**

The research focus was congruent with the philosophical and methodological positioning of interpretive phenomenology, an approach that seeks to uncover and find meaning in abstract yet everyday occurrences, particularly those that are the most familiar and taken for granted such as human-to-human relationships.<sup>26,27</sup> The investigation into the lived experiences and

reconstituted meaning for cancer care nurses serving AI patients were guided by van Manen's<sup>27</sup> methods of phenomenological inquiry. This study used a non-linear, iterative process during data collection and analysis.<sup>27,28</sup> This process reflects utilization of the hermeneutic circle of data collection-reflection-analysis-meaning making that is central to the phenomenological approach and philosophy.<sup>26,28</sup>

Between January and May of 2016, a convenience sample for this study consisting of 10 Registered Nurses (RN) living in the southwestern U.S. and meeting the inclusion criteria agreed to participate. One participant was lost to attrition resulting in a final sample of 9 RNs. Participants were recruited via email and word-of-mouth using professional and academic networks and in collaboration with two research mentors. Inclusion criteria were (1) RNs with at least 3 years of experience in providing cancer care to AI patients within the past decade; (2) ability to read and speak English fluently; (3) willingness and capacity to engage in repeated interview sessions over a 9 month period; and (4) access to a working telephone. Exclusion criteria were (1) RNs who were terminated from their work with AI patients for any reason; and (2) RNs under the age of 21. Although all 9 participants self-identified as female, they represented a variety of ages and racial affiliations in addition to wide diversity in their professional cancer care nursing experiences [see TABLE 1 Participant Demographics].

### **Ethical Considerations**

The study received human subjects approval from the institutional review board of my university. Participants were informed both verbally and in written form that their participation was voluntary and confidential, and that they could terminate their participation at any time without providing an explanation. Informed written consent was signed at the start of the first

interview with participants retaining a signed copy. Demographic data received a numerical identifier. Participants were assured that any identifying information revealed in the course of the interviews such as patient diagnosis, place names, or tribal affiliations would be redacted or altered during transcription so as to be unrecognizable.

### **Data Collection and Analysis**

Data collection and analysis procedures for the study intersected and were largely dependent upon one another, thus are concurrently described. I utilized an exploratory and hermeneutical interviewing strategy during repeated one-on-one interviewing with the participants. Interviews lasting approximately 1-hour were conducted in chronological order for each individual participant and not for the sample as a whole; this was both logistically convenient and in alignment with the interpretive phenomenological method of maintaining focus on the individual experience during the first phase of data collection.<sup>27</sup> Cross-comparison for the purpose of meaning-making did not occur until after all interviews were collected and analyzed. The setting for all in-person interviews was either a private location of the participant's choosing, such as their home or personal office, or in a private meeting space at my university. All of the interviews were digitally audio-recorded, immediately transcribed, and uploaded into ATLAS.ti (version 7.5) qualitative software.<sup>29</sup>

#### **The First Interview and Exploratory Analysis**

The initial interview began with 'what it was like' for participants providing care to AI patients with cancer in order to begin grasping the basic features of this particular relationship. Exploratory prompting was utilized to elicit memories, sensations, and experiential accounts such as "describe a time when you provided cancer care to an AI patient". While the interviews

were largely participant-directed, probing throughout the interview series was based on the four phenomenological lifeworlds of corporeality (lived body), spatiality (lived space), relationality (lived human relations), and temporality (lived time).<sup>27</sup> Integration of the phenomenological lifeworlds into thought-provoking lines of prompting and probing facilitated the later co-creation of meaning at the existential level.<sup>26,27</sup> Examples of lifeworld based probes and prompting include: (1) Spatiality: What was the environment like? How did that [described feeling/sensation/experience/relationship] impact you spiritually? (2) Temporality: How did it feel at that specific time? Describe how that [feeling/sensation/experience/relationship] changed for you over time? (3) Relationality: Describe your relationship with [a patient, family member, etc.]. Who else was there? How were they involved? and (4) Corporeality: What were you feeling physically when that happened? What was your physical response, if any?

At the conclusion of each initial interview, I prompted participants with a specific thought-provoking question or statement to contemplate during the interval between interviews (e.g., “Before our next interview, I would like for you to think more deeply about...”). This prompt emerged from the immediate data collection session and was intended to stimulate the reflective process and encourage thoughtfulness on the part of the participant prior to our next meeting.<sup>27</sup> Following the first and all subsequent interviews, I engaged in the following procedures: (1) immediate reflective writing in a journal to capture my first impressions and to note embodied responses generated by either myself or the participant that were not captured by the audio recording; (2) during the interim between interviews, I engaged in a period of contemplative dwelling with repeated exposure to the transcribed interviews and the creation of reflective memos exploring potential or tentative structures buried within the text; (3) tentative

coding of the emic data utilizing van Manen's<sup>27</sup> wholistic/sententious, selective, and detailed approaches. For example, entire passages, short phrases, and single words were all coded for potential significance or for further exploration in future interviews; (4) conscious refrainment from assigning any meaning to the participants' recollections in an effort to remain open and accessible to their individual experiences. Instead, I utilized continued reflective journaling to attenuate for my own inevitable musings; (5) regular debriefing with a research mentor in order to explore tentative coding patterns and to address my own assumptions and bias in an effort to prevent premature closure; and (6) preparation of the next line of questioning for each individual participant utilizing the emic coding and reflective text from each previous interview.

### **The Second Interview and Thematic Analysis**

The second interview was conducted either in-person or via telephone depending upon the participant's location and preference. This interview revisited what was recounted previously in an attempt to encourage elaboration on any points of interest suggesting implicit meaning.<sup>26,27</sup> This process was akin to peeling back the layers of an onion in order to gain access to the concealed core. Examples of questions that encouraged elaboration, clarification, and deeper exploration into the nurses' experiences include: (1) When you say [descriptor word], what do you mean by that? (2) In our last interview, you spoke about [a described experience, feeling, relationship, etc.]. Can you talk more about that and why you felt that way? (3) You seem [descriptive or emotion-laden word] talking about it now; what were you feeling when it happened? Where do you think that feeling arises from?

I continued to apply lifeworld-based probing and re-directing to "tease out" potentially buried feelings surrounding the phenomenon of interest; however, the interview remained open-

ended and largely participant-directed. Tentative thematic abstractions for each participant were then created.<sup>30</sup> This phase required a great deal of discussion and collaboration between myself and a research mentor, as is typical of the interpretive phenomenological method in general.<sup>30</sup> Despite the creation of tentative themes for each participant, continued attention was given to refraining from cross-participant comparisons. This period of analysis also attempted to move beyond what had been previously relayed in the first two interviews to explore what remained unspoken, and the next round of questioning for the third interview was created to transition from the concrete to the abstract through confirmation and exploration of the various themes and the overall potential meaning for each participant.<sup>27</sup>

### **The Third Interview and Confirmatory Analysis**

The third interview delved more deeply into previously described sensations, embodied perceptions, and the possible situated meaning for each participant. Compiled results from the first two interviews were presented to each participant with the opportunity for confirmation, elaboration, refinement, and discussion of themes.<sup>27,31</sup> This approach encouraged probing of the individual variations within the phenomenon with each participant, allowing for a creative and open method of exploring consciousness and understanding.<sup>30</sup> During this final interview participants were encouraged to intensely reflect upon their experiences of providing cancer care to AI patients.

At this point, themes and emic coding patterns among participants became repetitive. This was further confirmed with my research mentor during debriefing sessions and during random transcript checking. When new sensations or contradictions emerged, they were viewed as relevant and integrated into the preliminary analysis. Completion of the final set of interviews

resulted in multiple revisions of the individually-situated themes to accurately capture the highly personal and often deeply embedded nature of nurses' relationships with AI cancer patients.

#### Post-Data Collection Analytical Procedures

Analytical procedures for the first research aim included (1) final adjustments to the individual themes based on a period of contemplative dwelling with the data, debriefing sessions, and insight gleaned during reflective writing; and (2) considering each participant's experience as a whole and creating a wholistic/sententious description to reflect how this individual's lived experience contributed to the overall phenomenon.

No amount of codification or theme abstraction alone can produce phenomenological understanding; meaning occurs during the co-creation and transformation of text and is reflected in phenomenological tone throughout the study, especially during reflective writing.<sup>27</sup> Thus, numerous drafts of the individually-situated themes and wholistic/sententious descriptions were required to reach this level of thoughtful, contemplative text surrounding individual participant's experiences.

Analytical procedures for the second research aim entailed: (1) looking across individual participants in order to compare and contrast their experiences and to identify the underlying structures of this phenomenon; (2) reduction of a total of 36-individual themes into a set of 7 thematic descriptions capturing common themes and patterns seen across the sample; (3) composing each thematic description to begin with "Relationship is..." to reflect the unique attributes of the phenomenon under investigation; (4) distilling the thematic descriptions further into 7 accompanying metathemes from which a general structural description could be created; and (5) constructing a general structural description that explicated the shared experiences across

the sample at the experiential level. While meaning occasionally subtly emerged, I refrained from infusing any of my own interpretations into the text in order to accurately and authentically represent the participant's shared experiences.

Finally, the essential meaning of the phenomenon was explicated in a phenomenologically sensitive paragraph to fulfill the third research aim of interpreting the meaning of the AI patient-cancer care nurse relationship. This process delineates interpretive phenomenology from other approaches as it required the integration of my own reflections into the meaning for nurses who are engaged in this unique caring relationship with AIs. It positioned me as the researcher at the center of the phenomenon rather than as a peripheral observer through the reconstitution of shared meaning into a universally recognizable text.<sup>26,27</sup>

### **Methodological Rigor**

Assuring rigor in interpretive phenomenology requires that the interpretive process is conducted in a vigilant, thorough, and deliberate manner and that emergent patterns appear coherent and logical.<sup>26,32</sup> Trustworthiness for this study was established through an obvious sense of coherence between the aims and the findings with verbatim recordings, transcription, and emic quotes to support the analysis and tentative conclusions.<sup>27,33,34</sup> An easily traceable paper and decision trail was maintained using the debriefing notes and Atlas.ti (version 7.5) software.<sup>29</sup> To ensure reflexivity, I deliberately maintained a written journal and memos after each interview in addition to regular debriefings with my research mentor, which also contributed to the avoidance of premature closure and the reduction of bias.<sup>33-35</sup> Prolonged engagement and triangulation of data assisted in establishing credibility. Both typical and atypical findings were acknowledged and integrated into the findings. Regarding transferability, the results from this

study should resonate with readers and appear valid, useful, and meaningful.<sup>27</sup> Findings are not intended to be generalizable in interpretive phenomenological research.<sup>31,35</sup>

## RESULTS

Engaging in the hermeneutical analysis process resulted in 7 meta-themes explicated through a general structural description, and a meaning-infused essential description revealing the depth and complexity of this relationship phenomenon. Each meta-theme in the structural description begins with a thematic description explicating what this relationship is from the nurses' standpoint. Emic quotes are attributed to each participant, interview, and transcript section as organized by Atlas.ti<sup>29</sup> (e.g. P6-1, 237; meaning participant #6, interview #1, section 237).

### Structural Description

#### From Task to Connection

Relationship is paramount for nurses to transform nursing *care* into authentic *caring*. Relationship is not necessary for engaging in the work of nursing, but it is deeply desired by cancer care nurses in order to feel a sense of fulfillment and purpose. When nurses are able to establish an open, comforting, and compassionate relationship with AI patients, they feel as if they are being virtuous and ideal nurses. Once you “start the relationship, then I think they start trusting you, and then the relationship just grows”, illustrating the inter-reliance between trust and relationship, which then creates space for caring to take place (P4-3, 139). AI nurses inherently understand the centrality of relationship, and also express a feeling of being appreciated within their relationship with AI patients: “I think they've [AI cancer patients] learned to appreciate the relationship we have...they'll let me know, ‘Thank you’” (P8-2, 583).

Without relationship, nurses are relegated to engaging in surface-level conversation and only the slightest, most necessary touch. Their work as nurses has no meaning and is simply an unfulfilling “task” to be performed wherein the nurse feels like a “robot” (P5-3, 230). It is degrading, draining, and unsustainable. When relationship does not occur, nurses “feel frustrated and then sorry at the same time”, and pangs of regret and failure cling to them long after the patient has gone (P6-2, 76). It represents a missed opportunity for caring, regardless of whether the impetus to do so was professional, personal, or both.

### **Unnerving Messaging**

Relationship is thwarted by an inability to read verbal and nonverbal cues expressed by AI patients. When nurses are unable to interpret AI patients’ often subtle messaging, it causes nurses to feel disconnected from the patient and to doubt their clinical competence:

I feel more distant from the [AI] patient. It’s harder for me to relate to them. I feel that when it’s harder for me to relate and connect to them, it’s harder to read their symptoms and do my job to help keep them comfortable (P1-3, 144).

The formation of relationships partially relies on the ability to “read” the patient, but when this ability is inhibited by the patient’s muted or unexpected signals, it is unsettling and often vexing for the nurse. “If you do try talking, you’re met with silence....I go in with a shut-down expectation... and “I just don’t seem to have any sort of way of making that connection, that spark” (P5-2, 171). When nurses encounter AI patients exhibiting “blank stares and sometimes not even acknowledging that I had spoken”, they find themselves lost in a sea of uncertainty and confusion, struggling to make sense of the situation and to regain meaning and purpose in order to reconnect with what drives them to continue caring (P1-1, 36).

For AI nurses, the messaging is familiar and decipherable. They use both verbal and nonverbal tactics to facilitate connection, hope, and partnership, and do not need to spend precious time breaking the code between patient and nurse. By “taking their hands... right away, they feel, as a group, you’re connected” (P2-3, 169). Their relationships with AI patients are imbued with both spoken and unspoken meaning that is understood at an almost instantaneous and intrinsic level.

### **We Are One**

Relationship deepens when you can recognize self in the other (and other in self) regardless of contextual differences. When a nurse looks into her AI patient’s eyes and sees herself, she is able to transcend any barriers and differences between them. This act gives rise to a primordial recognition permeated with meaning as boundaries are erased in order to enact altruistic caring based in humanistic love. When nurses allow it, relationship becomes a way to honor our sacred connection to one another. Nurses imagine that patients also see themselves in their eyes, creating a sense of reciprocity, indivisibility, and exchange: “They’re looking at themselves in my eyes when we look at each other...What’s the difference? It’s nothing” (P3-2, 862). This sense of oneness also creates an obligation to provide care in a manner that nurses would like to be cared for, should they ever require it. For AI nurses, recognition is immediate and infused with understanding; there is an ancient and deep connection between AI people. When they look at their AI patients, there is a distinct sense of being in the right place, at the right time, doing the right work. Recognition contributes to the patient feeling comfortable as “they feel safe with their own people”, illustrating the powerful sense of mutuality experienced by those sharing heritage and identity (P8-1, 433).

When AI patients feel unrecognizable to nurses, it creates alienation and *othering*, as if “you’re taking care of someone from a different country” (P5-1, 108). There “is a wall in between me and them that you can’t really—of course you can’t see, but you can’t even figure out really sometimes how to break it down” (P5-3, 3). This hyper focus on separateness impedes the relationship and perpetuates a sensation of coolness between patient and nurse, twisting the meaning of the relationship into something unrewarding and estranging.

### **The Freedom of Unconditional Acceptance**

Relationship is facilitated by removing bias, assumption, and judgement and finding neutral ground for caring to take place. Relinquishing these obstructions caused one nurse to reflect, “I noticed that I had a few judgments of my own when I first started working with the Native American population...I understand that now. It’s just definitely opened my mind to see my blindness” (P7-3, 12). This transformation takes time, self-awareness, and a commitment to change from nurses, but the rewards are realized in a palpable strengthening of relationships. Relationships also become exponentially more fulfilling and even freeing as inhibitions are stripped away in favor of unrestrained acceptance of the patient by the nurse. However, an inability by nurses to release assumption or bias creates stunted relationships with the potential for fallacy:

When you know you’re going to have a Native American patient I think that you have an idea or an image that forms in your mind, like a preexisting idea of how this person is going to be... whether or not that’s true (P5-1, 112).

The nurse enters into the relationship anticipating disappointment and irritation, and any chance for “meeting in the middle respectfully” is dashed (P6-2, 146). Nurse and patient are closed off and isolated from one another in this scenario, like two ships passing in the night.

### **Attuning and Opening**

Relationship is a process of attuning to the AI patient in every dimension and becoming receptive to a new way of being. Attuning to patients requires speaking less and listening more; mirroring the patient’s preferred (and often slower) pace instead of marching forward at their own speed; and, relinquishing their own expectations in favor of honoring the patient’s preferences. These practices often came quite easily to the AI nurses, but for non-AI nurses a unique attunement is required with AI patients due to cultural variations, calling for a heightened sensitivity and a willingness to learn. Attunement is fundamentally embedded in the ability of nurses to respond authentically and benevolently to AI patients despite their own preconceptions. This requires a conscious act of relinquishing control over both the patient and the situation, a difficult task within the often urgent and regimented cancer care world:

[AIs] don’t expect things to happen quickly, or they don’t expect immediate results... [They are] culturally different, and so that urgency isn’t in them. They’ll come maybe, and they’ll get treated, but all in their own time, which is okay—I think something that I’ve learned is that it is okay (P6-2, 142).

Being attuned to AI patients gives the relationship great meaning for nurses by creating a sense of collaboration and synchronicity. Feeling out of tune with AI patients fosters a dichotomous and superficial approach to care as if, “you’re coming from this direction, they’re

coming from that direction” and like “you're taking care of somebody on the surface...you're taking care of their needs, or their problems, in that exact moment, but you haven't really made a connection or an impact”. This feels radically unsatisfying for nurses, yet they know that attunement often takes time and attention: “I think in my listening, my ability to care for her at several different times... we [eventually] connected because of my openness in wanting to learn, and then wanting to care for her however she wanted to be cared for” (P9-2, 63). There is an element of deference in this type of caregiving that stands out.

### **Atoning for the Past, One Moment at a Time**

Relationship is a means for honoring the struggles of AI peoples through the easing of suffering, even if only momentarily. The verb ‘honor’ is derived from the Latin *honorem*, meaning to show respect or reverence. Essentially, approaching the relationship from this perspective creates opportunities for nurses to facilitate both personal (immediate) and collective (historical) healing. “A lot of patients don’t realize that they are strong”, yet nurses are in a position to increase cognizance of this resiliency and to support it wholly (P8-2, 413). They are acutely aware of the substantial barriers and systemic complexities their AI patients’ encounter while seeking cancer care: “When you realize whatever it took to get down here [for treatment] or what they've been through before, it's humbling” (P6-3, 121). Threaded throughout many of the relationships is a strong sense of past injustices committed by non-AIs against AIs; these historical violations infiltrate present interactions in subtle yet insidious ways. “It’s difficult to touch someone in an atmosphere of distrust”, and this may also mean that “you're trying to make up for things that have happened in the past” during present-day cancer care (P9-1, 1005; P6-3, 5). While the past is unchangeable, many nurses felt compelled to use the present time to restore

trust between AI patients and cancer care systems and providers. For AI nurses, the past is implicit between themselves and their AI patients: “You understand each other and the history and your roots... I think most Natives have that deep understanding... I think that deepens the connection [between us], knowing the history” (P2-3, 31).

When relationships fall short, “it makes me sad because especially in the cancer business by the time it is figured out, it’s a lot farther than it [should] have been” (P6-1, 63). Thus, relationships have an adherence component in that patients may be “resentful” when they don’t feel respected, which in turn “clouds their judgement” about continuing care and perpetuates the historical pattern of disengagement from healthcare services and providers (P4-3, 187). Nurses use relationship as an implement for reducing the cancer care inequity, one patient at a time; a relationship comprised of respect and parity may literally save a patient’s life. Relationships are the most salient tool nurses have to counter four centuries of inequity within AI healthcare.

### **Humanizing the Inhumane**

Relationship is a conduit between the biomedical cancer care and AI worlds. It serves as a conduit between “crisp, clean and regimented” allopathic care and more nuanced, complex AI patterns of health and wellbeing (P9-2, 1029). As humans, we are always within our bodies, and nurses become the human image of cancer care through their “caring eyes” “positive” touch, and simple presence (P6-1, 239; P9-1, 1033). They often act as “the mediator, the middle person” between patients and families, physicians, and systems (P8-2, 461). Uniquely, AI nurses reside within their patients’ worlds, permitting them both a distinctive vantage point and attenuating the taken-for-granted nature of perception: “You think about these patients who come from the reservation and they come to the cancer center and it’s a whole new environment” and “It helps

me in that I understand both worlds and I don't take anything for granted" (P8-1, 433 & 489). The enclosed sterility of the cancer care world is potentially harmful to AI patients' healing: "It's not good for their spirit or their emotions, just to focus on only their physical" and AIs "need to touch ground, and they're not touching the ground" in the biomedical setting (P9-1, 749 & 757). Connecting with nature is another basic feature of being human, and nurses recognize this even within their own process of healing following the loss of a patient: "I kept looking outside and I wanted to see the sun... It feels so dark inside of you" (P2-2, 27).

When nurses feel nameless and faceless to their patients within the cancer care world, it is dehumanizing. The sheer amount of time and persistence it takes to earn the trust of AI patients and to reach a point of familiarity and ease is exhausting, and some nurses never reach that point. It is disappointing and calls into question their bearing and purpose as nurses:

I thought maybe she would even recognize my face, [but] when I have spent a significant amount of time with somebody for them to not even have facial recognition...I mean if they don't remember my name that's one thing, but that she didn't even recognize my face was surprising. After all that time we spent together in comparison to other interactions with other patients who not only remember my face but know my name... (P1-3, 73).

To be human is to have a name and to be recognized upon sight by other humans. When this fails to happen, it has implications for the meaning of the relationship between AI patient and cancer care nurse as it casts shadows of doubt on the depth of their shared connection at the most fundamental level.

### **Essential Meaning**

The nurses' meaning of the AI patient-cancer care nurse relationship is expressed as contradictory yet simultaneous patterns of joy and sorrow; ease and difficulty; obligation and vocation. It is challenging, often vexing, and sometimes heart wrenching; yet these relationships are also rewarding, inspiring, and humbling. From one moment to the next, nurses seek synchronicity with their patient as they dance to a life rhythm that reveals and conceals; enables and limits; connects and separates. Being in relationship with AI patients gives cancer care nurses great purpose within the universal human experience of suffering and healing.

## **DISCUSSION**

Meaning for cancer care nurses serving AI patients was expressed as opposing yet coexisting experiences. These paradoxical sensations were emblematic of Parse's human becoming paradigm in which human rhythmicity allows two people to continuously move with and apart from one another over time.<sup>36</sup> In many ways, the meaning for nurses in this study was located somewhere along this continuum and within this enigma, palpable yet elusive.

What these relationships meant to nurses was revealed in the "imaging and valuing" of their language.<sup>36, p37</sup> Their words formed descriptions that exposed the multifarious, fluctuating nature of engaging in a deeply personal relationship with AI patients who felt familiar and unknown, receptive and impervious, predictable and volatile. These contradictions may be a universal experience of nursing, part and parcel of the unpredictability of human beings that is potentially amplified during times of intense interfacing. The typically prolonged nature of cancer care adds yet another element to this nursing experience as relationships have the opportunity to become enduring yet undulating.

AI patients with cancer posed a challenge for many nurses in that their very way of being within the world felt distinctly different than the biomedical-allopathic (and mostly White) paradigm that nurses and nursing emanate from.<sup>13</sup> The AI nurses and the additional minority nurse readily identified and named the experience of being in relationship with a fellow person of color. There was a sensed solidarity present in their recounting that was noticeably absent from the rest of the White participants. Regardless of shared heritage or identity, the nurses' ability for seizing upon similarities while embracing differences between herself and the AI patient seemed to be deeply connected to her overall fulfillment and sense of purpose within the relationship. Those nurses that were unable to envision any piece of themselves in their patients found the relationship reduced to one of task-performance and superficial interactions that left them emotionally fatigued and longing for more.

Many of the nurses felt painfully unprepared to work with AI populations, reflecting a general absence of AI perspectives in their pre- and post-licensure training. The persistent dominance of Anglo neo-colonial structures in nursing practice, education, and research and our failure as a nation to reconcile our uncomfortable history with AI peoples subtly but consistently emerged in the data. A painful historical past seemed to linger within their present-day encounters and nearly all of the nurses sought to soften and humanize cancer care as a means of honoring and even atoning for this unique aspect of their AI patients' lives. All of the nurses relayed the need for adjusting and attuning their patterns of clinical practice to reflect their patients' (sometimes unfamiliar) verbal and bodily messaging. Many became more adept at this over time and came to appreciate a slower paced, quieter, and deeply respectful approach to care.

They found great meaning and purpose in relationships emergent from the confluence of patient and nurse that successfully transcended time, differences, and idiosyncrasies.

### **Limitations**

Although typical of the interpretive phenomenological method, a sample size of 9 participants does present limitations in regards to diversity and representativeness of the phenomenon under investigation. For example, the sample for this study lacked any participants identifying as male and was largely dominated by White, middle-aged females which potentially skews our perspective of what it is like to care for ethnic minority cancer patients. Additionally, only one of the participants in this study actually provided cancer care in an AI community; all other participants provided care at facilities adjacent to or sometimes far removed from AI communities. While this situation is emblematic of cancer care being centralized in more urban areas, it is possible that the experiences of nurses who reside within AI communities may be markedly different than those who live and work in areas dominated by non-AI populations.

### **Implications for Practice**

This study has several implications for cancer care nursing practice. First, illumination of the nuances of the essential AI patient-nurse relationship embedded in the cancer care process will contribute to the development of interventions designed to improve the patient experience. This may in turn promote earlier entry into cancer prevention and screening systems for AIs and enhance treatment partnerships, resulting in decreased mortality and morbidity. Secondly, understanding the meaning of cancer care relationships for nurses working with AI patients and communities may assist in developing improved methods of support and training for nurses. Adequate support and training for nurses is associated with greater job retention, increased

compassion, and the delivery of high quality and culturally safe care.<sup>16, 21, 24,37-39</sup> The responsibility for supporting nurses' in their endeavors to provide this type of highly compassionate and versatile care resides in nursing educators and leaders.<sup>24</sup> Lastly, refinement of nursing praxis will ultimately result in improved outcomes for *both* nurses and AI patients, reflecting the inseparability of the two entities within the cancer care relationship. The complimentary and mutually dependent nature of the patient-nurse relationship implies that strengthening and improving support for one entity may in turn positively impact the other.<sup>40</sup>

## CONCLUSION

As nurses fulfilled their many roles within cancer care, they formed significant and influential bonds with AI patients. Yet nurses who serve AI patients face unique challenges in the formation of effective and caring relationships with their patients based on their articulated descriptions collected and interpreted in this study. Patient-nurse relationships are comprised of a two-way exchange and certainly the AI portion of this dynamic is equally worthy of inquiry; however, considering my own experience as a nurse caring for this population, I made a conscious decision to explore both what was underrepresented in the literature as well as what was most familiar to me as a nurse-researcher. The philosophy and practice of interpretive phenomenology suggests that what appears the most familiar to us is often the most elusive.<sup>26,27</sup> This study represents the first step in a program of research aimed at fully illuminating the AI-cancer care nurse relationship in an effort to improve experiences and outcomes for both this complex population and the nurses who serve them.

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APPENDIX D:  
GUIDED SELF-REFLECTION

### **A1: Journal Entry 1**

How did this concept of the AI-patient nurse relationship within cancer care enter my life? Why has it emerged as a significant theme for me professionally as a nurse and personally as a human? My experiences with both Native communities and cancer have impacted me quite a bit more than I could have ever anticipated. I find that I am humbled and surprised by how challenging, distressing, and at times interested in and rewarded by this type of nursing. I look back at my ways of thinking –my preconceptions and assumptions, really –as a new nurse and how much it has changed over the past decade. I feel like my eyes were forced open by the often very difficult realities that I encountered on the Reservations –and before that in the Peace Corps. I gradually became aware of just how complicated health is for people, and how it’s equally as complicated to provide healthcare as a nurse. I can recall so many times where a moral or ethical issue came to the forefront with a Native patient and how their particular and unique history, culture, political status, and current situation further compounded it. When the delicate topic of cancer was introduced to the mix it seemed that tensions and emotions were further heightened and I often felt inept and confused about how to provide the best care. I often did not know what to say or how to comfort patients facing cancer. Perhaps this was not always a negative thing with my Native patients as I came to believe that presence can sometimes be more valuable than words. I have learned that sometimes as a nurse we don’t have to say anything. Contrary to our training, we don’t have to have all of the answers. We don’t always have to explain the unexplainable.

I guess what I’m alluding to is that I became much more comfortable with silence through caring for Native patients, as foreign as that initially seemed to me. Nobody told this to me; I was not taught this. I “learned” it through many awkward encounters, unfortunately.

A recent example always stands out to me. Mrs. \_\_\_ was a [tribal] patient undergoing extensive cancer treatment on my unit for an advanced pelvic cancer. From nearly the beginning she was “pegged” as being difficult to care for by the residents and the nursing staff. This was not based on her clinical state although it was quite an extensive surgical case, but on her perceived behavior and attitude. I found her to be quiet and observant; I can see how this might have been seen as being withdrawn and sullen. She and her husband expressed their distrust of the nursing staff and residents very early on. Somehow I persisted with them. I spoke less and listened more. I spoke about my time and experiences in two previous AI communities –this seemed to build a small amount of trust as we could relate to familiar place names and even some people. Would I have been able to build this bridge as a nurse without previous AI experience? I don’t know, but I do believe that there is something in a nurse’s approach that can transcend that common ground. There is some fundamental tone of openness and respect that is so quickly sensed by patients. Cancer in particular calls for respect –of the journey people are undergoing, of the fear and immensity felt, the gravity of the situation, the connotations behind the very word ‘cancer’. I stayed consistent with Mrs. \_\_\_ and her family, always listening more than I spoke, staying calm and respectful. We ended up building a beautiful nurse-patient relationship that brought forth a lot of thoughts and questions for me (and honestly pushed me back into grad school).

But for every Mrs. \_\_\_ in my nursing career I feel like there have been half a dozen other cases plagued by confusion, uncertainty, and even what I felt was inadequate care. Some times that inadequacy was related to systemic things like heavy patient loads, the chaos of inpatient

care, and staff and facility issues. But other times –the times that are much harder to identify and talk about –that inadequacy was deeply personal and weighed heavily on my interactions with Native patients. I always thought of myself as an open-minded and non-judgmental person but those assumptions are challenged in unforeseen ways as a nurse. We are faced with an emotional depth of caring that is unique to our profession and subsequently present opportunities for questioning. One of the hardest things about caring for Native patients is establishing their trust in you as a nurse and more importantly as a person (because, after all, if you don't trust the person you won't trust the nurse). I have so often felt like I was met with suspicion almost immediately. Why? Is it hundreds of years of betrayal by non-Natives that infiltrates the relationship? How frustrating it is that what feels like long ago events to me can remain such a living and breathing presence in the hospital room.

### **A2: Journal Entry 2**

I think it's important to reflect on why providing cancer care for Native patients and families is different than for other patients. There are the obvious language barriers in some cases, but nurses take care of non-English speakers quite regularly and most facilities have a system for dealing with this. This in no way discounts the power of language and the connection between language and behavior and culture. No, I think the challenges with Native cancer patients are much deeper and hidden. I have literally had conversations with patients telling me that there was no cancer before the White man came. I have no idea if this is true from a disease pathology/history standpoint, but the important part is that this is the perception for some people and when it is spoken out loud it is sending a message. This reminds me of people in [African country] during Peace Corps who insisted to me that HIV/AIDS was brought to Africa by Europeans as another attempt at eradicating the black population. Both of these claims are basically inarguable, especially as a White nurse. What am I supposed to say? Often I say nothing because it seems like such sensitive, treacherous territory. But what does my silence say?

I also think it's important to talk about what Native nurses go through in these situations. Nurses often form quite a strong bond with one another and to this day I am in touch with many of the nurses I worked with on the Reservations, both Native and non-Native. Many of these challenging and confusing scenarios that I reflect on in my own experience have also been experienced by Native nurses. Yes, race is a massive factor in this area I believe, but many of my Native nurse colleagues have vented the same frustrations as I have regarding our difficulty communicating with Native cancer patients. Sometimes I find that Native nurses are very torn between their Western training and their traditional perceptions of health. The community can have very high expectations for them. Cultural confusion is real and impacts nursing care, in my experience. Those of us who consider ourselves to be strong patient advocates can sometimes butt heads with physicians or systems that conflict with Native preferences or values. Cancer in particular is treated so aggressively and when the disease is already resented on so many levels including being perceived as a "colonizer's disease" there is a lot of room for miscommunication and misinterpretation.

As nurses, our relationships and interactions with patients are unique. We literally spend the most time with them and see them over prolonged periods, especially in the cancer realm. In some ways this works to our advantage because we have more time to build trust. But if the relationship goes bad then the experience can be horrible for everyone involved. Ensuring the delivery of adequate, culturally competent care is a blend of training and personal intentions. We

need to be given some tools in our training, but experience, personality, beliefs, and one's own moral compass play a role as well. I'm not sure that you can teach kindness in an adult (perhaps in a child). I look back at my years with Native patients and later in the cancer field and I acknowledge that despite my good intentions and those of many of my colleagues, we perhaps did not always appear kind. Nursing is so demanding, exhausting, and stressful. This impacts all patients but I wonder if Native patients in particular might be offended by this hurried, distracted, superficial delivery of care. There were so many times I wanted to just stop and sit with a patient, not because I was tired but because I felt like they needed their caregiver's presence. I was rarely allowed this opportunity. What message does it send when we treat patients like problems? Do Native patients expect this after decades of neglect and sub-par services? I know that it never set right with me and often followed me home at the end of the shift. My patients were alive and medicated and clean, but I knew that I had not met all of their needs. It was disconcerting and felt offensive. The reality is that trust and respect and listening take time, and nurses often don't have any.

### **A3: Journal Entry 3**

Returning to an earlier point that I made about past events and Native history being very much present during care...I do think there is something unique to this patient population in some ways. Really in the whole scheme of things the traumatic history of Natives in this country was fairly recent and the discrimination and oppression very much continues. When I walk into that hospital room I am literally the face of that history not only because of my race but also due to my profession and the position of power that both place me in. I know, and the patient knows, that I have not personally or individually participated in any of the trauma... but it's still THERE, in the room, hanging between us. I mentioned that like many well-intentioned nurses I often remain silent about this awkward feeling. I tried to sensitively educate myself about Native history and culture and I sought to "understand" in order to be a "good nurse". Now that I'm older and have been doing this longer I question how much a person can truly understand another's experience, not to mention the experience of an entire ethnic or cultural group. But of course most nurses will never walk in their patient's shoes and that is both inevitable and ok. What we should be doing is working to transcend that gap so that we are universally open, receptive, compassionate, and flexible. It shouldn't matter (at the fundamental level at least) who the patient is or what the context is—we should be able to adapt our care approach. It has been so hard, though, to know where to begin with Native patients including those dealing with cancer. Being met with suspicion can feel so frustrating—I have personally heard fellow non-Native nurses complain about this. I now have a greater appreciation for the idea that trust must be earned and not given. The problem again is 'time'. Time keeps coming up, both at the acute level with literally the day to day responsibilities and tasks of nursing and on a grander scale over the long-term.

The turn-over on Reservations among care providers is horrendous. I was one of those statistics. Even though I left the [tribal name] Reservation in less than two years and the [tribal name] in less than three due to my spouse, I was secretly relieved. On [tribal name] in particular I was emotionally exhausted with that job. I thought that if I had to take care of one more sexually abused four-year old, had to detox the same ten guys from alcohol, or had to care for the gangrenous diabetic leg of a grandmother with no running water in her house, I would scream. It felt like a war zone sometimes. It felt like a war that nobody outside of the Reservation knew

was even happening. My colleagues and I tried to support one another. We vented and drank a lot of alcohol and developed sarcastic senses of humor to cope with it all. But at the end of the day I think some of us felt very empty and like failures as nurses. Others did not. I can't speak universally for all and some of my friends are still there on the Rez doing the same job. Personally, I left the [tribal name location] feeling sad. I felt angry and embarrassed that these conditions and that type of disparity in care was happening in the U.S. I felt guilty because although no [tribal member] ever said it to me, I represented that U.S. to a certain degree as a White person and a federal nurse. I had just come home from 2.5 years in Africa where I expected horrendous conditions and disparity; I did not expect it in [southwestern state], at least not to that degree. It was a shock.

I had grown up in a rural, Western area and had been on Reservations before. I knew Native people and had sought out a more accurate Native history. But working deep within it at the level that a nurse does is an entirely different experience. Superficial contact or even conversations or friendships with Native people cannot substitute for actually immersing yourself in the situation like you do as a nurse living and working on a Rez. I would say this echoes my Peace Corps experience. Nothing can prepare you for the intensity of the actual experience. I remember being really surprised by some of the conditions and challenges my Native patients were subjected to that I had never witnessed when caring for other populations. It just seemed so inherently unfair, like these patients had to start ten steps behind to achieve good health. I felt sympathy, for sure, but realized pretty quickly that sympathy is a fairly unproductive emotion. Mostly I felt sad, angry, and frustrated. I felt useless as a nurse to a certain degree. I felt like I was a small part of an already broken system that I had no power to influence. If I felt powerless, imagine how my patient's felt... I could not imagine.

So yeah, we are met with suspicion sometimes when we walk into the room.

#### **A4: Journal Entry 4**

I notice that I keep talking about my nursing experiences with Native patients and communities using terms like 'confusing', 'exhausting', and 'sad'. It all seems so negative when in reality there was (and continues to be, in a different capacity) so much about it that was positive. If it were not positive then I wouldn't miss it the way that I do. Despite the suspicion, historical trauma, and rampant social issues there were so many patients that touched and inspired me. People were often grateful for the care we gave, and they said so. More than that I remember quiet, peaceful conversations that made me feel connected to my patients. I felt the weight of the responsibility that nurses carry when we are present for birth, death, illness, and healing. I always feel that, no matter who I am caring for, but the added cultural component with Native patients brings in an interesting and almost reverent dimension. At the risk of generalizing and based on my somewhat limited perceptions as a non-Native nurse, I would venture to say that many times I felt more respected as a nurse by Native patients. Much of this has to do with a cultural tendency towards respect and politeness, I feel. When I write about delivering inadequate care it rarely (if ever) stems from a Native patient direct telling me or implying that to me. Instead it is based on my own deep feelings and then later conversations with Native colleagues and friends about their experiences with nurses. Cancer care in particular seems to carry some particularly painful or negative feelings for people and the type and quality of care given has a huge impact on people's experiences. All illness should be treated sensitively,

but like I mentioned before, there are often some very specific emotions tied to cancer that make it unique.

All of these layers make the Native patient-nurse relationship complicated. Yet so many relationships have been supportive and good. When is that relationship “good”? I think when there is open, unrestrained communication guided by mutual respect. There does not have to be total agreement –many times I did not agree with a patient’s decision but fully supported them none the less. There needs to be a certain level of comfort, and near total trust. I never expect my patients to let me into their inner worlds yet it often happens due to the nature of the relationship and the often complex situation we are both in. Cancer or any illness is a time of vulnerability. How hard would it be to let your guard down –whether on purpose or by force due to illness – with a total stranger? And would it be harder still if that stranger were from another place, culture, generation, or race? These things matter and because it’s impossible to “match” nurses with patients these are very real things that we must all contend with. So I have been surprised at times, I guess, when Native patients do place so much trust in nurses. I am so eternally grateful when they assume the best out of me and I am not seen as a threat because I have some idea of the massive overhaul this might require mentally and emotionally. It’s amazing, really, that nurses (and non-Natives in particular) are not met with open hostility more often.

I only recall one incident on [tribal place name] where hostility was directed at me due to my race. I was having trouble maintaining the O2 sats on an infant who was a “frequent flier” to our unit. His father was a well-known drug abuser and Mom often came in with visible black eyes and other signs of abuse. Mom was quiet, polite, and cooperative. She clearly was a connected, concerned, and caring mother but I know there were some serious social issues in the family. Dad came and went during baby’s frequent stays with us and this particular time he was very agitated (and clearly withdrawing from some type of substance). The [tribal member] CNA and I fought with this baby’s O2 monitors on and off the whole shift. I appreciate how scary and frustrating it is for parents when machines connected to your child beep non-stop. Towards the end of the shift as I tried for the 100<sup>th</sup> time to get a decent pulse ox reading Dad suddenly snapped and said, “I don’t want a White nurse anymore!” I froze. The CNA, a very dignified middle-aged woman who I worked closely with and deeply respected, said something sharp to him in [tribal language]. They had a brief exchange and then he left the room, slamming the door behind him. I finished, left the room (still stunned, feeling incredibly awkward and uncomfortable), then came back a bit later for another task. By then I was angry –I’m not sure why. I guess I was hurt and scared. The Mom looked down at her feet and quietly said, “I’m sorry about what he said”. All of my anger dissolved. I could feel her embarrassment and shame. I had spent many a night shift with this mother and we had always worked well together for the sake of her sick baby. I didn’t know what to say other than, “It’s ok”. After a minute or so I said, “I know he doesn’t want a White nurse...but there is no one else.” It was true; the entire unit was staffed by White RNs that night. I recognized the lopsidedness of that, and I respected the fact that it might seem like nurses are always doing something “to” patients in a way that might be foreign or frustrating. I also know his outburst was more likely related to this withdrawing process and the pain that he was clearly in. I had to tell myself repeatedly not to take it personally, but what could be more personal than the very color of my own skin?

I also recognized that these types of race-based incidents hurt us all. The mother was embarrassed. The CNA was angry. I was hurt. Dad was frustrated. No one was comfortable. I

still remember the “sting” of that isolated incident all these years later. I prided myself on doing my very best for that sick baby and yet it was something that I could not change that caused a problem. It felt impossibly sad.

#### **A5: Journal Entry 5**

Recently a Native student that I work with asked me what drew me to this kind of work in the first place. I had to think about the answer quite a bit. At first it just seems like I kind of fell into this field but that isn't entirely true. Just as becoming a nurse was a conscious, intentional decision, so have been my various jobs and positions. I've always been interested in other cultures. Even as a child I loved reading National Geographic and learning about history, especially the history of the rural, Western Colorado area I was born and raised in. That history included a lot of Native history. But it wasn't until I went to nursing school and was introduced to social justice and service learning under the tutelage of the Jesuits that I began to appreciate the potential for nursing to play a role in alleviating health disparities. My liberal, faith-based training awakened some type of new thinking and a call to action in me even though I did not consider myself conventionally religious. I began to really think about things like inequality, colonization, and poverty. I began to realize that not only should I be concerned about these things as a human but that my chosen profession had an obligation to address them as well. Once I was in the clinical phase of my nurse training I began to literally see the impact of poverty on my patient's health. Much of it didn't feel right to me. I had several professors who had worked for Indian Health Service and I thought that serving that community might be a truly productive, fundamental way of using my skills and training to combat some of that injustice and inequity. First, however, I completed my Peace Corps service in [African country]. That was a whole other experience unto itself but it is relevant to how I ended up in Native communities as it both challenged and cemented my personal and professional commitment to underserved populations.

What strikes me as I write this is that I seem incapable of distinguishing between or separating my personal and professional ideals. I think they are intertwined completely, which may be something unique to certain professions such as nursing. Of course most jobs call for ethical standards of some sort but the health professions are special in this sense. It is important to me that what I do for a living is compatible with my own morals. This doesn't mean that I have to directly be administering care; there are many ways to enact what I believe in. So maybe I chose IHS because I wanted to help in the purest sense. I don't like the word 'help' very much, though. It sounds superficial, egotistical, and as if I pity the recipient. That could not be further from the truth and certainly had I been focused on “helping” I never would have survived in Africa and then later on the Reservations. People don't really want to be helped, they want to help themselves.

Like I mentioned previously, I have a hard time accepting that this level of inequality and disparity occurs in this country among the original inhabitants. It seems so deeply embedded and systematic, though; I long ago lost any preconceived notions about the impact that I would have as one, solitary nurse. All of the good intentions and righteous indignity in the world do very little at the end of the day. Change is often more subtle, takes time, and must be driven by those it directly impacts. But I also refuse to sit back passively and maintain the status quo. So to answer my student, I actively chose to work with Native communities for principled reasons but also was drawn to it on an academic and personal level.

Another one of my Native students asked me what my family thought of my interest in working and researching with the Native population. She was specifically curious about what my parents thought. (Her exact words were, “Do they think you are weird?”). I love how comfortable these students are with me and I value the very honest discussions about sometimes tough topics like race and tribal sovereignty that we have). I think to some degree my family and many other people do find it odd when a non-Native person seeks out employment with IHS or tribal facilities. I would often hear phrases about the “lucrative” federal benefits being a major factor for nurses, but it almost seemed futile to explain everything that I am writing here to most people. Like my comments referring to [tribal place name] as a “war zone” at times, most people off of the Rez have no interest in what goes on in Native communities. They make assumptions and express generalizations or broad judgments. At the most they might show a vague sense of discomfort with the whole topic –the remnants of settler colonialism, possibly, or at least white privilege. There is usually that sense of “us” and “them” and exasperation with the Native focus on past events. When people would find out where I lived and worked in [southwestern states] they would often launch into their opinions on the Native quality of life. I was occasionally asked, “Why don’t the Indians just get over it?” In some ways this is not my argument to have. These bright, articulate, empowered students that I work with could tear that question to shreds. But because I have been a nurse on the Reservations and in an urban area serving Natives and am now pursuing research in that field, I do have to respond. This sometimes means responding to my own family members. What I have found is that over time with calm, collected, simple explanations –often through stories and real-life examples from my work –I can change someone’s perspective ever so slightly. My parents now say that they pay attention to news about Native issues in their home state that appear in the media. This is huge. This is the result of all of our conversations over all of these years. My parents visited me on the Reservation and asked a million questions. Even that small exposure can have a long-lasting impact. You do have to see it to believe it sometimes, yet most of America is totally isolated (by circumstance or choice) from the Native reality. I am not, and so I cannot turn away. This is how I answered my two students. I wonder what they think of this, and of me, sometimes.

#### **A6: Journal Entry 6**

I’ve written about how the nurse-Native patient relationship is unique partially due to the sheer amount of time that we spend together. This is certainly significant as we have much more contact with patients and families than any of the other health professions which both deepens and potentially complicates our interactions. Like I mentioned, if there is a lack of trust or poor communication in the relationship it makes for a very long 12 hour shift or hospital stay for all involved. But that relationship goes beyond the time spent together; I think patients, including Native patients, expect a very different kind of care from nurses. Certainly historically some Reservations were only staffed by a nurse and I think this has influenced the Native perception of the profession to this day. There is also the component of Native healers and midwives that may bleed into today’s care scenarios. How might nurses be viewed differently than physicians or others? I think we are expected to be more kind, patient, and gentle. Some of this might be associated with the profession traditionally being largely female; it would be interesting to explore how the increase in male nurses has changed the perceptions of the profession as a whole and for Native patient’s in particular. Physicians play a very different care role in my experience. Although the complexity of cancer often requires that they spend a great deal of time educating

and presenting options to patients, in my experience it is still the nurses that perform the vast majority of the hands on care. We literally have more physical contact and with this certain cultural issues may arise. I remember in [tribal place name] being warned by the [tribal member] CNAs not to touch any of my patient's hair if at all possible as it was spiritually significant to many [tribal members]. It is entirely possible that a physician could work in that community for years and never know that, yet it was essential that I did as a nurse. Our proximity and the type of care that we provide impacts the kind of knowledge and skills we should have. This intersection is exactly where I feel so much breakdown, miscommunication, and misunderstanding might occur. Like I keep repeating, I truly feel that the vast majority of it is unintentional and most nurses want to be sensitive and kind and most Native patients are patient and understanding. But bridging that cultural gap in care requires a certain level of humility and vulnerability whereas nurses are trained to be quite confident. Problem-solving and analytical thinking are essential for clinical care but might not be sufficient for the other side of nursing. We have to be proficient at all of it.

#### **A7: Journal Entry 7**

The only way that I can get to the bottom of any of this is by telling stories. The irony in this is not lost on me as storytelling is very much a part of many Native cultures and has certainly been present in many of my care experiences. For example, Mrs \_\_\_ that I wrote about earlier required very complicated, time-intensive wound care several times each shift and we would often pass the time by talking. It was a good form of distraction for her from the physical and mental uncomfortableness of the situation, I think, and many of these conversations evolved into stories about our families or Indian country. She really appreciated that I could relate to a small part of her world. I think she felt so alone and isolated in Tucson and truly was more than six hours from her home, husband, and children. I cannot fathom dealing with that loneliness in addition to facing cancer.

Another experience occurred when I was working on the border of the [tribal place name] Rez in a facility that served both the non-Native and Native populations. I performed conscious sedation on a [tribal member] woman for a short procedure and we had some trouble maintaining her airway. We had to stop the procedure and reverse the sedation –it was pretty intense for several minutes but luckily never felt out of control and she recovered quickly. Once she was more awake and her husband was at her side I explained to them what had happened. Looking back I'm not sure why I was having this conversation with them instead of the physician, but at any rate I felt that I explained it well enough and in a non-terrifying way. I emphasized that at no point had her life truly been in danger yet I vividly recall the look of absolute fear on both of their faces. Before the procedure they had seemed fairly comfortable –the usual pre-procedure “jitters”, but receptive to my explanations and education and very calm and comfortable. As I explained to them why we had to stop the procedure they seemed suddenly suspicious and frightened. I didn't downplay the complication but spent a lot of time explaining and reassuring. It didn't seem to alleviate their fear much and I felt concerned as they returned to the Rez. Sure enough, several weeks later I got a call from the Director of Nursing about the case. Apparently the patient and her spouse had told the referring doctor on the Rez that “those people in \_\_\_\_\_ tried to kill me”. They claimed that the patient had actually “died on the table” and had been “brought back to life” by the medication. They were now terrified of us and refused to come back to the facility to re-attempt the procedure using a different technique. I explained what had

happened to the DON and he sort of laughed it off and was relieved, but I was not. I felt terrible and like their perception that we had “toyed” with life and death was perhaps deeply rooted in a cultural or spiritual dimension that we were not fully appreciating as non-Natives. The fear in their faces and their later version of events to the Rez physician indicated that they either did not understand my explanation or they did but were interpreting them in a very different way. This could also be attributed to an individual response and have absolutely nothing to do with being [tribal name], but I have my doubts. I had heard the wife and husband speaking to one another in [tribal language] which suggested to me that they were very connected to their culture or traditions. Of course all of this is speculation to some extent, but I have had similar experiences with White patients and they did not have the same degree of fear, suspicion, and trauma as a response. I wondered if a fragile trust that the [tribal name] woman had placed in me, the facility, and Western medicine had been truly broken. I felt like we had “lost” her and that she probably would never come back –and this had been a preventative cancer screening to make matters worse.

Perhaps if we had performed some kind of healing ceremony afterwards she would not have departed feeling like we had so casually walked the line between life and death. I could not entirely understand how she could interpret the events like she did but my instincts told me that our care had somehow violated something in this patient and that this violation might be related to her culture. To this day I feel confused and regretful about that situation, and I wished that I had some type of guide to let me know how we should have handled it better. In a later conversation with a [tribal name] colleague she mentioned that there were some strong beliefs about the “doorway” between life and death but she did not elaborate and I did not pry. Where do you draw the line between being informed and culturally competent and being disrespectful and overly curious? Again, my tendency was to let the Native person reveal what they were comfortable with but perhaps I should have asked that patient and her husband more questions. I don’t know what would have helped and what would have exacerbated the situation, and that is exactly the conundrum nurses find themselves in when caring for Native patients.

APPENDIX E:  
INSTITUTIONAL REVIEW BOARD APPROVAL

1618 E. Helen St.  
P.O.Box 245137  
Tucson, AZ 85724-5137  
Tel: (520) 626-6721  
<http://orcr.arizona.edu/hsp>

Human Subjects  
Protection Program

**Date:** January 05, 2016

**Principal Investigator:** Natalie Mae Pool

**Protocol Number:** 1512281830

**Protocol Title:** The Meaning of the American Indian-Cancer Care Nurse Relationship

**Level of Review:** Exempt

**Determination:** Approved

**Documents Reviewed Concurrently:**

**Data Collection Tools:** *Demographics Form\_Pool (V.3).docx*

**Data Collection Tools:** *Interview Guide\_Pool (V.5).docx*

**HSPP Forms/Correspondence:** *F107\_Pool.doc*

**HSPP Forms/Correspondence:** *F200\_AIandNurseRelationship\_Pool\_REVISED (V.3).doc*

**HSPP Forms/Correspondence:** *Signature page.pdf*

**Informed Consent/PHI Forms:** *Informed Consent\_Pool (V.5).pdf*

**Recruitment Material:** *Networking Script\_Pool (V.3).docx*

**Recruitment Material:** *Study Flyer\_Pool (V.4).jpg*

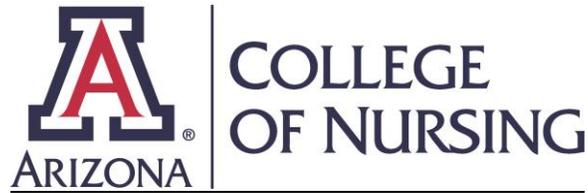
**Recruitment Material:** *Verbal Script\_Pool (V.5).docx*

**Recruitment Material:** *Written Recruitment\_Pool (V.6).docx*

This submission meets the criteria for exemption under 45 CFR 46.101(b). This project has been reviewed and approved by an IRB Chair or designee.

- The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).
- All research procedures should be conducted in full accordance with all applicable sections of the Investigator Manual.
- Exempt projects do not have a continuing review requirement.
- This project should be conducted in full accordance with all applicable sections of the IRB Investigators Manual and you should notify the IRB immediately of any proposed changes that affect the protocol.
- Amendments to exempt projects that change the nature of the project should be submitted to the Human Subjects Protection Program (HSPP) for a new determination. See the Investigator Manual, 'Appendix C Exemptions,' for more information on changes that affect the determination of exemption. Please contact the HSPP to consult on whether the proposed changes need further review.
- You should report any unanticipated problems involving risks to the participants or others to the IRB.
- All documents referenced in this submission have been reviewed and approved. Documents are filed with the HSPP Office. If subjects will be consented, the approved consent(s) are attached to the approval notification from the HSPP Office.

APPENDIX F:  
WRITTEN RECRUITMENT



Dear *[insert name]*,

My name is Natalie Pool and I am a graduate student from the College of Nursing at the University of Arizona. I am writing to invite you to participate in my research study about Registered Nurses' relationships with American Indian cancer patients. You may be eligible to participate in this study because of your nursing experience with American Indians and cancer care. I obtained your contact information from *[source]*, who highly recommended you based on your professional and caring attributes.

If you decide to participate in this study, you will be interviewed three times over several months regarding your nursing experiences with this population and topic. Compensation will be provided in the form of a gift card at the completion of each interview. The information will be used to explore your experiences with American Indian cancer patients in order to increase our understanding of the complex relationship between nurse and patient within this specific group and setting.

Remember, this is completely voluntary. You can choose to be in the study or not, as well as to discontinue your participation at any time. If you would like to participate in or have any questions about the study, please contact me at [nataliepool@email.arizona.edu](mailto:nataliepool@email.arizona.edu) or (480) 370-4477. Please provide your phone number with an optimal time for me to contact you.

Please share this letter and my contact information with other nurses that you feel may be interested in participating in this study.

Thank you very much.

Sincerely,

Natalie M. Pool, BSN, RN  
PhD Candidate, College of Nursing  
Minor, Department of American Indian Studies  
The University of Arizona

APPENDIX G:  
NETWORKING SCRIPT

Dear/hello [*insert name*],

I am contacting you about a study being conducted by a graduate student in the College of Nursing at the University of Arizona. I know the student, Natalie Pool, from my work with her at [*fill in with past experience when providing this script to the nurse*]. The study is concerned with the relationship between American Indian [*Native American*] patients and cancer care Registered Nurses. I think you might be a good candidate for participating in this study based on your professional nursing experiences.

If you would be willing to participate, please contact Natalie at [nataliepool@email.arizona.edu](mailto:nataliepool@email.arizona.edu) or (480) 370-4477. I'm sure she will be very grateful for your assistance in this project. Thank you.

Sincerely,  
[*insert name*]

APPENDIX H:  
VERBAL SCRIPT

“Hello, my name is Natalie Pool and I’m a graduate student in the College of Nursing at the University of Arizona. Is this a good time to talk?

I’m returning your [*telephone call/email*] about my project researching the relationship between cancer care registered nurses and American Indian [*Native American*] patients and communities. Thank you for contacting me.

Are you still interested in hearing more about the study?

[If *No*]: Ok, thank you very much for your time. Thank you again for contacting me, and have a great [*day/night*]. Goodbye.

[If *Yes*]: Ok, great. The goal of this study is to examine registered nurses’ experiences caring for this group; we know a lot about Native American cancer patient’s perspectives on healthcare systems and providers, but very little about nurses’. I will be interviewing registered nurses multiple times over several months to hear about their experiences.

Is this something you are interested in participating in?

[If *No*]: Ok, thank you very much for your time. Thank you again for contacting me, and have a great [*day/night*]. Goodbye.

[If *Yes*]: Ok, great. I need to make sure that you qualify to participate in this study. With your permission, I need to ask you a couple of questions. I will not be recording any of your answers.

1. What field of nursing do you currently work in or have you worked in the past where you had contact with Native American cancer patients? [*Must have cancer connection in some way*]
  - a. How many years [*have you worked/did you work*] in that field? [*Must be minimum of three years*]
  - b. [*If past experience*]: Have you ever been terminated from employment for any reason during the time that you cared for Native American patients? [*Must be no*]
2. Do you read and speak English fluently? [*Must be yes*]
3. Will you continue to have access to a telephone or a device with internet capability, such as a computer, smart phone, or tablet over the next six months?
4. Are you over the age of 21? [*Must be yes*]

[*Does not qualify to participate*]: Unfortunately, you do not qualify to participate in this study. However, I’m extremely grateful for your time [*today/tonight*] and wish you all the best. Thank you for your time. Goodbye.

[*Qualifies to participate*]: You meet the criteria to participate in this study. Your participation would be completely voluntary.

Are you still interested in participating?

[If *No*]: Ok, thank you very much for your time. Thank you again for contacting me, and have a great [*day/night*]. Goodbye.

[If *Yes*]: Ok, I’m going to provide you with some more information and schedule your first interview. Once again, participation in this study entails being interviewed approximately three times by me. This process will take several months if you continue to be interviewed. You can stop participating at any time. Each interview will last about an hour. The interviews will take

place wherever you feel the most comfortable. I also have a private office space available at the College of Nursing for interviewing. The first interview will be in-person with me, but later interviews may be either in-person, on the telephone, or by using the internet, such as through Skype or FaceTime. The interviews will be audio recorded by me. It's important that you know that any personal details or information about yourself, your patients, or your experiences as a nurse will be kept confidential.

Do you have any questions about this process?

If you are still interested in participating, let's schedule your first in-person interview now.

APPENDIX I:  
INFORMED CONSENT

## **The University of Arizona Consent to Participate in Research**

**Study Title: The Meaning of the American Indian Patient-Cancer Care Nurse Relationship**

**Principal Investigator: Natalie Pool, BSN, RN, PhD Candidate**

**This is a consent form for research participation.** It contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to discuss the study with your friends and family and to ask questions before making your decision whether or not to participate.

### **Why is this study being done?**

The purpose of this study is to describe the meaning of American Indian-cancer care nurse relationships from the nurses' perspective. This study will involve researching the experiences of registered nurses who have provided cancer care to the American Indian population in some way in order to improve care delivery and the nurse-patient relationship.

### **What will happen if I take part in this study?**

If you choose to take part in this study you will be interviewed in-person by a researcher at least once concerning your experiences of providing cancer care to American Indian patients and communities. This interview will take place in a private setting of your choosing and last about an hour. Two more interviews also lasting about an hour will most likely be necessary. These additional interviews may be conducted either in-person in a private setting of your choice or via telephone or the internet (i.e. Skype, FaceTime, etc.), depending upon your preference and location. If you live outside of the Tucson-area, you will need to have either telephone or internet access to continue the interviewing process. All of the interviews will be audio recorded.

### **How long will I be in the study?**

The interviewing process for this study is expected to take approximately 3-6 months from the first to the last interview, depending upon how many you participate in.

### **How many people will take part in this study?**

Ten nurses will participate in this study.

### **Can I stop being in the study?**

Your participation is voluntary. You may refuse to participate in this study. If you decide to take part in the study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you and you will not lose any of your usual benefits. Your decision will not affect your future relationship with The University of Arizona. If you are a student or employee at the University of Arizona your decision will not affect your grades. If you are an employee at Banner-University Health, your decision will not affect your employment status.

**What are the costs of taking part in this study?**

There are no costs to you for participating in this study other than your time. If you are outside of the Tucson-area, you will need to have access to a working telephone or the internet.

**Will I be paid for taking part in this study?**

You will be compensated for your time if you choose to participate in this study in the form of a \$25 gift card upon completion of each interview. If the interview was conducted on the telephone or internet, the gift card will be mailed to you upon completion of the interview.

By law, payments to subjects may be considered taxable income.

**What risks, side effects or discomforts can I expect from being in the study?**

This study is anticipated to have minimal risks. There are no physical, social, or legal risks. In the event that you experience any psychological distress related to the potentially sensitive nature of the topic of study, you may call a national 24-hour crisis hotline (**1-800-273-TALK**) for immediate assistance and referrals for follow-up care. The economic risk is also considered minimal in the form of the time you spend being interviewed.

**What benefits can I expect from being in the study?**

You will not benefit as a result of participating in this study.

**What other choices do I have if I do not take part in the study?**

You may choose not to participate in this study without penalty or loss of benefits to which you are otherwise entitled.

**Will my study-related information be kept confidential?**

All efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law.

Also, your records may be reviewed by the following groups:

- Office for Human Research Protections at the University of Arizona
- The University of Arizona Institutional Review Board

Your name, location, and any other identifying details will be removed from all of the recorded interviews or significantly altered by the researcher to ensure confidentiality; this will also occur for any patient identifiers (i.e. diagnosis, tribal affiliation, etc.) that are discussed during interviewing. Again, all identifying details will be either removed from the study or altered so as to be unrecognizable.

### **Who can answer my questions about the study?**

For questions, concerns, or complaints about the study you may contact the researcher, Natalie Pool, at [nataliepool@email.arizona.edu](mailto:nataliepool@email.arizona.edu) or (480) 370-4477.

If you do not feel comfortable contacting the researcher you may contact Dr. Mary Koithan at [mkoithan@email.arizona.edu](mailto:mkoithan@email.arizona.edu) or (520) 626-2036.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at 520-626-6721 or online at <http://orcr.arizona.edu/hssp>.

An Institutional Review Board responsible for human subjects research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

### **Signing the consent form**

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

\_\_\_\_\_  
Printed name of subject

\_\_\_\_\_  
Signature of subject

\_\_\_\_\_  
Date and time

AM/PM

APPENDIX J:  
INTERVIEW GUIDE

**Project Title:** The Meaning of the American Indian Patient-Cancer Care Nurse Relationship

**Primary Investigator/Interviewer:** Natalie Pool

### INTERVIEW GUIDE

#### Interview #1:

**Intro:** We're going to begin today's interview with some basic questions about your experiences as a nurse providing cancer care to Native American patients. Try and be specific about these events, and pay particular attention to how you were feeling at the time.

#### **Examples of Grand Tour/General Questioning**

- Describe a time when you provided care to a Native American cancer patient. What was it like?
- What is it like when you care for a Native American patient with cancer? How is this different than providing care for non-Natives?
- How would you describe your relationship with the Native American patients/families/community that you care for?
- How have you been affected/impacted by providing cancer care to Native American patients?
- How have you been impacted by this relationship?
- Describe a situation when a Native American patient presented to your care with late-stage cancer. What was that like? How did it feel?
- What does it mean for you when their cancer might have been prevented or treated earlier? How does that make you feel?
- How did it feel when that [*a described experience, feeling, relationship, etc.*] happened? Does it feel differently to you now?

#### **Examples of Probing/Prompting Based on the Four Phenomenological Lifeworlds**

- **Spatiality:** What was the situation like? How did that feel spiritually? What kind of emotions were you feeling? Describe that feeling to me.
- **Temporality:** How did it feel at that specific time? How does it feel now? When did you feel that way? Describe how that [*feeling/sensation/experience/relationship*] changed for you over time?
- **Relationality:** Who else was there? How were they involved? Describe your relationship with [*this patient, that family member, etc.*].
- **Corporeality:** What were you feeling physically when that happened? Tell me how this experience impacted you physically. What was your physical response, if any?

#### **Examples of Reflective Prompts for Participants to Consider during Intervals between Interviews**

- Between now and our next interview, I would like for you to think about what you meant when you used [*word/phrase*] to describe your relationship with [*this patient, that family member, etc.*]. Let's talk more about that relationship in our next meeting.
- I think it's significant that you remembered [*an experience, feeling, relationship, etc.*]; I want you to think about why that stands out to you when you look back, and let's talk more about that next time.
- When you shared the story about [*an experience, feeling, relationship, etc.*], you seemed [*upset/angry/frustrated/proud, etc.*]. It will be helpful to spend some time reflecting on those feelings over the next few weeks and really exploring where they come from, and we'll talk about that next time.
- Today you described a [*stressful, painful, positive, etc.*] experience of caring for a Native American patient. Before our next interview, try and recall an experience that was

[*peaceful/rewarding/negative, etc.*], and let's focus on what made them different and how you felt in each scenario.

**Closure** (see prompt below).

### **Interview #2: Examples of Elaboration/Clarification/Confirmation Questioning**

**Intro:** Since we last met, I've been reading and re-reading your interview, and I've come up with some questions about what we discussed. I need to probe more deeply so that we can better understand your experience and what is really going on with this type of nursing relationship. Before you left last time, I asked you to think about [*reflective prompt from interview one*]. Let's begin with your reflections about that topic.

- When you say/said \_\_\_\_\_, what do you mean by that?
- Is this [*a described experience, feeling, relationship, etc.*] something you only experience with Native patients? Why does/did it feel that way to you?
- In our last interview, you spoke about [*a described experience, feeling, relationship, etc.*]. You used the word [*stressful, painful, frustrating, positive, successful, etc.*] to describe it. This seems like it had an impact on you. Can you talk more about that experience and why you felt that way?
- You seem [*upset/angry/frustrated/proud, etc.*] talking about it now; what were you feeling when it happened? Where do you think that feeling comes from?
- What do you think was *really* going on [*during that situation/with that person*]? Why do you feel that way?

Continuation of the lifeworld-based probing and reflective prompts from above.

**Closure** (see prompt below).

### **Interview #3: Examples of Questioning Aimed at Meaning**

**Intro:** I've continued to spend a lot of time with your previous interviews over the past few weeks/months. Certain ideas and words are really beginning to stand out and grab my attention, and I'd like to discuss those more with you today to see how you feel about them. But first, let's start with what you have been reflecting on since we last met. [*Remind participant of reflective prompt from interview two*].

- If you could sum up your experience as a nurse engaging in cancer care with Native Americans in three words, what would they be and why? How do you feel about all of it?
- When you look back, how would you describe the overall energy surrounding that whole [*experience/relationship*]?
- You've mentioned [*a described experience, feeling, relationship, etc*] several times now. This seems like it was meaningful and important for you. Can you tell me more about it? Why does it stand out to you?
- What do you think it means that you are/felt [*upset/angry/frustrated/proud, etc.*] about that? What significance does that feeling have for you?
- What other times in your life have you felt that way? How do you think that is connected to your experiences as a nurse in this situation?

Continuation of the lifeworld-based probing from above.

**Closure:** Thank you for your participation and time today; I really appreciate it. Remember, you can stop participating at any time. If you feel like today's interview is impacting you negatively in anyway, please contact the 24-hour crisis resource (I-800-273-TALK).

APPENDIX K:  
DEMOGRAPHICS FORM

**Project Title:** The Meaning of the American Indian Patient -Cancer Care Nurse Relationship

**Primary Investigator/Interviewer:** Natalie Pool

**Participant Number:** \_\_\_\_\_ **Date (mm/dd/yy):** \_\_\_\_\_

### DEMOGRAPHICS FORM

PI/Interviewer to administer to all enrolled participants after Informed Assent and Consent is complete.

INTERVIEWER READS: The following are some basic questions regarding your background to help us know what type of people participated in this study. All the information you provide will be kept confidential and will not be shared with anyone else besides the research study staff. You may refuse to answer any of the questions.

What is your age range?	<input type="radio"/> 21-30 <input type="radio"/> 31-40 <input type="radio"/> 41-50 <input type="radio"/> 51-60 <input type="radio"/> 61-70 <input type="radio"/> 71 and above <input type="radio"/> Prefer not to answer
What is your self-described gender?	<input type="radio"/> Male <input type="radio"/> Female <input type="radio"/> Prefer not to answer
What is your self-described ethnicity and/or race? (Select all that apply)	<input type="radio"/> White (Non-Hispanic) <input type="radio"/> African-American/Black <input type="radio"/> Hispanic or Latino/Latina <input type="radio"/> Asian <input type="radio"/> Native Hawaiian or other Pacific Islander <input type="radio"/> American Indian or Alaska Native <input type="radio"/> Prefer not to answer
How many total years have you been a Registered Nurse?	<input type="radio"/> 3-5 <input type="radio"/> 6-10 <input type="radio"/> 11-15 <input type="radio"/> 16-20 <input type="radio"/> 21-25 <input type="radio"/> 26-30 <input type="radio"/> 31 or more <input type="radio"/> Prefer not to answer
What field(s) of nursing <i>did you work/do you work in</i> where you have regular contact with Native American cancer patients? (Select all that apply)	<input type="radio"/> Medical-Surgical/Surgical-Oncology <input type="radio"/> Oncology (select Inpatient or Outpatient) <input type="radio"/> Surgical (select Peri-op, Pre-op, or Post-op) <input type="radio"/> Outpatient Clinic/Primary Care <input type="radio"/> ER/ED/Urgent Care <input type="radio"/> Radiology/other Diagnostics <input type="radio"/> Public Health/Community Health <input type="radio"/> Case Management/Care Coordination <input type="radio"/> ICU <input type="radio"/> Hospice/Palliative Care <input type="radio"/> Other _____ <input type="radio"/> Prefer not to answer
How many combined years <i>did you work/have you</i>	<input type="radio"/> 3-5

<b><i>worked in the field(s) where you have regular contact with Native American cancer patients?</i></b>	<ul style="list-style-type: none"><li><input type="radio"/> <b>5-10</b></li><li><input type="radio"/> <b>11-15</b></li><li><input type="radio"/> <b>16-20</b></li><li><input type="radio"/> <b>21-25</b></li><li><input type="radio"/> <b>26-30</b></li><li><input type="radio"/> <b>31 or more</b></li><li><input type="radio"/> <b>Prefer not to answer</b></li></ul>
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**Notes:**

APPENDIX L:  
SAMPLE SECOND INTERVIEW GUIDES

## Participant #5

**Reflective prompt from first interview:** “less threatened” by Native American patients due to their reserve, compliance, and quietness – “less pressure” on you as the nurse and less physically demanding in comparison to cancer patients from other (White) ethnic groups. However, you also said it was “more emotionally challenging” because of the disconnect between patient and nurse.... What does it feel like to be caught between those two experiences (less physically demanding/more emotionally challenging)? You also mentioned that being a more experienced nurse, various experiences have “broke your heart” and as a result you “build up those layers” to protect yourself –can you elaborate more on this, particularly in relation to the story about the wife who accused her husband of faking his leukemia diagnosis? How was your reaction different than the new grad’s, and why? How do those “layers” impact your care overall with Native American cancer patients?

**Lifeworld-based questioning from first interview:**

- “All of us were...appalled” about wife thinking husband was faking leukemia diagnosis
  - How did it physically feel to hear the wife express this view? (corporeality) What was it like being in the same room as her when she was expressing this? (spatiality)
  - “Her concern was how are they going to be able to survive without him being able to work” “track record” of poor work ethic... pt/family lives several hours away ... “no family here when he first got diagnosed” “some people are just really surviving” –how did all of these things impact your relationship with the wife? With the patient? (relationality)
  - You sensed that the wife didn’t understand the diagnosis and was upset, not that she didn’t care –why did you sense that? How did it change your perception of her? (relationality)
- Nurses on current unit are not experienced with Native patients – elaborate more...
  - How does your extensive nursing experience impact your relationships with NA patients? (relationality); Have your perceptions changed over time? (temporality)
- NA patients “don’t seem to do that well” with cancer diagnosis, don’t follow through –how does that feel when you think about that? (relationality)
- Teaching younger nurses to be more empathetic –“put yourselves in their shoes”
  - How does it feel to put yourself in a NA cancer patient’s shoes? (corporeality)
- Native patients are “present minded”, don’t want to “talk to you about what’s going to happen in the future”
  - People don’t do a good job of teaching them –“talking to someone that’s a stone” –how does it feel to be talking to a stone? (corporeality)
  - Subdued or no response = nonchalance? Asking questions = more enjoyable for nurse?
  - Does caring for a present-minded patient change the way time flows? (temporality)
- “We live in different worlds” “Feels like you’re taking care of someone from a different country”–elaborate more...(spatiality)

- Returning to prompt... NA patients don't question what you are giving them (medication), telling them to do (get up and walk), seem very complaint –but risk is they might be nauseated or in pain but not tell you
  - “I don't think I've ever met a Native American patient that isn't closed off” –how does it feel to care for someone who is closed off? (corporeality)
- “If I had to take care of three native American patients in one shift I would probably leave frustrated”
- “I'm not a robot” “I'm a human being” –how does being a human and not a machine change the way you deliver nursing care to NA patients? (spatiality)

#### Participant #8

**Reflective prompt from first interview:** Elaborate more on one of your biggest frustrations with Native family members that know that a patient has a language barrier, for instance, and yet they drop them off and leave them at the facility. You talked about how you kind of reset yourself and say “well, I don't know what's going on with this family” but that you often see that pattern with this patient population.

Another thing you said was, “If I had cancer my mom, my dad, my brothers, my husband, I would have a huge support team and I would at least have one of them at every one of my treatments and they would never leave my side.” Think about that exact scenario in relation to your own cultural background and then compare it to this other way of being that you see with Native family members.

#### **Lifeworld-based questioning from first interview:**

- Trying to get oral chemo med to a patient –tons of legwork, phone always off, did not want to provide financials –seemed “noncompliant” and maybe suspicious -
  - Then you learned about poor cell service on Rez, mail box far from home, etc. – described as “an eye-opener for me” –what does it feel like to have your “eyes opened” by your patients? (corporeality) What does that experience mean to you?
- Similarly, you often said “I felt like I care about your life but you don't” –mentioned this in one way or another several times in first interview
  - How does it feel when it seems like you are the only one putting forth effort? (relationality)
  - Describe ‘frustration’ for me... Now describe ‘frustration’ as a cancer care nurse.... How are you physically feeling in that moment? (corporeality)How does it impact your relationships with Native patients? (relationality)
- In relation to dealing with HIS: “I feel like the norm for us is that we push, push, push to try to help this patient and I feel like there the feet just get dragged, dragged, dragged...”
  - It seems like the pace of care is not aligned... How does caring for so many patients under the IHS system change your perspective about time as a cancer care nurse? (temporality) How does it impact the way that you feel about cancer care?

- What does it feel like to have urgency and not have that reciprocated by the system? By the patients? By the families? (temporality)
- Talk more about the story of the patient who made the joke about being “afraid of white people”...
  - Both humorous yet a connecting moment; you also related to it as someone with direct experience with discrimination... What emotional impact does it have on you today as you look back on it? (spatiality/temporality)
  - Related to your experiences with Native patients preferring Native nurses: “a piece of me says I’m a good nurse why wouldn’t you want me? But the bigger piece of me understands the bigger picture and why they feel more comfortable with a Native American...” –described as “a little frustrating”... How does it feel to have this conflicting reaction/response? (spatiality) How does it feel to be unwanted, even if you understand it to a degree? (spatiality) Has your reaction to this situation changed over time? (temporality)
- “If somebody passed away I might cry but I’m never going to let somebody make me so mad that I cry”...elaborate more on this perspective about emotions...
  - How has this perception about emotions developed for you over time? (temporality) How does this approach impact your relationships with your Native cancer patients, many of whom do pass away or are difficult to care for? (relationality)
- Talk more about the “eerie feeling” you described getting sometimes when you are trying to educate a Native patient who doesn’t seem to understand or respond...(corporeality)
  - If it isn’t a language barrier, you described being very persistent and “bugging” them until they like you and want you to be their nurse.... What does it feel like to be so actively pursuing your patient? (relationality) Imagine that scenario right now and describe what it physically feels like. (corporeality)
- Let’s talk more about the Native patient that thanked you and the team for saving his life – you described being happy and thankful yet also felt guilty and like it was undeserved...
  - Think back to the moment he said that –what was your immediate physical response? (corporeality) Where do you think those many different/conflicting emotions come from? (spatiality) How do you feel about that patient today, looking back on your experiences with him? (relationality/temporality) What do you think it means that you feel like you did not deserve his thanks?
- Described how many Native patients closely watch how you treat other Native patients...
  - What does it feel like physically to be “watched” so closely? (corporeality) Discuss how this scenario changes your relationships with both Native individuals and the population as a whole. (relationality)

APPENDIX M:

WHOLISTIC DESCRIPTIONS WITH INDIVIDUAL THEMES IN LEVEL-ONE MATRICES

### **Participant #1** **Wholistic/Sententious Description**

This participant is a young, Caucasian woman who has been a RN for just over three years, all of them on an in-patient medical oncology unit at a large, urban hospital in a southwestern city. She is primarily a bedside nurse but occasionally fulfills the role of team-lead on her unit. She is married and hoping to start a family. Along with her youthful appearance, she comes across in interviewing as focused, serious, and very sincere about her desire to deliver what she considers to be high quality nursing care. She considers an ideal patient-nurse relationship to be “open” when a patient is “responsive” to her inquires. In some ways, she assumes that it is obvious and accepted that nurses are benevolent and caring. It is important to her that the patient “trust” the nurse, and when this does not occur it is “definitely a barrier to good care”.

While nearly all of her patients are undergoing some form of cancer treatment and are diverse in regards to race and ethnicity, she reports that she often cares for AIs. Many of her AI patients are sent to her facility from rural or reservation areas while others are local or from other urban areas. Her relationships with this particular group are characterized by a frustrating inability to establish rapport, and subsequently, the deep emotional connection that she finds essential for delivering highly attuned cancer care. “It’s emotionally draining, the amount of patience that I have to exude to hide my frustration” with the difficulty in establishing camaraderie. She struggles to read their body language and overall demeanors; they come across as flat, subdued, or even non-responsive with “blank stares and sometimes not even acknowledging that I had spoken”. She is thwarted by her attempts to engage in even the most basic conversation, finding that “the open ended questions I ask, they just give very simple answers that do not really promote furthering the conversation...It’s a lot more like drawing information out of somebody to get the information you need, rather than a conversation.” She finds this type of communication pattern exasperating. It creates a void between them and she feels hampered in her ability to advocate, interpret vital messages, and build trust, creating sensations of inadequacy and separation:

I feel more distant from the [AI] patient. It’s harder for me to relate to them. I feel that when it’s harder for me to relate and connect to them, it’s harder to read their symptoms and do my job to help keep them comfortable.

She describes experiences where she observes some AI patients who seem unusually needy (“childlike” “like communicating with a child”) or over reactive (“dramatic”), which she attributes to a “knowledge deficit” about health in general and cancer in particular. “I feel like it [over reacting to a complication is] also related to education level... Her reaction to a situation was far more severe than the situation warranted. If she had had more education, perhaps that wouldn’t have been her reaction, [that] panic mode”. She feels that better education provided by the nurse might alleviate some of the fear, yet the conundrum is that AI patients often appear unresponsive or disengaged as she tries to convey this very information:

As I was going through everything and pointing out to him on his copy of the paperwork what he was supposed to be paying attention to, it was just, “Okay. Okay. Okay. Yeah. Okay.” It made me feel like he wasn’t even listening.

Another perplexing characteristic of her experiences is their refusal to call her by her name, referring to her only as “nurse”, compounded by an apparent lack of facial recognition even after

having spent a prolonged period of time together. She describes this scenario with two AI patients, saying of one,

She didn't call me by my name. She just called me 'nurse' the whole time. I thought that was very interesting. Like, "We've gone through all of this. We really connected. We've had all this emotional stuff going on and you don't even call me by my name".

Similarly with another patient she recalls, "I mean if they don't remember my name that's one thing, but that he didn't even recognize my face was surprising." She attributes this behavior to "detachment" from the situation, or perhaps "different social skills" that are culturally situated.

Occasionally, she is able to break through to an AI patient, most often after they have "opened up" to her in some way after a physically or emotionally difficult episode:

It made me feel like I could definitely do my job better at that point because she was opening up more and I felt she was more receptive to what I was saying. I felt like I could be more receptive to what she needed. I could get a better understanding of what she needed from her care and get a better understanding of her understanding of what was going on to make sure that I could fill in the gaps and educate her where need be and make sure she had the emotional support she needed. I felt like I could connect with her more emotionally also because she was so upset after everything. She really opened up to me and was crying. I felt like that was a big hurdle because then she was able to talk more frankly with me. I think that definitely helped me provide better care to her.

Vulnerable occasions such as these signal a turning point in the relationship, and from that moment forward she begins to foster feelings of protectiveness and concern, which in turn brings them closer together:

When we've been through something emotional together, and I feel like I've connected with somebody, and it's definite—I don't know if it's a nursing instinct, or a maternal instinct, or what exactly it is, but I wanted to be sure that she was getting everything she needed.

It is the patient's exposed vulnerability that seems to finally unite them as well as impacts her own behavior. "I feel like I react maternally and protectively because I am seeing the situation, and I am my patient's advocate. I am trying to do the best thing for them...I think that definitely brings out a maternal, protective quality". She is "touched" by patients who have finally become receptive and "more comfortable" with her. As she reflects on this transformation, she acknowledges that she has learned over the past three years to adjust her expectations and approach to caring for AI cancer patients:

Seeing these patterns, I hate to use the word 'stereotyping', but I feel like that would be an instinctual response. I see that this patient is Native American, I'm going to anticipate that I'm going to have communication barriers. Maybe I need to be more aware of my communication skills with them to help facilitate effective care. Being more direct might help. Simply flat out asking them what they need, or what they need from me, or what their goals are. It's difficult to ask open ended questions, so maybe close ended questions ...would help me understand better what they need... I might anticipate that I should change my communication tactics to have a better response.

She summarizes her relationships with AI patients as an “educational experience” and that it feels “like traveling to a foreign country” where “different communication and body language” are used. It has been “eye opening” and at times difficult for her “because I don’t feel like I learned anything about [caring for AIs] in school. I’ve learned it all from my experiences.”

**Sententious Formulation:** Nurses initiate relationship through conventional methods of social introduction and expect that patients will respond appropriately, but when this does not occur they are left feeling disconnected and disoriented.

Level One Matrix  
 Interview #1; Interview #2; Interview #3

	<p><b>#1:</b> The focal experience revolved around a young AI female patient with highly preventable and treatable metastatic cancer who was informed of her short-term prognosis during the two days the nurse provided care. The nurse initially found it both confusing and frustrating to care for her, struggling to communicate and establish trust. A poignant event occurred on the second day when the patient desperately needed the nurse. This moment of vulnerability opened the nurse’s mind, stimulating a plethora of intense sensations and emotions. She came away from the experience feeling very connected and close to the patient, but also heartbroken and left wondering about her outcome to this very day.</p>	<p><b>#2:</b> The nurse often cares for a newly diagnosed AI male who coded during a chemo treatment on her unit, then later returned from the ICU. She describes a troublesome pattern of trying to provide education and ascertain how much he understands about his diagnosis, treatment, and prognosis, causing her to feel exasperated with him during these momentary encounters. But gradually, over time, she feels like she has earned his trust and now finds it a “pleasure” to care for him even though his responses remain subdued. Still, he refuses to call her by name despite their familiarity; this is unsettling to her in a way that she struggles to pinpoint or articulate.</p>	<p><b>#3:</b> This middle-aged AI woman is mostly described in terms of a singular episode in which she “panicked” and “overreacted” after aspirating while brushing her teeth. This episode felt annoying and bewildering to the nurse, who saw the event as trivial and fairly routine, and found the patient to be overly dramatic and immature. The nurse had difficulty communicating with this patient due to her subdued yet often “childlike” responses. They never really connected and her recollections of this particular relationship seem characterized by distancing and irritation on the part of the nurse.</p>	<p><b>#4:</b> Generalized (potentially significant) quotes about caring for AI cancer patients</p>
<p><b>Corporeality:</b> “we are always bodily in the world”, we meet people “first of all through his or her body”; “when the body is the object of someone else’s gaze, it may lose its naturalness”, both revealing and concealing.</p>	<p>You know the feeling like when your stomach drops</p> <p>She was very shy about her body, which I can respect. Many older women, when I try to protect their modesty, and they say, “Oh honey. Once you have kids you</p>	<p>It’s like pulling teeth to get acknowledgement</p>		<p>I feel more distant from the patient. It’s harder for me to relate to them. I feel that when it’s harder for me to relate and connect to them, it’s harder to read their symptoms and do my job to help keep them comfortable.</p> <p>Whereas, when I’ve had that</p>

	<p>don't have any modesty anymore." That's very different. Well, this poor young girl had a lot of modesty. I felt like I could relate to that. I haven't had kids...I feel like I would be very modest about my body as well</p>			<p>conversation and that icebreaking time with somebody getting to know them, then I feel like I know what their baseline is, for example. If they're not at their baseline, I can recognize it. If they're coming in with a lot of pain, I can see their baseline once they're comfortable and know if they're having pain again. Know when something is out of the ordinary, so we can then delve in to it and dig until I figure out what the problem is. Whereas when I have no baseline to go off of, it's harder for me to figure out what the problem is</p>
<p><b>Spatiality:</b> "felt space"; "inquiring into the ways we experience spatial dimensions of our day-to-day existence"; "we become that space that we are in"; "world or landscape in which human beings move and find themselves in".</p>	<p>"she didn't address me much because we were standing there face to face talking, so she didn't need to address me by name"</p> <p>"I was so touched that she felt close to me and comfortable with me"</p>			
<p><b>Relationality:</b> "relation we maintain with others in the interpersonal space that we share with them"; "develop a conversational relation which allows us to transcend ourselves"; "human beings have searched in this experience for the other, the communal, the social"</p>	<p>I got her into the shower to clean her off and was trying to give her her space while at the same time staying close in case she needed anything. [ALSO SPATIALITY]</p> <p>Somebody else came and answered her call light, and she was too embarrassed to talk to them about what was going on and requested that nobody else answer her call lights that day and that only I come in and help</p>	<p>I didn't get a lot of verbal acknowledgement of what I was saying—not, "Okay, I understand. That makes sense," just blank stares and sometimes not even acknowledging that I had spoken</p> <p>As I was going through everything and pointing out to him on his copy of the paperwork what he was supposed to be paying attention to, it was just, "Okay. Okay.</p>	<p>The best way to communicate with her was short, simple, to-the-point sentences that were very basic that made me feel like I was communicating with a 10-year-old</p> <p>You know when you have a young adult patient who's in the hospital, and they're scared, and they regress? It was like that. It seemed like she was regressing.</p>	<p>[With] most people, when I start to have conversation and they're very responsive and I ask open ended questions, their answers promote conversation...Whereas, with the Native patients I care for, I feel like the open ended questions I ask, they just give very simple answers that do not really promote furthering the conversation...It's a lot more like drawing information out of somebody to get the information you need, rather than a conversation</p>

	<p>her</p> <p>... every conversation felt closed off, and it was difficult to communicate.</p> <p>It was like communicating with a child</p> <p>I felt like then it was easier for me to be more comfortable with her and easier for me to communicate and cater to what she needed better because I felt like she was really opened up to me and me helping her</p> <p>It made me feel like I could definitely do my job better at that point because she was opening up more and I felt she was more receptive to what I was saying. I felt like I could be more receptive to what she needed. I could get a better understanding of what she needed from her care and get a better understanding of her understanding of what was going on to make sure that I could fill in the gaps and educate her where need be and make sure she had the emotional support she needed. I felt like I could connect with her more emotionally also because she was so upset after everything. She really opened up to me and was crying. I felt like</p>	<p>Okay. Yeah. Okay.” It made me feel like he wasn’t even listening.</p> <p>Over several months he’s really become more open and he’s seems much more receptive to the education</p> <p>I don’t think he knows my name, but he does recognize me. Which is interesting. I still feel that he recognizes me, and we can still have a good rapport, and a good relationship throughout his stay.</p>	<p>I was a little frustrated. When I went in there and saw her and I panicked in relation to her behavior and her reaction. Then once it was all over and stuff, I was like, “This was silly. Why did this even happen?” It seemed a little disproportionate</p> <p>I feel like it’s also related to education level because with the older woman, her reaction to a situation was far more severe than the situation warranted...if she had had more education, perhaps that wouldn’t have been her reaction, panic mode</p> <p>That panic seems like a behavior, because children lack the life experience and knowledge to know that this isn’t the end of the world. I feel like she lacked that awareness</p>	<p>I look at it [acting maternal towards AI patients] as a good thing because I look at it more as protectiveness. I relate it to my experience because when something is happening with a patient, there’s a situation that’s changing, and I don’t feel that I’m getting the responses that I need from my resources likes doctors. Then, I feel like react maternally and protectively because I am seeing the situation, and I am my patient’s advocate. I am trying to do the best thing for them and when I don’t get the responses that I need, it’s very frustrating. I think that definitely brings out a maternal, protective quality</p> <p>Seeing these patterns, I hate to use the word ‘stereotyping’, but I feel like that would be an instinctual response. I see that this patient is Native American, I’m going to anticipate that I’m going to have communication barriers. Maybe, I need to be more aware of my communication skills with them to help facilitate effective care. Maybe be more direct. Being more direct might help. Simply flat out asking them what they need, or what they need from me, or what their goals are.</p> <p>It’s difficult to ask open ended questions, so maybe close ended questions to facilitate better—would help me understand better what they need. If I directly ask, “what do you</p>
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	<p>that was a big hurdle because then she was able to talk more frankly with me. I think that definitely helped me provide better care to her.</p> <p>Knowing that she had let me in that way and that she felt more comfortable with me, I was so touched by that. Knowing how reserved she had been before that and seeing how far she had come with me, made me feel... I was so touched that she felt close to me and comfortable with me.</p> <p>I really wanted to respect that because I could tell that it was a very difficult thing. After she had gone through that I'm sure she felt a little traumatized. She had really come a long way emotionally, I think. I wanted to respect that. I was more than happy to oblige her. I mean she seemed in a very sensitive place. I didn't wanna hurt her.</p> <p>I felt very protective and "This is my patient, please treat her well." "I just felt so protective that she get what she needed, that she was comfortable, and that she had a dignified death experience</p> <p>It's emotionally draining, the amount of patience that I have to</p>			<p>want to happen today?"</p> <p>Maybe I would get a better response than trying to make a connection with them first. Trying to go through all that icebreaking stuff first, maybe it's not necessary and it would just get in the way. Certainly, it's something that I would meet the patient and see how we're going to communication first before making a decision, but I might anticipate that I should change my communication tactics to have a better response</p> <p>As I've seen more and more Native patients and see these themes, then it seems very consistent from one patient to the next, that they have these different social needs than someone of our culture. If I can anticipate that and plan my care around knowing that, I think it would be more effective. I've learned that not from school, because I don't feel like I learned anything about that in school. I've learned it all from my experiences</p> <p>3/4 WORDS PHRASES: Educational experience. Like traveling to a foreign country. Different communication and body language. Eye opening.</p>
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	<p>exude to hide my frustration”</p> <p>It made me feel like I didn’t know how to care for this patient</p> <p>I didn’t matter what the diagnosis was. It didn’t matter who she was. It didn’t matter what her situation was. The bottom line was that she was a young woman, who had a family, and she was gonna’ die. That was all that mattered. That was no matter what the other circumstances are, that’s devastating. That’s all that mattered then</p> <p>I could attest that it was definitely a barrier to good care if she did not trust who she was with</p> <p>When we’ve been through something emotional together, and I feel like I’ve connected with somebody, and it’s definite—I don’t know if it’s a nursing instinct, or a maternal instinct, or what exactly it is, but I wanted to be sure that she was getting everything she needed</p> <p>She didn’t call me by my name. She just called me nurse the whole time. I thought that was very interesting.</p>			
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	<p>Like, 'We've gone through all of this. We really connected. We've had all this emotional stuff going on and you don't even call me by my name.'</p> <p>I saw her again, but I don't think she remembered me...she showed no recognition...there was nothing, like we'd never met before</p> <p>I was a little surprised that she didn't show any recognition at first. Then, when I started to think about it more later, I wasn't really surprised because I think it fit with everything else</p> <p>She didn't know my name to begin with, she called me 'nurse' every time she addressed me the first time we met. I thought maybe she would even recognize my face, [but] when I have spent a significant amount of time with somebody for them to not even have facial recognition... I mean if they don't remember my name that's one thing, but that she didn't even recognize my face was surprising. After all that time we spent together in comparison to other inactions with other patients who not only remember my face but know my name and all this stuff about me that we've</p>			
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	<p>talked about</p> <p>She definitely seemed to lack what we would consider social skills in our culture—I mean she had different social skills. I feel confident that it’s all culturally related...this seems to go right in line with our other experiences. How she called me ‘nurse’ rather than call me by name and she [seemed] very detached. It seemed consistent with that characteristic, that she’s just detached from what’s going on</p> <p>When I walk in somebody’s room and they remember me, I’m able to connect with them better. It helps communication, which in turn helps provide thorough care.</p> <p>When there’s that lack of connection, it makes it more challenging</p> <p>Her reaction, I think, required somebody to act maternally and protectively and take care of her. She was needing, at that time, somebody to take care of her...I feel that I was matching her—my reaction matched what I could see she needed. She needed, at that time, somebody to take care of her and be very understanding and kind and sympathetic. To me that says ‘maternal instincts’. I</p>			
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	think it's a response, you know those maternal instincts and qualities come out when the situation warrants it			
<b>Temporality:</b> “subjective time”; “appears to speed up...or slow down”; “temporal way of being in the world”; “past, present, and future constitute the horizons of a person’s...landscape”; reinterpreting the past; “perspective on life to come”	I wish I could have had more time to help her. It’s a lot more like drawing information out of somebody to get the information you need, rather than a conversation			

### Thematic Summary

**Theme #1:** AI patients' body language and physical responses feel flat, subdued, and vexing. She feels an *unsettling sense of uncertainty* about if they are listening to her or absorbing the information adequately because there is so little physical reaction. She is less adept at reading their physical symptoms, increasing her anxiety about potentially mismanaging a complication or issue and hampering her ability to effectively advocate on the patient's behalf. She in turn tries to suppress or hide her pent up frustration over this lack of bodily engagement by maintaining a professional and calm appearance even if internally she is aggravated. She experiences increased connection and comprehension when she is allowed into their physical space, which is sometimes triggered by an unavoidable caregiving act inherent to nursing.

**Essence: A vexing inability to "read" bodily messaging negatively impacts her ability to connect emotionally with her AI patients, but it is through deep contact with the physical body that she is sometimes able to transcend that void.**

**Theme #2:** A lack of reciprocity on a relational level is experienced by her as a *distancing* and *closing off* between herself and the patient. She describes an emotional void and inability to form an immediate bond related to her lack of understanding about AI culture, stilted communication patterns, opposing expectations, and perplexing behavior. Having her patients "open up" is a significant event for her; this seems to be a requirement for progression of the relationship to occur and signals that she has adequately reached them. However, at no point does she reveal her own opening up to the patient. The emotional "work" and exposed vulnerability seems to be one-sided. Yet, she is often left feeling *apart* and *separated* from AI patients despite considering *closeness* to be essential for developing a caring nursing relationship.

**Essence: Her primary way of gauging the success and depth of her caring relationships with AIs is through the patient-directed act of being 'open' or 'closed'. When 'opening' does not occur, her expectations are dashed and she is left feeling ineffective and inadequate.**

**Theme #3:** Despite the barriers between them, she experiences pronounced feelings of protectiveness and concern while striving to ensure her AI patient's physical and emotional comfort. She often characterizes her patients' demeanor as "childlike" regardless of their chronological age, symbolizing her maternal role within the dynamic. She does not view this characteristic negatively, instead associating it with safety, advocacy, and fulfilling the patient's needs during times of extreme vulnerability. Her relationships with patients are highly individualized, personal, and of a one-on-one nature. She makes very little mention of family members, external spiritual sensations, or any other entities. In her eyes, they are coupled together in the cancer care scenario with very distinct parts to play.

**Essence: Her relationships with AI cancer patients are highly exclusionary, strictly coupled, and sometimes characterized by maternalistic inclinations.**

**Theme #4:** She is baffled when her well-known AI patients fail to recognize her or call her by name, referring to her only as 'nurse'. Although she questions the meaning of this *impersonal interaction*, it seems to symbolize the doubt she has about her ability to establish the deeply emotional relationships with her AI patients that she expects to occur in order for "good" nursing care to be provided. She initially feels wounded, but perhaps as a measure of self-protection, she attributes this tendency to an AI-specific cultural oddity that she does not comprehend. The painful alternative is that her patients value their relationship in an entirely different manner than she does, causing her to feel disoriented about her assumptions and expectations.

**Essence: Feeling nameless and faceless to her AI cancer patients is alienating and disappointing, calling into question her impact and identity as a cancer care nurse.**

**Theme #5:** Her relationships with AI patients tend to improve and become more positive and fulfilling over time. Collectively, she characterizes her initial suppositions, interactions, and perceptions rather negatively, but her trepidation about caring for AI patients' lessens over time and several relationships evolve into dynamics that feel openly communicative and containing more parity. When she becomes the preferred nurse of an AI patient, it signals a *major transformation* in their nurse-patient dynamic and brings great joy and fulfillment. She has learned that a crucial component of improving these relationships is to *spend time* with her AI patients in order to build rapport, increase understanding, and establish trust. Occasionally, she finds herself wishing for *more time* –both in the sense that many of these cancer patients have terminal prognoses and also longing for the opportunity to engage in a long-term nursing relationship that is mutually benefitting.

**Essence: Over time, she learns to adjust to her patients; her own growth and flexibility leads to personal insight while altering the way she approaches care in future interactions with AI patients.**

## Participant #2

### Wholistic/Sententious Description

This RN is a middle-aged, highly experienced nurse who self-identifies as AI. Although she has been working in the outpatient oncology field for about a decade in a mid-sized southwestern town, she also has nearly a decade of experience with general medical-surgical and mother and infant care in larger, more urban areas where she was exposed to a variety of patient populations. Currently, she serves a mixed Caucasian, Hispanic, and AI community comprised of several different tribes. She lives close to extended family but far from her children, who are attending college in other states. Although soft-spoken, she speaks with clarity and great detail, requiring very little prompting. She is fluent in her Indigenous language and a slight accent can be detected. Because of her bilingual proficiency, she is often asked by both colleagues and patients to translate or otherwise act as a cultural interpreter, even with those from a tribe different than her own. Although this sometimes adds to her workload, she feels that “my role is very important” and embraces these requests as part of her job as an AI nurse.

She feels committed to her work, and her relationships reflect this sense of purpose and meaning, particularly in relation to the high incidence rates and late-diagnoses of cancer that she observes in the AI community. “I don’t feel obligated being there [in an AI community]; it’s just that I feel it’s important to be there because I could help change that and get people in the early stage [of cancer]”. She finds that their shared identity promotes a deeper and almost instantaneous relationship with her patients:

When I go into a room, I see a Native patient, immediately they want to ask me where am I from, how long have I been doing this. “It’s so nice to see a Native person come into my room.” They start sharing. They open up a lot more than they would open up to a non-Native nurse.

Her patients and their families are instantly recognizable to her, as she is to them. There is no separation between them, and their relationship is one of comfort and stability within an often tumultuous cancer journey. Instant connection is further facilitated by an unspoken understanding of time, ancestry, and place:

You understand each other and the history and your roots where you’re from, where you come from. Like in [tribal name], you’re raised by being taught who you are, to understand who you are, know where you come from. Those are the things, as a Native child, you get taught. I think most Natives have that deep understanding...they’ll say, “Yeah, but where’s your mother from”? So you go back to where your mother is, which is on an Indian reservation. I think that deepens the connection, knowing the history and knowing where you’re from...

Her ability to speak an Indigenous language is also central to the process of developing trust and connection. “I get close to them because they immediately open up to me as a Native nurse and because I can speak the language fluently”. It is clear that a sense of openness is central to her ability to establish “close” relationship with her patients as well as a strong connection between language and building trust. She describes a scenario in which a patient was willing to travel hundreds of miles just to be treated at a facility where a nurse who spoke her language worked because “...it was important for her to be talked to in the language that she would understand better. I got, from her, that [sense of] trust, too”. In another instance, she was able to rectify a negative experience for a patient by using their shared language. “His face was upset, so I approached him [and used our] language, and there, the relationship—his whole face changed to

a trusting [expression]—I could tell he was now trusting the system”. Like facial expressions, she inherently understands cultural boundaries and physical cues common to AI patients, and she uses body language to her advantage:

You just innately know that I’m not going to sit so close to you where our knees touch. I have that boundary. I understand that. I get that cue and I respect that. Then they immediately open up... I think it just helps to put your hand on the shoulder, “I am here”. It’s like, “look at me, make this eye contact, let’s work together”.

Despite the importance and rewards of this job, she also finds it to be challenging and depleting at times. “Now I understand what they mean by compassion fatigue. I am exhausted. I need to get away... I need [to] take care of myself...I needed to get back in touch with who I really am.” This feeling of fatigue is sometimes brought on by frustrating attempts at educating individual patients (“I’m tired. I have many other things to do. We go through this over and over. Maybe you just don’t want to learn...you don’t want to heal yourself”); ineffective cancer care systems (“The system is really not good for the Native patients”); or a lack of closure related to the death of a patient (“It’s like a loss, you know, that that person that we really enjoyed is now gone. We’ll never see him again. It was like I could feel [a] hole...It feels so dark inside of you”). However, every time she contemplates leaving, she is pulled back into place by patients who convey their respect, appreciation, and absolute gratitude for her, recalling an experience where “once the family understands, then yeah, I feel [the] reward, I feel like I accomplished something...Now they can go forward and then support each other...on the right path to cancer treatment.” She is exactly where she needs to be as an AI nurse. “I’m glad to be their nurse and I’m glad to be the one to explain the situation that they can be part of the healing process.” Again and again, this message (seemingly relayed from the entire universe) is reinforced. Yet she does not feel trapped; the focus is on what is best for the People rather than her own needs as she wonders, “What if I wasn’t here?”

She summarizes her relationships with AI cancer patients as being comprised of “respect” and feels that delivering “education as information” and remaining “sensitive to culture” are crucial. It’s important to her that the “whole family understands the plan” and that together, they “become a team”. She sees herself as a central part of this team, but no more important than any of the other members.

**Sententious Formulation:** Caring for culturally-congruent patients creates a relationship that is deeply committed and inherently understood, fostering belonging for nurse and an expression of gratitude from the patient.

Level One Matrix  
 Interview #1; Interview #2; Interview #3

	<p><b>#1:</b> The nurse was astounded to discover during routine conversation that a familiar Non-English speaking elderly AI woman was unaware of her own cancer diagnosis, instead believing that she was being treated for a “bone disease”. The nurse felt morally compelled to confront the diagnosis head on and in Native language in an effort to bring rectitude to the situation. She felt this experience was successful and fulfilling when the patient expressed her understanding and gratitude.</p>	<p><b>#2:</b> Potentially Important generalized quotes (not patient-specific)</p>	<p><b>#3:</b> Like the rest of the staff, the nurse had made the assumption that a long-term male AI patient and his wife understood English. During one particular visit it became apparent to the MD that both the patient and his wife possessed only a vague understanding of his treatment. Even though this was not her assigned patient, the MD requested that the nurse provide translation, which felt like both an encumbrance on her time and an absolutely crucial act for her to perform. She felt foolish for having made an assumption and seemed to want to make up for lost time with this couple, lending a sense of urgency and importance to this single visit.</p>	<p><b>#4:</b> A male AI patient called the facility to share that he was being admitted to the hospital next door; this act alone suggests his intimacy with the staff, including the nurse. She described him lovingly as “always laughing and joking” and she made the effort to visit him at the end of her shift. They spent the visit laughing and telling stories in Native language, and she walked away from the encounter feeling refreshed and energized despite it being the end of a long work day. Shortly thereafter she learned that he passed away. This was a shock to her and she tried to grieve his loss but did not find “closure”. The experience seems bittersweet and incomplete for her.</p>	<p><b>#5:</b> She illustrates the power of being culturally/ethnically/linguistically matched to a patient. She is able to improve the experience of a NA cancer patient not only logistically, but at a much deeper level once they switch to their indigenous language. He immediately opens up to her and reveals to her his frustrations and fears, and most importantly, his story. But, this experience seems to transcend language and taps into other culturally-tailored approaches to care such as deep listening and using time as an intervention to reinstate trust.</p>
<p><b>Corporeality:</b> “we are</p>		<p>Then they’ll say, “Oh, I’m</p>	<p>I sat close enough to</p>	<p>It’s like a loss, you know,</p>	<p>He was very upset. His face was upset,</p>

<p>always bodily in the world”, we meet people “first of all through his or her body”; “when the body is the object of someone else’s gaze, it may lose its naturalness”, both revealing and concealing.</p>		<p>so glad that you are here.”          Then I immediately just become part of that little circle that they guarded, just sit next to them and—even though they say, “Oh Natives, they don’t want eye contact and it’s not appropriate to directly look at them in the eye,” that is not so true. I do that eye contact. I do that touch on the shoulder, not really—me being a Native woman, you don’t really touch ‘em on the knee. It’s usually on the shoulder or just be like, “I’m here.”</p> <p>I do that eye contact. Then I open them up with that actually. I feel like they feel like, “Yeah, she does. She cares about me.”</p> <p>Yeah, it [cancer] feels like it’s a huge thing. At the same time, it doesn’t have to be.</p> <p>I can see that they’re guarding and they’re saying like, ‘we don’t like this plan, we don’t like the medication, we hear about things about chemo therapy that’ll just kill ya’ or just kill us...the</p>	<p>look at the wife and say—talk to her eye to eye and then look at him and say, “This whole time that I’ve been treating you, I had no idea that you didn’t understand this.”</p> <p>He’ll look at me, and this is kind of like a boy, but that’s okay and my eye is still with him. That helps him know that, “I care about you.”</p> <p>I’m still in that eye contact, so therefore, he doesn’t evade my question. He’s trying to but then he looked back at me and he told me, “Yeah, I didn’t really understand where my cancer was. I knew I had cancer, but I didn’t know where it was.”</p>	<p>that that person that we really enjoyed is now gone. We’ll never see him again. It was like I could feel the hole.</p> <p>I kept looking outside and I wanted to see the sun. I want that sunlight. I want that sunshine. It feels so dark inside you. That’s how it felt.</p>	<p>so I approached him</p> <p>Then it turned into [tribal name] language, and there, the relationship—his whole face changed to a trusting—I could tell he was now trusting the system to where, before, when I saw him he mentioned that, “Maybe my skin’s too dark. They didn’t see me—,” that kind of response</p> <p>After I was able to connect with him and then answer some of his questions, then his whole face changed. He felt comfortable, and no longer was he upset that he’s now going to drive 180 miles in the afternoon to go home. All of a sudden, all that changed</p> <p>I was able to see him physically relax and become more comfortable. His facial expression changed, and he asked more questions and told more stories</p>
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patient's actually suffering.  
She's gonna die'.

I'm the one who starts to feel uncomfortable, but she gets too close to me. She starts to cling onto my arm...I feel uncomfortable with that. Then I have to get her hand and unlock her arm and then put her hand back on her or her purse...I'm talking to her about something else and I put her hand back with her purse or whatever that she has. Me, I got too close, but to her it's like, 'that's my friend, that's my friend, I need her today, you're gonna interpret for me, I'm gonna cling onto her'. Yeah, she gives me that feeling

They didn't want to look at you in the eye. They kinda look away from you. Then I know that—so you just innately know that I'm not gonna sit so close to you where our knees touch. I have that boundary. I understand that. I get that cue and I respect that. Then they immediately then open up.

I think it just helps to put

		<p>your hand on the shoulder, I am here. It's like, look at me, you know, make this eye contact, let's work together.</p> <p>At the same time, I felt, from this guy, that—how would I say it? The trust that a Native woman is going to touch and draw your blood—that idea, I could almost feel that from him, that trust and that touch from a non-Native—I almost felt that that's what he meant</p> <p>As a Native woman, you have that eye contact with the husband, the wife, the son, taking their hands, and right away, they feel, as a group, you're connected. Now, we're connected. We're all in this room. [They feel] "She identified herself by shaking our hand, acknowledging each family member." Then everybody puts their heads together. I think that's what they really like. It's just a natural for me to do that</p>			
<p><b>Spatiality:</b> "felt space"; "inquiring into the ways we experience spatial dimensions of our day-to-</p>		<p>I felt like, "Okay, I am in the right place here, a nurse."</p> <p>Then it helps me to—</p>		<p>I kept looking outside and I wanted to see the sun. I want that sunlight. I want that sunshine. It</p>	

<p>day existence”; “we become that space that we are in”; “world or landscape in which human beings move and find themselves in”.</p>		<p>because I’m close to the reservation, I’m close to my mother’s house, I’m close to the people there, and then they have these ceremonies in our culture to help. It’s not really for me, but I’ve attended them to help myself.</p> <p>I want to be there to really—in the center of the reservation to educate, to be the one to be making that change. How do I do it?</p> <p>...when I leave the room sometimes, yeah, you feel like you want to take a break now, you want to go and sit down somewhere and forget about it and recoup and then go back to the infusion room. Yeah, that’s how I would feel. I just wanna get away from that infusion room for a while. I take the long walk—the long hallway back. I don’t take a shortcut...kind of hide out</p> <p>The other thing is just that understanding of where you’re from, like from the Indian reservation. Basically, that’s where your roots are, and I think that’s just</p>		<p>feels so dark inside you. That’s how it felt. [ALSO CORPOREALITY]</p>	
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		<p>understanding who you are and where you're from...</p>			
<p><b>Relationality:</b> “relation we maintain with others in the interpersonal space that we share with them”; “develop a conversational relation which allows us to transcend ourselves”; “human beings have searched in this experience for the other, the communal, the social”</p>	<p>Then, when I realized, after a couple of weeks of being here, that my role here is really, really important, especially to explain to a non-English-speaking woman—my first question to her was, “Where, how long ago did you find out that you had cancer?” She said to me, “What are you talking about cancer?” Then I thought, “Did I overstep my line? Was her family not wanting to tell her?” At the same time I was thinking, as a nurse my role is to help this woman understand why she’s here.</p> <p>I explained to her what her situation was. I asked her, “Do you want to know what you are really here for?”</p>	<p>I get close to them because they immediately open up to me as a Native nurse and because I can speak the language fluently</p> <p>Sure enough, when I go into a room, I see a Native patient, immediately they want to ask me where am I from, how long have I been doing this. “It’s so nice to see a Native person come into my room.” They start sharing. They open up a lot more than they would open up to a non-Native nurse.</p> <p>I’m glad to be their nurse and I’m glad to be the one to explain the situation that they can be part of the healing process. That’s what I’m really—I’m glad to be here for, to let them know that they can also take part in their healing.</p> <p>There’s that power of your mind and that’s what I share with them because the Native to Native, we understand that, especially with our tribe. You don’t want to think negative about</p>	<p>I’m being careful not to scare the wife at the same time.</p> <p>...she did almost start crying and she said, “I’m so glad that you’re here, because he wasn’t gonna come today. He said, ‘Oh, let it kill me. I will not do it no more’...I felt like, yeah, I’m glad to be here too.</p> <p>When I get to that point where, “Okay I’m gonna leave now. I’m gonna put in my resignation,” and this happens again. He wouldn’t have come and he would have just let this take over.</p>	<p>When I got to his room, he was happy to see me and then just started to tell stories and joking and we were laughing. We were laughing.</p> <p>It was so much fun. It’s relief. It kind of helped me dealing with patients all day long and then to go on to him and feeling like, okay, he’s gonna be sad, but actually he was laughing till—that was good. Yeah, I thought, ‘I’m glad I stopped by. I needed that laughter.’</p>	<p>He looked at me and he said, “Are you [tribal name]?” I said, “Yes,” and then he told me why he was upset... Then he said, “I’m really upset. I think they forgot about me.”</p> <p>Immediately, he asked me, “Where are you from, what is your clan?” Then he started asking me [medical] questions, “This port-a-cath, how does it look? What is it made of? How long will my treatment be? I didn’t understand that from the doctor.”</p> <p>Afterwards, I felt that, “I’m glad I spoke to him,” and, now, he went home totally understanding. I’m feeling from him that this experience is really bad.</p> <p>It’s getting worse. [He thought] “I think I’m not going to come back or I will skip the treatment or just ask for other alternatives”</p> <p>I showed him, and then speaking the language, and we had already identified who we are, where we come from, what our clans are. He opened up, and then he talked to me how he had been bleeding, that he didn’t know for six months that he was bleeding. He didn’t realize what was going on</p> <p>What it means to me is that my role is very important...that experience yesterday made me feel, “This is very</p>

	<p>She said, “Absolutely.” I told her, “You have this cancer in your bone marrow. I’m wondering if your family understands that.” She said, “I don’t even know. . . .she really appreciated me telling her what that situation was.</p>	<p>yourself. You don’t want to think that, “Okay, the doctor said I’m not gonna make it. Okay, I gotta prepare.” I’ve seen Native women overcome that.</p> <p>I see that mistrust and these are the kids that are educated. They can speak English but I feel that mistrust to that doctor or the whole cancer center.</p> <p>It is a lot of work, a lot of detailed information so that they can understand and I feel like I gotta do it at the beginning...yeah, it is quite a lot of work. I’m feeling like it’s a big job.</p> <p>Then once the family understands, then yeah, I feel [the] reward. I feel like I accomplished something. I gave this whole group of family an understanding. Now they can go forward and then support each other. That feeling of that affection that I got the family on the right path to cancer treatment.</p> <p>I know enough not to just dwell on that [death of a</p>			<p>important work I’m doing. What if I wasn’t here?”</p>
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		<p>patient], but it does, into your mind and then you just kinda like let it go. I just wanna know the ending. That's all. Then I feel like then I will feel at peace with that person... I think that's what I yearn for.</p> <p>Occasionally I'll yearn for that. I wanna be at peace, the attitude. I'm not part of the family, but I want that closure too.</p> <p>I'll feel like I've now entered that family circle and they immediately feel like, okay, you're gonna take care of us, we trust you now because you know what you're talking about it, you explained it to us and that'll help cuz we totally trust you. That connection that you feel from them, and then I feel like, but I don't wanna get too close. I feel like that sometimes. I didn't mean to get too close, but here I am in the circle now and we're all speaking the same language.</p> <p>"Oh my God, everybody's asking for you," meaning the Native patients. Then I surprised myself, my</p>			
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response to that. I turned my phone off. I forward all of it to the reservation. I barely came back into civilization this morning, I don't wanna hear about it...I surprised myself.

Now I understand what they mean by compassion fatigue. I am exhausted. I need to get away, so I did... I need to be away. I need me. I need myself, take care of myself...I needed to get back in touch with who I am, who I really am.

I could feel their spirits just like, aww, I'm so glad you're gonna be my nurse. Immediately I just feel that connection right away.

I can't describe it. It's like you just have that understanding that—it's a nonverbal. You kind of know. You read each other. I think that's what it is.

I'm tired. I have many other things to do. We go through this over and over. Maybe you just don't want to learn...you don't want to heal yourself

...sometimes those can frustrate me and then some would get too needy and I just wanna get away.

...sometimes I feel like I don't deal with this no more. I don't wanna be a chemo nurse no more. The system is really not good for the native patients. The drug companies do not understand...

You understand each other and the history and your roots where you're from, where you come from. Like in [tribal name], you're raised by being taught who you are, to understand who you are, know where you come from. Those are the things, as a Native child, you get taught. I think most Natives have that deep understanding...they'll say, "Yeah, but where's your mother from?" So you go back to where your mother is, which is on an Indian reservation. I think that deepens the connection, knowing the history and knowing where you're from...

The next question is, “What is your clan?” That clanship is that deep, rooted connection

I don’t feel obligated being there [in a NA community];it’s just that I feel it’s important to be there because I could help change that and get people in the early stage [of cancer]

That’s what I’ve been hearing lately. “Oh, we heard about you, that you speak the language, so we came this way.” She said, “No, I heard about you, and I want to be there.” What I get from that conversation that I had with her, was that it was important for her to be talked to in the language that she would understand better. Then the trust—I got, from her, that [sense of] trust, too

There’s another cancer patient that’s going to come here and who wants to try to beat cancer and that she’s going to join us, and as a team, we’re going to help her

It goes back to the roots, knowing where you're from and knowing who you are, and then the trust develops right away. This woman knows who she is. She knows where she's coming from. She knows her clan. She knows what she's doing—that trust

I'm not the only one to do this. I don't take every Native patient because I know if I did that—if I do that, I'll be burnt out. I've learned to delegate. I've learned to know when it's my limit

After a few months working there, I was trying to tackle everybody, and then I noticed I was getting burnt out. Over time, I learned that it's okay to say, "No, I can't do that right now. I can't take that one right now. I'm sorry. You might want to get interpretation, but my hands are full." Then maybe the next time, I might be able to get that Native person...I've learned to be comfortable with that, and it's okay

3-4 WORDS/PHRASES:

		<p>Respect. Education as information. Sensitive to culture. Understanding the plan. Whole family. Becoming a team.</p>			
<p><b>Temporality:</b> “subjective time”; “appears to speed up...or slow down”; “temporal way of being in the world”; “past, present, and future constitute the horizons of a person’s...landscape”; reinterpreting the past; “perspective on life to come”</p>		<p>I ask questions about way in the past 1940s and ‘50s, that’s probably when we first named “cancer” in [NA language]. I wonder before then if they had—what words they had used. Nobody knows.</p> <p>Even though I’m away from cancer treatment and patients, I found myself wondering, my mind wandering off.</p>	<p>This is a guy who’s been coming over the years and is seeing the doctor by himself, so everybody, even me, assumed that he totally understood everything.</p> <p>Then I had to go back and say, “Okay, let’s step back. Let’s start from the beginning...From the time you started coming, what did you really understand? Did you understand that you had cancer?” Then he said, “Well yes, but I didn’t understand where the cancer was.”</p>		

### Thematic Summary

**Theme #1:** Her perceptions of her relationships with AI cancer patients are almost completely defined by their shared ethnicity. Her approach to communication (verbal and non-verbal), methods of delivering education and care, and understanding of her patients on both a day-to-day and deeply existential level is completely viewed through her own “Native lens”. Just as she is inseparable from her own identity and heritage, so are her experiences and subsequent relationships with this particular patient group. She uses this “sameness” to her advantage, seeing it as a significant benefit to building a mutually open, trusting, and even rewarding relationship. She observes that many AI patients open up and are less guarded with her compared to other non-AI nurses/staff; this reinforces for her that despite the challenges inherent in this type of work, she is in “the right place” not just as a nurse, but as an *AI nurse*.

**Essence: She is beholden to this community, tapping into their sameness and shared identity to forge connection and create a feeling of being at home for both her and the patients. She intrinsically understands their collective (traumatic?) pasts and the communal present moment at a level that transcends explanation but gives her great purpose.**

**Theme #2:** The centrality and embedded meaning within indigenous language plays a prominent and profound role in her relationships. It is a connector, an immediate and identifiable sign of a shared history and a common ground. It facilitates trust through its very use, but also has its limitations in the biomedical world. She experiences difficulty in bridging that gap, having to repeat and redefine terms and procedures. Her colleagues and even herself sometimes make false assumptions about an AI patient’s level of comprehension. At times, she uses metaphor and story to convey meaning in either language, which can be an extremely satisfying and fulfilling experience as expressions of comprehension and trust appear on her patients’ faces. At times there is an increased burden placed on her time and workload as the only bi-lingual nurse on staff, but she does not seem to resent this added responsibility, choosing instead to embrace her skills.

**Essence: Indigenous language creates a literal and symbolic bridge between nurse and patient, which is both a gift and an accepted burden. Providing clarity and confusion, language creates an enigma that she must content with mostly alone as a Native-speaking nurse.**

**Theme #3:** She uses multiple methods to convey her caring intentions to patients: non-verbal techniques (specifically, light touch and eye contact), humor, and presence. All play significant roles in conveying meaning, clarifying confusion, establishing rapport, and building a sense of collaboration and togetherness. She found one patient’s own sense of humor despite his terminal circumstances to be healing *for her*. She intuitively senses when to apply any of these approaches within gender and age-specific cultural confines; they are tools that make her better at the “work” of building trusting relationships within cancer care as well as garnering her patient’s attention when something crucial needs to be conveyed. These tactics also involve and integrate the entire family into the patient’s journey.

**Essence: Connecting through touch, eye contact, and presence builds trust and collaboration, allowing her to convey deeper meaning and to create fleeting moments of healing for herself.**

**Theme #4:** She recalls past bouts with “compassion fatigue” and is “surprised” at her own annoyance with being needed so desperately by AI cancer patients and families on such a continuous basis; she is “exhausted” in every way. She is cognizant of how rare she is (an indigenous language-speaking, experienced oncology RN); this is both an encumbrance and an honor, creating a constant tension between responsibility and self-preservation. She often feels appreciated and “in the right place”, but lacks “closure” with many patients who pass away or disappear from care. She searches for ways to keep herself whole and healthy. This is an ongoing struggle, but it has eased over time as she recognizes more and more signs that she is exactly where she is meant to be.

**Essence: Although at times her work and relationships deplete her at the bio-psycho-social-spiritual level, requiring her to step back and replenish herself periodically, there is great honor and purpose in serving the AI community that ultimately overrides any sense of exhaustion or defeat she may have.**

### Participant #3 Wholistic/Sententious Description

As the sole retired participant, this RN brings a more reflective and sometimes wistful tone to her interviews. She is a petite woman of Asian-Pacific Islander origin who still carries a distinct accent from her first language, which she continues to speak with her husband and adult children. She has been a nurse for several decades, nearly all of it spent in a single AI community. Despite retiring several years ago from a cancer care-coordinator position on a semi-rural reservation, she has remained in close contact with community leaders and several specific patients and their families. A relentlessly optimistic and pleasant person, she was diagnosed with cancer towards the beginning of the interview process and completed treatment by the conclusion of the study in remission. This event is important to acknowledge as it has a significant impact on how she not only views cancer, but also her interpretation of past experiences and ongoing relationships with AI cancer patients. It seems to have affirmed her spiritual beliefs and deepened her connection with several AI patients who were also in treatment at the same time she was.

Her relationships with AI patients are most directly influenced by her spiritual orientation with a focus on altruism and service. This is especially important to her because AIs have “always been classified as underserved”, indicating that she has a moral impetus to serve this population. She explains, “I always believe that humanity is helping each other. Life is helping each other, serving one another “and, “because of my faith, this [other] person is holy”. She has made a conscious effort to erase the boundaries and differences between herself and her patients, instead choosing to focus on how their likeness unites and binds them together as people:

[An AI person] is just like me. This person has the same fears, the same aspirations in life. It's the whole human emotions and the whole gamut...I will feel the same. This person will feel the same thing the way I feel it. It may be on a different level or whatever, but I said, "It's a person. This person is just like me." I said, "You look at their eyes... you look at yourself in the eye and...they're looking at themselves in my eyes when we look at each other." I said, "What's the difference?" It's nothing. It's actually this person feels the way I feel.

This moral and ethical positioning is apparent throughout many of her recalled experiences. Seizing upon their similarities creates a feeling of belonging and recognition that is important for connection to form. Yet she is also aware that despite their shared humanity, she is a guest on tribal lands. “Even if we’re healthcare workers here, we’re like visitors...because we’re not a member of the [tribe], and we are here to work for them.” This position does not seem to diminish her ability to forge close bonds through intimate conversation (“counseling sessions” where faith and hope are discussed in detail) and by responding to bodily cues. With one terminally ill patient in particular, she felt physically attuned to her emotional needs, recalling,

You can sense that she just feels so distraught and all that stuff. I felt good that I was able to see her instead of just talking. On the phone you sense that there’s a lot of loneliness and sadness there, but when you see them physically, there’s more to that...It’s like being able to connect with each other.

She goes on to clarify, “it’s more than talking that they need. It’s your presence, your physical presence”. She seems to find this bodily connection to be important for conveying comfort and support during cancer care, but it is also reciprocated by the patients. “It’s just sometimes so

unexplainable...they're just able to express [themselves] when they come to you and they give you a hug.”

In addition to her spiritual orientation, she approaches her care of AI cancer patients from an internal locus. “To me, [it’s important] to have a heart and to have respect. I mean those two, I think they come together [when you’re] really working with them sincerely”. This heart-centered and respectful approach seems to be particularly appreciated by the community and personally fulfilling for her. “They always remind me about that, “You do it with your heart.” I guess they mean something with that... [When] we put all our heart into our work, we get something back out of it. We learn from them.” She seems to suggest that not only does an exchange between patient and nurse occur during a relationship, but also that something meaningful and enlightening is gained from the interaction.

As her own cancer journey unfolds, she is overwhelmed by the outpouring of support, concern, and love from her former patients. Their shared diagnosis seems to change the tone of their relationships. “Although they were open before, now they consider me as their friend and somebody who has experienced...what they have experienced, and [gone] through the journey that they went through. It’s more like we’re in the same club.” She finds reassurance and strength in her patients. “I still have fears, being human, but they are my greatest support now. They’ve organized prayer groups...It’s so comforting.” This scenario feels completely natural and unsurprising to her as she had already come to know the warm embrace of this community long ago. Sharing this disease has bound them together at a profound level as well as increased her capacity for empathy as a nurse; there is now a level of understanding between them that transcends words. “The side effects and all that stuff—I would be a lot more compassionate and more sympathetic and more empathetic... [Our relationship] has changed. There’s a deeper understanding.”

Where others see dysfunction and despair in AI communities, she finds potential and hope among both individuals and the community as a whole. With a smile, she shares, “there are so many good things happening in the community that the outside world—or the non-Indian world—is so oblivious about.” She feels compelled to participate in this study because ““If you are going to work with them, be interested with the people and the whole community as a whole, their cultures and traditions, because at [that] point, you’ll be able to bridge two worlds.” She offers further advice:

My message to anyone who is working with the Native Americans is if you’ve never had the experience and you’re thinking about doing it, just jump into it and have that openness to learn about the people, to know about the people. It makes it a two-way path. Both of you, each one receiving something -giving and receiving- is more of what’s happening. It’s a very priceless experience. You cannot put a price to the years or months or whatever length of time that you work with the Native Americans because they are unique. Yes, they are people, yet they are unique. They have their traditions and culture and stories to tell.

She summarizes her relationships with AI patients as “a blessing” and “special”, and shares that her continued work in the community has “become my ministry”.

**Sententious Formulation:** Nurses access their patients at the deepest level by erasing the boundaries between them and cultivating a relationship built on humanistic love.

Level One Matrix  
 Interview #1; Interview #2; Interview #3

	<p>#1: Prior to her work in the cancer field, the nurse spent 12+ years as a nurse researcher with the same tribe, allowing her to familiarize herself with many of the people, places, and cultural aspects. During this time she was mentored by a tribal member but found it “easy” and “natural” to connect with AI people, signifying her overall positive interpretations of her experiences. She began seeing former research participants appearing to her as cancer patients, which proved to be a somewhat disturbing yet also ordinary experience.</p>	<p>#2: The nurse describes a middle-aged AI female cancer survivor whom she had a close and supportive relationship with during initial treatment. The nurse arranged for her to attend a cancer support group. Later, the patient developed widespread metastasis, which the nurse found it to be both a saddening and inspiring situation. These contrasting sensations were amplified for the nurse after her own cancer diagnosis when the patient was able to return the gift of support and encouragement.</p>	<p>#3: A middle age AI man with a terminal cancer diagnosis was brought to the nurse’s attention through the community network. She found him in a rehab/hospice setting that he detested. He requested to go home for hospice and she felt deeply compelled to honor his wishes; she immediately went to work arranging the logistics and negotiating familial conflict in order to make this happen. Looking back, she feels proud of this experience and is satisfied that she fulfilled her obligation to honor the individual.</p>
<p><b>Corporeality:</b> “we are always bodily in the world”, we meet people “first of all through his or her body”; “when the body is the object of someone else’s gaze, it may lose its naturalness”, both revealing and concealing.</p>	<p>If they’re talking to you, they’re not going to look at your face.</p> <p>...they know that [cancer has] been there. They know that it's around. It's just pulling them out, drawing them out, to really accepting it as it is... Getting it out of the chest.</p> <p>Then they were telling me—they said, "Somebody's new and they don't know you. In time, when they start knowing us better, a handshake to us is like extending our self to them and knowing us better. Then they would always say, "With you, it's not a handshake. We hug you when we hug each other. That's different because you fully well understand us, and you've been just so involved in us."</p> <p>When you find that niche in the work that</p>	<p>She was telling me, “I really, really want to talk to you.” You can sense something like an urgency or— you can feel like it’s more than talking. It’s like you need to be there.</p> <p>...you can feel something. It’s just that—it’s more than talking that they need. It’s your presence, your physical presence, or they need the one-on-one thing.</p> <p>Okay, there was really that urgency. She thinks that it’s something different. It’s different this time. She can feel it. Life is ebbing more.” I said, “Well, I’m glad I found you. Here you are.” No mention of, “Oh, I feel so sorry for you,”</p> <p>You can sense that she just feels so distraught and all that stuff. I felt good</p>	

	<p>you're so passionate about, you just go for it. Okay, I'm retired. But still there's that aching in your heart. There's still that, "Well, I need to do this." I said, "I think we would be able to do it if we have the right people, if we just touch the right people in the community." It'll take time. I know it takes time.</p>	<p>that I was able to see her instead of just talking. On the phone you sense that there's a lot of loneliness and sadness there. But then when you see them physically, there's more to that...It's like being able to connect with each other</p>	
<p><b>Spatiality:</b> "felt space"; "inquiring into the ways we experience spatial dimensions of our day-to-day existence"; "we become that space that we are in"; "world or landscape in which human beings move and find themselves in".</p>	<p>I would always encourage them, or we'd go on—we would go to the community cancer center and—anything, just so they would come out of the reservation. There's a world outside of the reservation, which makes them feel better. As a person, I would like to feel better too.</p> <p>...if we are going to work in the Native community, if you are going to work with them, be interested. With the people and the whole community as a whole, their cultures and traditions, because at [that] point, you'll be able to bridge two worlds.</p> <p>It's [talking circles] holy ground for them.</p> <p>It's not just the patient that you're dealing with now. It's the whole family setup. The environment. You get to see how they live, where they live.</p> <p>I'm still myself, but when I work with these people, it seems like their world and my world—I mean their beliefs and my beliefs were—it just came together. I was able to understand them better. Although I had some kind of hesitancy at first, but once I understood them, here they are meeting me.</p>		<p>I said, "You know what?" Now that we found you, we'll make sure...that you are [moved]"—and he hated the place. We got that working and started calling people. I said, "We'll move you out because you hate this place."</p> <p>He wanted people to come and visit him, so he got his wish. Anyways, I was able to work with him for several months. Let me see. Then it was getting close [to death]. He said, "You know what? I want to die at home. I want to go home." I said, "Okay...You want to go home. You want to die there."</p> <p>I said, "What can we do for him? He deserves this kind of service, and I know that as a community member, as a Native American here—that's an important thing, to go home."</p> <p>It completes his journey. To me, it's a complete journey. Although we found him much later, but I think the last few weeks that we took care of him, somebody was there that he could—what do you call it—he could depend on.</p>

	<p>We are meeting in the middle, and we just embraced each other, understanding each other.</p> <p>I said, "You guys are lucky you can bridge two worlds."</p> <p>Our world is closing in. It's getting smaller and smaller. The more you understood about other cultures, it's a lot easier to live with each other. That's the way I look at it. Trying to respect one another and being tolerant. It doesn't mean you have to be tolerant about their violent tendencies, but if you understand them deeply or why they're acting this way.</p> <p>There are so many good things happening in the community that the outside world—or the non-Indian world—is so oblivious about. To this day, I still want to write a book about my experiences</p>		
<p><b>Relationality:</b> “relation we maintain with others in the interpersonal space that we share with them”; “develop a conversational relation which allows us to transcend ourselves”; “human beings have searched in this experience for the other, the communal, the social”</p>	<p>It was a continuous thing, a continuation of the trust relationship that we had. For me, it was easy.</p> <p>To me, it is not just dealing with their—dealing with their disease, it’s about the person. To me, the disease is not just them. I’m looking at this person. This person is just like me.</p> <p>...this person feels the same way as I do. I mean...she has all the potential as a person, just like me. They could have gone to school just like me, but because of circumstances, because of their cultures and</p>	<p>It makes you feel so sad that she’s worsening, and—but then you carry on. When you go visit her, you try to be empathetic...</p> <p>Sometimes you give [her] a call, just, “Hey, hi. How you doing?” Then she would say, “Oh, it’s so good to hear your voice. It’s so good. You just made my day.”</p> <p>“You have gotten so strong on death.” I said, "You have such a story. You have such a journey to tell." I said, "Here you are, and you should be an inspiration to</p>	<p>We got all his friends to come and visit him. He was happy about that. [It] was not like he was thrown away or alienated...During his waking times, he used to wonder—he was so depressed—wondering, "Nobody visits me. Does anybody care or love me?"</p> <p>You've done something for a person. I think he died happy because his wishes were...They were honored. To me, to be able to help someone—it's just a good feeling to be able to make that—for a person to make that transition and complete his journey. It's a fulfilling feeling, that you're able to help someone. As nurses, we know</p>

	<p>traditions, it's different.</p> <p>It's like, 'if I open up, I'm sharing myself. Will I be able to trust this person?' There was a lot of—what is the word—there was a struggle inside of them to really open up, until you reach that point when, I think, part of your relationship...has been established. You may not be able to get it in the first few weeks or months that you've been with them, but it's—the longer that you are with them—it's the continuity.</p> <p>"...don't feel bad, because you're new, they're not going to trust you."</p> <p>...even if we're healthcare workers here, we're like visitors...because we're not a member of the community, we are here to work for them. We are here to work with them.</p> <p>I experience that fear with them, so I know there's a lot of fear [about cancer]. I'm experiencing it myself right now, now I know. I'm able to relate better now, because of my health issues myself.</p> <p>I'm close to them. To me, personally, it's become my ministry.</p> <p>To me, it is such a...grace and a blessing. As a nurse, with my experience, I would say I just found it so—just a great experience for them to be telling me—sometimes we would not even talk about the cancer, because they're worried about their son who</p>	<p>all your community members and to your family members. You have so much to tell and how you're dealing with it."</p> <p>Now she's the one giving me all the support, so we give each other—it's like a relationship now that we are going through the same thing, but I said, "You've gone through more than—I'm just starting"...I could better understand [her] now with what I'm going through. I said, "Oh, my god." I said, "I could clearly relate to [her] now, all the fears that she had." Because although I know what's going on with me, reading and everything, I still have fears, being human, but they [her patients] are my greatest support now. They've organized prayer groups... I feel so comfortable with that. It's so comforting.</p> <p>I said, "You are so strong," and I said, "You are my role model. I wanna look up to you, and here we are."... She liked that. She was quite happy, being able to give me positive vibes also.</p> <p>Now my connections with my [AI] peer is more as a person who has gone through the same journey with them or experience</p>	<p>we're always trying to help.</p>
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is in jail...

What they're getting from you, and what you are getting from them...you create a very solid relationship, and with that solid relationship with them, you are able to put your—the *all* of you.

It's something that you do, really want to do for others. To me, that's ministry...It's so enlightening and so—it's refreshing to the soul all the time.

To me, to have a heart and to have respect. I mean those two, I think, to me, they come together. To have a heart, really working with them sincerely...

Make them feel hopeful because there are others in the family, the community that will provide a support for her. It's to make cancer is not the end of everything. Having cancer is not the "That's it. We're going to die right away." No. I want them to have hope during the times that—who knows how many weeks, how many days, weeks, or months? They still have life to live. I want them to be hopeful for that and live life the way it should be. Just providing them hope to still have quality of life, to still be able to live in a most normal way, except there are times when you will be sick, of course, but you will be able to go through that, ride that. It is part of having that illness.

With them being so spiritual themselves, so

	<p>in tune with nature...we embrace that. We embrace that kind of relationship. Actually, it was very exhausting. Really. Because you're dealing with patients whose emotions are already down...I felt exhausted emotionally, physically.</p> <p>There is that common feeling—I don't know. It's just sometimes so unexplainable... Sometimes it is just—they're just able to express it when they come to you and they give you a hug.</p> <p>It's almost like now it's complete. They have embraced me. We're all part of the club</p> <p>"Look. Your Native American God is also the same as my God."</p> <p>Because he is just like me. This person has the same fears, the same aspirations in life. It's the whole human emotions and the whole gamut...I will feel the same. This person will feel the same thing the way I feel it. It may be on a different level or whatever, but I said, "It's a person. This person is just like me." I said, "You look at their eyes... you look at yourself in the eye and...they're looking at themselves in my eyes when we look at each other." I said, "What's the difference?" It's nothing. It's actually this person feels the way I feel."</p> <p>I think in health care now, we've gotta see the person, not whatever race or whatever you are... I just feel it's so special to work with these Native Americans.</p>		
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Because of my faith, this person is also holy...It's a holy person that you're dealing with. The very first breath that human kind got is the same—there's a line of the breath that we all have now. The very first breath that our Creator gave to Adam and Eve, it's the same breath that—it's a long, continuous breath that we're all breathing, so this person is just like me. I said, "I look at this person because we are equals. We are the same." A person may be taller or bigger or whatever than me, but it's a person.

As long as there's life—to me, as long as there's life, there is hope...working with patients...you always want them to be hopeful. Sickness or illness or anything terminal is not—to me, I don't believe - really terminal.

Although they were open before, now they consider me as their friend and somebody who has experienced almost similar to what they have experienced and going also through what the journey that they went through. It's more like we're in the same club.

First of all, I'm not a member of the tribe. While I was there working with them—I was doing everything with them—they still look at me as a professional...But after retirement, like I said, there's more friendship and there's more connection and sharing

	<p>They always remind me about that, “You do it with your heart.” I guess they mean something with that. It’s just coming to work and doing what is right and making sure that I’ve given attention to a lot of them.</p> <p>First of all they’ve always been classified as underserved. We put all our heart into our work, working with them because we get something back out of it. We learn from them.</p> <p>I thought they would never be accepting of other faiths, but they incorporate everybody. That worked really, really nicely and easily for me because we’d talk about our spirituality and all that stuff in small counseling sessions and small visits. Strengthening your faith will help healing in some way because you’re fully convinced that spiritual God that we all believe in, he’s our healer. He’s our ultimate healer. Believing in that will really help us heal. That was very strong. I truly believe when people talk to other people, they really look into each other’s eyes because they’re human creatures out there</p> <p>We’re all one. As humans, we’re all one regardless of our color of skin. I could look at this black kid. He’s the same as me. Humanity is just one. I strongly believe in that. There should not be any if’s or but’s...I always believe that humanity is helping each other. Life is helping each other, serving one another</p>		
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	<p>It's like peeling onions. I said, "Oh, I would be able to live with these people," after showing some signs that we're similar in so many ways...It was very comforting. Those ideas were so comforting. I guess working with the Native Americans, it would just be the same with any race or any whatever. As long as you get to know them, then you try to adapt or to adjust your own thing. I'm sure they would be doing the same similar thing. If they come our way they would try to adjust or to adapt to our ways</p> <p>The side effects and all that stuff—I would be a lot more compassionate and more sympathetic and more empathetic. I'd put more effort to make them feel more comfortable, to make them feel that it's okay but we just have to keep working at it...I feel more empathetic towards them. It has changed. It's now deeper There's a deeper understanding</p> <p>My message to anyone who is working with the Native Americans is if you've never had experience and you're thinking about doing it, just jump into it and have that openness to learn about the people, to know about the people. It makes it a two-way path. Both of you, each one receiving something—giving and receiving is more of what's happening. It's a very priceless experience. You cannot put a price to the years or months or whatever length of time that you work with the Native Americans because they are unique. Yes, they are people, yet they are</p>		
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	<p>unique. They have their traditions and culture and stories to tell.</p>		
<p><b>Temporality:</b> “subjective time”; “appears to speed up...or slow down”; “temporal way of being in the world”; “past, present, and future constitute the horizons of a person’s...landscape”; reinterpreting the past; “perspective on life to come”</p>	<p>To me, it [attending a talking circle] was a moment of meditation...so I said, “You let them pray.” This is their time to pray.</p> <p>A lot of times you just—you just be in the moment with them. Just let it be whatever—because this is their time...</p> <p>I have already done some crying with them at my office so I just sit there and just listen, just being there, being present.</p> <p>Now they look back and they feel better because they're able to understand it [cancer] a little bit better, what they're going through, than compared to three, five years ago, ten years ago, when a family member was going through it and they were just—no clue what it was. They were lost who to approach.</p>		

### Thematic Summary

**Theme #1:** She describes strong spatial sensations of her AI patient's worlds integrating and intermingling with her own, often in profoundly meaningful and spiritual ways. She is deeply cognizant of the distinctive nature of life on the rural reservation and how this physical and cultural space shapes and isolates her cancer patient's experiences or "journeys" as well as her own. She has the sensation of being a "visitor" on Indian lands, yet found it "easy" to integrate AI beliefs, traditions, and preferences with her own as she finds them inherently compatible. This is hugely comforting, causing her to feel a sense of belonging and sameness. When asked what happens when the two worlds collide or are found to be incompatible she was largely unable to articulate any response, choosing instead to hyper-focus on the ideal "fit" between herself and this community.

**Essence:** She seamlessly meshes her world with that of her AI patients on a spiritual level, creating a "middle ground" where caring occurs while finding this experience to be deeply satisfying and comforting.

**Theme #2:** She looks into her patients' eyes and sees herself; reversely, she supposes that when they look into hers they see *themselves*. This act of conscientious mirroring is very much tied to her spiritual foundation and resides at the center of her way of being in the world. Pragmatically, she relies on this perspective to guide her care delivery, striving to deliver the type and quality of care that she would want for herself if placed in her patient's shoes. She recognizes her own vulnerabilities in her patients and this is somehow comforting to her, especially when she observes them thriving and remaining hopeful despite their terminal prognoses. This is especially poignant as she completes her own cancer journey, heightening her awareness and deepening her ability to empathize to the point where words are no longer needed to describe their shared suffering and joy.

**Essence:** Through a shared intrinsic sacred humanness, the boundaries and differences between individuals are erased while calling forth our inescapable bond to one another, particularly during times of illness and vulnerability that transcend words and are simply felt with the heart.

**Theme #3:** She develops long-term relationships with patients and families to the point where they began to "give back" to her, offering support (prayer, laughter) and even physical connection (embracing) during her own difficult health diagnosis. She readily and eagerly accepts this sustenance, finding it uplifting and engendering a sense of belonging to both place and community. Rarely do nurses acknowledge their reliance on patients for emotional, mental, spiritual, and even physical support, preferring instead to focus on what we *give* to patients with no expectation of anything in return. Her reality is that the "return" has been both welcome and even a natural progression of the nurse-patient relationship, and she even assumes that it brings joy to her patients to be able to give back to her as the nurse.

**Essence:** She finds community, comfort, and belonging as patients and their families provide support to her during her own health crisis; this role reversal is not foreign but instead perceived as an organic progression of the altruistic nurse-patient relationship.

### **Participant #4** **Wholistic/Sententious Description**

As a Clinical Nurse Specialist working in the surgical-oncology field for over two decades, this nurse brings extensive experience and a long-term perspective to the study. Although the bulk of her interactions with AI patients have occurred in a large facility in a southwestern metropolitan area, during the first few years of her career she regularly cared for members of a Great Plains tribe in another state while working at a smaller hospital. She makes note of the differences between the two AI groups, recalling “more traumas” and seemingly more elevated rates of “alcohol abuse” and “poverty” in the Great Plains region as compared to the AI population she interacts with currently, but she wonders if this is perhaps more related to her cancer specialty focus. She is middle-aged, Caucasian, married and with two high school-aged children. Her voice is soft and retains a noticeable Midwestern inflection.

She feels that a positive patient-nurse relationship is something to be developed during cancer care, but she places the initial effort almost exclusively on the nurse. “Make sure you discuss the cultural issues and what’s important to them, and how they want to be treated... and figure out how and why they want certain things done.” She stresses, “I think you should do everything in your power to make sure that that happens.” She attempts to defer to the patient’s needs and requests as much as possible within the confines of the biomedical cancer world. At least two experiences illustrate this sense of commitment, the first being when an AI patient asks for the return of a bio-specimen following a surgical procedure:

[It goes] back to finding out what the patient wants, and how important it is to them, and trying to make that happen. To me, it’s just what we need to do to provide the best care that we can, because if you don’t try to get whatever organ or body part that was taken out in surgery, and they really feel like that’s going to help them in the next life, or however they feel about it, then I think they might be resentful to us for not trying. That might cloud their judgment the next time that they have something done...

She is not only eager to respect the patient’s request, but also aware that to disregard it may have negative long-term implications, such as decreasing their likelihood of returning for future care. In another incident, she was asked to participate in a bedside healing ceremony, which she found emotionally meaningful:

I was touched because I thought they'd want to have just their family in there with the healer. They said, "You've been a part of this since the beginning. Please come in and be with us." I was shocked because I wasn't expecting that. I felt like I was a part of their healing, that they considered nursing to be a part of their healing. I think that's why they included me.

This particular nurse-patient/family relationship was unique, she suggests, adding “they would invite certain nurses in there. I didn’t really see them doing that with the physicians.” When asked to reflect on how she reached this point of trust, inclusion, and intimacy with this AI patient and family she says, “I think part of it was they were so scared when they came in...I think that they were more open to form relationships with [nurses].” Thus, at times the patient’s vulnerability may act as a stimulus for the relationship while increasing its depth.

As an experienced nurse, she recounts the value of slowing down her pace of care and truly being present in a way that is different than with non-AI patients. “If you really want to

connect with that patient and provide them what they need, you've got to take the time," she reflects, adding, "Be in the present with them, and then it just seems to help the relationship with the patient. The patient feels that 'this nurse is dedicated to me. She's making the time to sit here with me'". This alternate way of *being* is not without discomfort for her, however. "Sometimes you're thinking about all the other stuff that you have to do, but you have to make sure that nobody knows that's what you're thinking of...I think [AI] people trust you more if you give them that time." In addition to time and presence, she has also learned how to conscientiously use silence as a tactic for building a trusting relationship and becoming more clinically attuned to the patient:

I think silence shows them that you care. I think that helps start the relationship, and then I think they start trusting you, and then the relationship just grows. To me, it's nice because then when they open up more, then you can help them more, just because they'll tell you more about [if] they are in pain, are they having nausea, just certain symptoms. It helps me a lot with symptom management, because then they open up more and tell you stuff...[When] you walk in there and they're not laying there all tense and not talking, you can do something about what they're experiencing.

Again, this approach was at first "a little uncomfortable" for her, but she also realized, "this silence is helping. We don't need to talk all the time. Sometimes we just need to be there to listen." She admits that "I'm still uncomfortable with silence. I know it's the right thing...but I still don't like just sitting there. It's not my first nature". Similarly, she initially found some AI patient's body language and communication patterns to be awkward for her, recalling "they would talk, but they wouldn't be looking at you" and "it took a little while before they answered the question. For a while, I was thinking in my head, 'Did they understand what we just said, or do they just need time to think of the answer that they're going to say?' The culture was different". However, she persists despite her discomfort, relinquishing her preferences in favor of a more measured, deferential, and flexible approach to care.

There are times, however, when the relationship feels hindered by the layered complexity of her patient's lives, particularly those that reside far away on reservation lands where "it just makes it harder because you have to spend more time on certain things, especially getting resources for at home. Sometimes there are more levels or layers that you have to go through". When she is unable to coordinate proper care or follow-up with a reservation-dwelling patient, she "feels horrible" and "it leaves a little void...it just feels unsettling." In order to feel at peace with herself, she says "I really want everything tied up, those loose ends", but cautions that "you have to learn to deal with [imperfection], or you'll burn out as fast as you know." She characterizes her overall relationships with AI patients as "kind of rare, because it's difficult but it's rewarding at the same time. It seems like each one's a new experience".

**Sententious Formulation:** When nurses set aside their own expectations and cultural preferences in favor of presence, silence, and time, a caring and open relationship forms.

Level One Matrix  
 Interview #1; Interview #2; Interview #3

	<p>#1: She describes an unusual yet significant experience in which she was asked by the AI patient and family to arrange the return of a removed bio-specimen; despite her decades of experience, she had never coordinated this type of thing before, but she instinctually and intrinsically felt compelled to honor their wishes. Perhaps as a result of this conveyance of respect, she was then invited to participate in a bedside ceremony with this family and a traditional healer. Although she experienced a certain level of confusion about the meaning of events during the ceremony, she felt honored to be a part of this patient’s healing process, seeing this event as representative of her core values as a nurse.</p>	<p>#2: Generalized (non-patient specific) quotes about working with the AI population; potentially significant.</p>	<p>#3: She briefly describes a recently diagnosed young, female AI patient who was reticent to communicate with her, coming across as shy. Her mother often served as her voice piece. At times the nurse found the patient’s body language and slowed verbal communications “uncomfortable”, but over time she became more accustomed to them and cultivated a greater sense of patience and ease with their interactions.</p>
<p><b>Corporeality:</b> “we are always bodily in the world”, we meet people “first of all through his or her body”; “when the body is the object of someone else’s gaze, it may lose its naturalness”, both revealing and concealing.</p>	<p>Then certain things with communication were a little bit different because a lot of times the patient didn't have—at first I thought the eye contact. They don't like you to have direct eye—or at least this family didn't. We'd have a lot of eye contact. They would talk, but they wouldn't be looking at you.</p>		
<p><b>Spatiality:</b> “felt space”; “inquiring into the ways we experience spatial dimensions of our day-to-day existence”; “we become that space that we are in”; “world or landscape in which human beings move and find</p>	<p>At first I thought it was really odd, but when they explained that when they die, they want everything—their whole entire body—to go into the earth, then I was just like, "Oh, okay." It's not just like they wanted to see their body part. It was</p>	<p>It’s a little frustrating because you just expect the resources and everything to be there [on the reservation] the same as they are other places.</p> <p>Sometimes there's another layer that you</p>	<p>She spent most of her time beading, and I think that helped her take her mind off of everything she was going through. It got her out of the hospital.</p>

<p>themselves in”.</p>	<p>spiritual, where they needed that for their place of rest, so it was like, "Okay."</p>	<p>have to go through before you can do certain things.</p> <p>Some things you really have to work with and figure out a safe way to make sure that they're safe at home...sometimes it's hard finding resources. I think it just makes it harder because you have to spend more time on certain things, especially getting resources for at home. Sometimes there's more levels or layers that you have to go through...</p> <p>I like to know, just to make sure that they're not going and getting in any trouble after they leave here. When you don't get that, to touch base with them, it leaves a little void...it just feels unsettling. It's just like, I get great satisfaction after checking, saying, "Okay. I talked to them. I know they're doing okay." It's like an unknown when you don't get that.</p>	
<p><b>Relationality:</b> “relation we maintain with others in the interpersonal space that we share with them”; “develop a conversational relation which allows us to transcend ourselves”; “human beings have searched in this experience for the other, the communal, the social”</p>	<p>They did a lot of things, probably, that I didn't understand</p> <p>...you asked a question, it took a little while before they answered the question. For a while, I was thinking in my head, "Did they understand what we just said, or do they just need time to think of the answer that they're going to say?" It was a whole—the culture was different.</p> <p>I was touched because I thought they'd want to have just their family in there with the healer. They just brought me in. They said, "You've been a part of this since the</p>	<p>It's just not with the Native Americans. It's with all the patients. I think there's just—if you do what they need and you take care of them, then there's that trust. I've noticed it with the Native Americans, too. If you help them and make them feel better, help them with their symptoms and spend time with them, that that relationship's there, too. I think that with almost all the cultures that we take care of, I think they really trust nurses.</p> <p>The big things are the time and the trust, I think. And being willing to do what they need... I think just doing those things that are very important to them and asking them</p>	<p>She was newly diagnosed, and her mom did a lot of the talking for her, but then when the mom would step out, then she would start talking to me more...</p> <p>I think [talking to her] was uncomfortable, too. After a while, you just expect it, and then you're like, okay, we just need to take a minute here, and then you just wait for her. She always gave you an answer. It might be a few minutes later, but...You just have to be more patient, or just wait.</p>

	<p>beginning. Please come in and be with us." I was shocked because I wasn't expecting that. Yeah. Just touched. I felt like I was a part of their healing, that they considered nursing to be a part of their healing. I think that's why they included me.</p> <p>Even after the results came back that it was cancer, I sat in the room with the patient and didn't say anything for a long time. To me, it feels different because I'm used to people talking all the time. The silence part was a little bit different for me, but I think that's what the patient needed. During that time, for some reason, I think it made us closer, that I just sat in there and was there with him...I think that meant a lot to him.</p> <p>At first it felt, to me, a little uncomfortable. Then as I was in there, you could just see how much more relaxed he was. Then I felt more comfortable, where "Oh, this silence is helping. We don't need to talk all the time. Sometimes we just need to be there to listen."</p> <p>I kept wanting to reword the question that I asked him. I wasn't sure if they were just thinking about it or if there were questions that the patient or the family had. That's why I kept thinking, "Do they know what I just asked?" Then after a day or so of communication, then you get "Okay, they want to think a few minutes before they</p>	<p>when they first come in, "What can I do to care for you?" That opens it up so they can tell you what's important to them.</p> <p>I just think that nursing, we're givers. If we can't give everything that the patient needs, we don't feel like our job is complete. We want to meet everybody's expectations. If we can't do that, then we don't feel like we did a good job for that day. It seems like most of the nurses I know, they're hard on themselves. It's a hard thing.</p> <p>I'm still uncomfortable with silence. I know it's the right thing in that situation and stuff, but I still don't like just sitting there. It's not my first nature, and I still don't like doing it. I'm a big talker, but silence to me, sometimes, is very uncomfortable.</p> <p>I just get this feeling like okay, just be present. Be in the present with them, and then it just seems to help the relationship with the patient. The patient feels that "this nurse is dedicated to me. She's making the time to sit here with me". I just think it helps form your relationship.</p> <p>Just asking them how they like to be cared for, what will help them in their journey through the whole time they're in the hospital, and a lot of times, they'll think about it for a few minutes, but most people will tell you.</p> <p>Yeah, because it's [following up with AI cancer patients] like a satisfaction thing...I</p>	
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	<p>tell you the answer." It was a little bit different for me.</p> <p>They just said that the ceremony was just as important for them as what we were doing with the chemotherapy. That tells me a lot.</p> <p>I think part of it was they were so scared when they came in of all the stuff that he had been going through. Just the weight loss, the fatigue...I think that they were more open to form relationships with us.</p> <p>I felt special because not everybody invites you into their family like that, and so I felt like we had a connection there. I felt really special to be included in their ceremony, and when they did family things they would invite certain nurses in there. I didn't really see them doing that with the physicians.</p> <p>Going back to finding out what the patient wants, and how important it is to them, and trying to make that happen. To me, it's just what we need to do to provide the best care that we can, because if you don't try to get whatever organ or body part that was taken out in surgery, and they really feel like that's going to help them in the next life, or however they feel about it, then I think they might be resentful to us for not trying. That might cloud their judgment the next time that they have something done</p>	<p>always check things off my list...I like to have everything checked off my list so that I could feel good about what I've done that day, too. Part of it is how I feel about things, and I really want everything tied up, those loose ends</p> <p>If they're talking more, then I'll talk more. Each one's different. The Native American female that I just took care of the other day, she was very silent at the beginning, but by the end of her couple-days stay, she was really interactive with me...I think she just got used to seeing me, and knew that we had the relationships through the whole thing, so at the end she was very talkative</p> <p>I think silence shows them that you care. I think that helps start the relationship, and then I think they start trusting you, and then the relationship just grows then. To me, it's nice, because then when they open up more, then you can help them more, just because they'll tell you more about, are they in pain, are they having nausea, just certain symptoms. It helps me a lot with symptom management, because then they open up more and tell you stuff. It helps me, because then you walk in there and they're not laying there all tense and not talking. You can do something about what they're experiencing</p> <p>I think not in all cultures, but I think in the Native American cultures, I think it's hand-in-hand. I think the silence first, and trust comes after</p>	
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		<p>Start fresh from the beginning, and make sure you discuss the cultural issues and what's important to them, and how they want to be treated. Then, go from there, because once you get the assessment done, and figure out how and why they want certain things done, then I think you should do everything in your power to make sure that that happens</p> <p>WORDS DESCRIBING THIS RELATIONSHIP: Difficult sometimes. It's kind of rare, because it's difficult, but it's rewarding at the same time. It seems like each one's a new experience</p>	
<p><b>Temporality:</b> "subjective time"; "appears to speed up...or slow down"; "temporal way of being in the world"; "past, present, and future constitute the horizons of a person's...landscape"; reinterpreting the past; "perspective on life to come"</p>	<p>Being part of nursing, I got to go back, spend time with the patient, explain things a little bit slower and see if they had any questions. I think it was a time thing. When they would ask me to do stuff, I would do it. I think there was a good trust in there. Between the time and the trust, I think that's why they included me.</p>	<p>If you really want to connect with that patient and provide them what they need, you've got to take the time.</p> <p>It's frustrating because you just want to do one call to get everything arranged, and sometimes it ends up to be five or six calls, instead of one. It takes more time. Then you can't do certain things at certain times [on the reservation], so then that puts a time constraint on it.</p> <p>For me, [not meeting all of their needs] feels horrible. I hate not thinking that I provided the best care for everyone, but you have to learn to deal with that, or you'll burn out as fast as you know.</p> <p>Yeah, it's an uneasy feeling that you're like, "Oh, I hope everything's going okay with</p>	

		<p>that patient,” but you’re usually so busy too, that you don’t get a lot of time to think about all that, to dwell on everything.</p> <p>A lot of times, if you give them enough time, they’ll tell you exactly what they need</p> <p>When you’re standing there, sometimes you’re thinking about all the other stuff that you have to do, but you got to make sure that nobody knows that’s what you’re thinking of...and I think people trust you more if you give them that time</p>	
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### Thematic Summary

**Theme #1:** Compelled by a strong duty to be a *good nurse*, she has high expectations for the completeness and sensitivity of cancer care. Her altruistic intentions are sometimes thwarted by the cultural and situational complexities of her AI cancer patients and families, resulting in increasing frustration as she *wades through the many layers* of bureaucracy and physical distance separating them. These barricades are both tangible and symbolic, serving as a point of dissonance that stands out amongst the otherwise highly fulfilling nature of her work. When she is unable to *break through* these barriers and *close the loop*, she is overcome by a sense of unsettling failure that lacks closure and totality. She protects herself against these feelings to avoid burn out and carry on.

**Essence:** **Challenged by the layered complexities of caring for AI patients, she conscientiously evades burnout through persistence and seeking closure in order to find peace and fulfillment within the relationship.**

**Theme #2:** She uses *time as an intervention*, creating space for openness, understanding, and trust building. She views time as a powerful tool for accessing and connecting with this particular patient group. During these decelerated moments, she senses that spending time in physical proximity to the patient facilitates *presence* and sends a message that she is dedicated and can be depended upon throughout their cancer journey. This is a learned approach that took years to cultivate and is in opposition to the typical nature of her care delivery with other patients. She has been forced to slow down, yet is not resentful of this altered pace, and has even come to relish it.

**Essence:** **She has come to appreciate a slowed pace in which she uses time as an intervention to convey dependability, reassurance, and presence.**

**Theme #3:** As with time, her embrace of *silence* as a form of connection is an approach that she distinctly associates with AIs. She feels very little need to be silent with non-AIs, but embracing silence has cultivated a level of patience and tolerance in her that is sometimes surprising. While sitting silently beside a patient immediately after he received distressing news, she overcame the urge to speak and instead *became attuned through silence* to what he needed in that exact moment. In an instant, they became enjoined. She senses that her willingness to suspend words is somehow meaningful and encourages tendrils of deep trust between patient and nurse.

**Essence:** **Embracing silence, she finds rare moments of attunement and meaning, in turn intensifying, strengthening, and cultivating connection and trust.**

**Theme #4:** She is committed to maintaining a sense of openness and broad-mindedness when caring for AI patients and families, even when she is uncertain of or mystified by certain events or behaviors. Remaining non-judgmental allows her to penetrate her patient's deepest lives regardless of their dissimilarity to her own. Once allowed in, she finds great honor and respect in the experience of *being included* in sacred aspects of healing. These are signals to her that she has broken through to the patient at the highest level –perhaps even at the spiritual level – a responsibility that she takes seriously and carefully protects.

**Essence:** **She is deeply honored by the invitation to witness her patient's most sacred moments and carefully protects this highly private aspect of their relationship.**

### Participant #5 Wholistic/Sententious Description

An RN for over twenty-years, this participant is quick to point out that although she is in a clinical managerial position now, she has made a conscientious decision to “remain at the bedside” where she can have regular and “fulfilling” interactions with patients. She has worked in many fields of nursing in the same southwestern state, but reports having the most contact with AI patients while working in cardiology and her current specialty, inpatient hematology-oncology. She is fair, middle-aged, and a divorced mother. She comes across as being taciturn at times but repeatedly asks me if the results of this study will help nurses improve their relationships with AI cancer patients; she seems eager to learn and to move beyond the frustration that she describes in the interviews.

She feels separate and apart from her AI patients and their relationship is one of “cool distance” exacerbated by the patient’s subdued and withdrawn body language. “I don’t think I’ve ever met a Native American patient that isn’t closed off... They don’t really make eye contact, which makes me just want to go in and do my tasks and then leave the room”. Repeatedly, she describes both specific and generalized interactions with AI patients that feel flat to her as they fail to respond to her educational or conversational entreaties as expected, leaving her irritated and devalued:

It makes me feel that I'm not being listened to, or maybe valued, that what I'm trying to explain or educate is not going anywhere. I get very frustrated. I think I do get angry. I just wish that they would at least acknowledge that what I'm saying is something that could happen, or something that they should be taking care of or watching for. If you do try talking, you're met with silence. Either they don't add to that conversation, or I guess maybe they feel like they don't know me, so why am I talking to them like that? I go in with a shut-down expectation, like, "I'm going to be cordial. I'm going to be polite. I'm going to take care of what they need. I'm going to ask them if they need anything," but I'm not going to go in there and say, "How's your family? Where are you from? Oh, that's interesting" because I just don't seem to have any sort of way of making that connection, that spark.

Adding to this dissonance is the perception that her AI patients are “foreign”. This sense of alienation from one another is heightened by the fact that as a Caucasian nurse, they come from “different worlds”, and if a patient reveals that they come from the reservation, she feels “I don’t know anything about the reservation...it’s almost like they came from a different country because my experiences are limited. It’s like people coming from Serbia or something.” The patient feeling *unknown* and *foreign* to her seems to have a profound effect on their ability to connect:

There’s just such a difference with their culture that it seems like there at times is a wall in between me and them that of course you can’t see, but you can’t even figure out really sometimes how to break it down because, I mean, I have no experience with living on a reservation or knowing what it’s like or what their experiences are...it makes it harder for you to form a bond.

She is acutely aware that as foreign as they seem to her, she is equally alien, perhaps “just another White nurse”. She assumes that neither can comprehend the other’s world, and this only

solidifies an overriding sense of *otherness*. Over decades of work as a cancer care nurse, she has come to dread caring for this group because of the way it makes her feel: disconnected, culturally inept, and emotionally unfulfilled. “If I had to take care of three Native American patients in one shift I would probably leave frustrated... because I would’ve had no outlet... It’s like taking care of a patient that speaks a different language.” For this nurse, camaraderie facilitated through casual conversation is essential for establishing not only a caring relationship, but also for her ability to hone in on her patient’s clinical state and for supporting family members:

When you have a relationship or a level of compassion or understanding of what they’re kind of going through... it’s sort of like you’re a detective and you’re peeling away at these different layers to try to get to know your patient better so that you can give better care... It just gives you insight as to how to handle the families and the patient and take good care of them, make them feel good.

When that relationship is lacking, she feels like a “robot” and becomes focused on tasks rather than nurturing a connection with the patient. At times, these tasks and interactions move at a noticeably slower pace due to the patient’s focus on the present where “the sense is they want to know what you’re immediately talking about but they don’t want to necessarily talk to you about what’s going to happen in the future or what they’re going to look forward to”. The future, she insists, “is not something that they want to hear” about. Consequently, she feels that this present-mindedness “slows me down, or it makes me a little bit more aware of the present... rather than thinking of all the different things that are going to be happening... It makes me pause, makes me kind of more reflective”. She often interprets the quiet demeanor and present-mindedness of AI patients as compliance and respect, finding it both undemanding and taxing, a contradiction she describes further:

I think physically it’s easier. Emotionally I feel disconnected as a nurse...[but] I think that Native American people, they accept everything but they don’t give you a lot of feedback...my emotional feeling is that I’d rather take care of someone that has more of an interaction with me than somebody I don’t feel I have that connection with.

Silence also conveys that “you’re the authority figure and that they have that form of respect for you and they wouldn’t even possibly think about telling you about any problems they have or anything that would add to your burden”. She describes a single AI patient and family in which she was able to positively connect due to a family member’s willingness to engage in conversation with her, which “made me want to...try to explain things more to them. It was much more enjoyable taking care of that family and that patient because I felt like I was making a difference in her care”. There is a part of her that longs for more “warm and open” experiences such as this and to change the more typical dynamic as it stirs up sensations of guilt and regret, saying “it makes you feel bad, though, as a nurse, because you don’t want to be [distant] with anybody. You don’t want to feel that way”. She recounts the passing of an AI patient who had been on her cancer unit for many months, recalling:

Because he was there so long, I feel like, how come I didn’t get to know him better? How come I don’t feel as touched? I mean, I’ve been a nurse for a long time, so I definitely have barriers up so that I don’t get my heart broken every time someone dies...I can’t have my soul touched by everybody, or I’ll never continue being a nurse.

She speculates that they were “two people that kind of have barriers”, thus prohibiting them from ever forming a connection.

She wishes for education and tools that will help her and other nurses to transform the relationship into one that reflects the parity, kindness, and connection that she finds more easily with other types of patients, suggesting that “maybe there should be different questions that you can ask [AI patients]... We do some open-ended stuff, but it’s almost as if there could be a better couple of questions in there...not that I even know what the questions should be”. She summarizes her relationships with AI patients as “respectful”, “impersonal”, “easy” and “cold”, descriptors that reinforce the contradiction and complexity of her lived experience.

**Sententious Formulation:** When nurses engage in *othering*, it creates a cold and distorted relationship that is unfulfilling and tinged with regret.

Level One Matrix  
 Interview #1; Interview #2; Interview #3

	<p>#1: She begins by describing a middle-aged AI gentleman from a near-by reservation dealing with an ongoing cancer diagnosis. The story is striking in that the staff perceived that his wife thought he was “faking” the illness. This caused the nurse to feel baffled and somewhat horrified, and served to confirm for her the negative cultural “differences” between AI and non-AI cancer patients. Yet as an experienced leader on her unit, she tried to demonstrate non-judgmental care of this couple to the younger nurses. The conundrum and hypocrisy in this scenario is unusual.</p>	<p>#2: Generalized quotes about AI cancer patients (potentially significant)</p>	<p>#3: Providing care over several days for a young female AI cancer patient proved to be a somewhat unexpected experience for her. She assumed the family was from an entirely different culture based on her observations of their dynamics, and was surprised to discover they were AI. She found herself having far more interaction and gaining fulfillment from the father rather than the patient. His communicated interest in the situation stimulated the nurse on an emotional level. Once emotionally engaged, she felt that she was able to better educate and reach out to the whole family. Still, she was left feeling disconnected and distant from the actual patient and attributed her standoffishness to both personality and culture.</p>
<p><b>Corporeality:</b> “we are always bodily in the world”, we meet people “first of all through his or her body”; “when the body is the object of someone else’s gaze, it may lose its naturalness”, both revealing and concealing.</p>	<p>The younger nurses can’t even really wrap their heads around that thought, like how can somebody not either know what leukemia is or not know how detrimental that diagnosis is?</p> <p>You should put yourself in their shoes...I always try to make certain that nurses aren’t judging people by a quick response to what was going on</p>	<p>I think that nurses don’t do as good a job teaching with them because it’s sort of like talking to somebody that’s a stone. They’re not going to absorb what you’re saying, it’s just reflecting off of you</p> <p>I don’t think I’ve ever met a Native American patient that isn’t closed off</p> <p>They don’t really make eye contact, which makes me just want to go in and do my tasks and then leave the room</p> <p>It just seems like the body language that's there</p>	<p>They had the same very flat affect, but you could tell they loved her and cared about her so much, but they didn’t show a lot of emotions</p> <p>Like even that dad, when he was talking to me I felt like he was warm because he was very caring about his daughter. I really liked that</p>

		<p>is not something that is conducive to the continuation of small talk</p> <p>I don't feel that sense of pleasure that I feel with taking care of other types of patients. I don't feel like I get that positive expression, feedback, whatever it would be, that makes me feel more satisfied about my job</p> <p>I just went back to feeling less fulfilled and that it's difficult to care for [AI] patients at times because of the fact that you do feel less satisfied</p> <p>There's a cool distance, there's a coolness. When you don't have two people involved in a conversation, it's very one-sided. It just feels that you're the nurse robot that goes in there and says, "Blah, blah, blah, blah, blah" and then you don't know really what happens after that. Not that every single [AI] patient is like that. I mean, I have had a couple that were warm and open</p>	
<p><b>Spatiality:</b> "felt space"; "inquiring into the ways we experience spatial dimensions of our day-to-day existence"; "we become that space that we are in"; "world or landscape in which human beings move and find themselves in".</p>	<p>I think part of it is there's distance, physical distance, and then maybe they've not ever experienced [cancer] before</p>	<p>I guess perhaps it's just we live in completely different worlds. I can't imagine what it would be like to live in a community where people don't have electricity or water or don't think about their future...it's just very different from the way I was raised and brought up</p> <p>I guess it feels like you're taking care of someone from a different country. Like one of the patients that are Russian or Serbian or from Mexico or something, that the Native American patient even though that they live in the United States, they truly are from a different country.</p>	<p>You just felt like the questions you were asking weren't going to be answered. She was very nice and polite and helpful, but that was it. Almost like you're an outsider, I guess</p>

		<p>It's a different existence, different rules, different beliefs, and different cultures and language</p> <p>They say "oh geez I live on the reservation." I mean, I don't know anything about the reservation...it's almost like they came from a different country because my experiences are limited. It's like people coming from Serbia or something. I have no experience with that, I don't know what it's like</p> <p>There's a level that that's missed, like you can get only to the surface of the [AI] patient, you can't go any further than that.</p> <p>I think that you may distance yourself when you're taking care of them. I don't know if it's just because they're putting off the vibe that they want that distance, or if it's more of you protecting yourself without even realizing it, that you're going to be distant from these patients. I just don't really feel like there's ever a very strong bond that develops.</p> <p>It just makes you feel that you're taking care of somebody on the surface, like you're not really—you're taking care of their needs, or their problems, on that exact moment, but you haven't really made a connection or an impact</p> <p>You're coming from this direction, they're coming from that direction, and who knows if you'll meet in the middle.</p> <p>And maybe their pattern is "It's another white nurse coming in here. She's going to give me</p>	
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		<p>my meds, and we're going to just have this very on-the-surface-type of day."</p> <p>There's just such a difference with their culture that it seems like there at times is a wall in between me and them that of course you can't see, but you can't even figure out really sometimes how to break it down because, I mean, I have no experience with living on a reservation or knowing what it's like or what their experiences are...it makes it harder for you to form a bond</p> <p>I can put them at ease if I know stuff about them, because then I can kind of bring it up when there's a lot of anxiety or stress in a particular situation with them. Or it kind of breaks down the wall that we have in between us, and so we have some sort of, I don't want to say a relationship, but we have a connection. You're connected with that person</p>	
<p><b>Relationality:</b> "relation we maintain with others in the interpersonal space that we share with them"; "develop a conversational relation which allows us to transcend ourselves"; "human beings have searched in this experience for the other, the communal, the social"</p>	<p>There wasn't like a lot of family support in the hospital with him, but his wife was very upset with him and wanted him to stop fooling around, staying in the hospital, and come back and work. And all of us were just appalled "how could she be like this?", "how could she think that this man has leukemia and you know...?" It's just so culturally different from how you know people that aren't Native American respond to someone getting leukemia</p> <p>We were mad, we were angry at the wife when she said that he needed to just come home and work and stop fooling</p>	<p>There's not a lot of exposure on our unit to the Native American population. When we do have someone that is Native American, they don't seem to do that well with their diagnosis. Like you maybe see them once or twice but then you don't see them again [because they died]</p> <p>I think that maybe you don't put as much time into trying to [educate] them because of the fact that you know it's not received... it really doesn't even seem like they're really even paying attention to what you're talking about</p> <p>I think that their nonchalance is contagious, so [when] they're being nonchalant it makes you then nonchalant</p>	<p>But even just asking a couple questions a shift or even a couple questions of like wanting to know things made me want to teach them more. It made me want to try to explain things more to them</p> <p>It was much more enjoyable taking care of that family and that patient because I felt like I was making a difference in her care</p> <p>I was like "wow, you guys are Native American"...I remember that I was very surprised that she was not Hispanic</p> <p>I think, culturally, [AI] men are the more</p>

	<p style="text-align: center;">around.</p> <p>And I think that especially younger nurses, they don't understand what it's like to have to rely on somebody to support the family and then that person is now in the hospital and especially with the Native American culture, you know that the man is supposed to be out there working and taking care of the family and if he's not, who's going to take over for him?</p> <p>The newer nurses were outraged. They felt like the wife wasn't supportive, and they must've had a horrible relationship. Being an older person, and having gone through life experiences, I felt that I could be compassionate towards what the wife was feeling... I think I felt less reactive towards the wife. I didn't feel that anger towards the wife because I almost felt that I could understand why she was so angry, or why she was so upset.</p> <p>I never really got very close to him, but I was surprised when he went to the unit...but there were nurses that really felt very close to him...It just surprised me, because of the fact that when I had taken care of him, he didn't really say too much...I was surprised that there were some people that were really very close. Or felt very close to him. I don't know. I mean, I don't think it's just me, but other people did have a feeling of</p>	<p>Especially certain Native American patients, you try to teach them something and they don't even seem to be listening to what you're saying. They don't give a lot of eye contact or necessarily sometimes discuss things back with you so that you can have a two way conversation</p> <p>I don't have very strong relationships with Native American. We see them and then they leave and then sometimes they come back or sometimes you never see them again, but I don't seem to have developed relationships. I've never had any Native American patient that I have kept in contact with or communicated with outside of the hospital</p> <p>When you know you're going to have a Native American patient I think that you have an idea or an image that forms in your mind, like a preexisting idea of how this person is going to be...you would have these preconceived notions of how this person is going to be, whether or not that's true</p> <p>For the most part when you have a family member there with the Native American [patient], they kind of just sit off to themselves. You don't see a lot of conversation, you don't see a lot of questions about what's going on or what the treatment plan is. They may physically take care of their needs but I don't see much else other than that</p> <p>When you take care of that Native American patient and you have a family member that's</p>	<p>predominant person when it comes to asking about healthcare ...It was her dad that was always talking to me. It wasn't her mom. It wasn't her sister. It's almost like, "he's taking care of all of this".</p> <p>They were a very modern Native American family...like if I would start talking about things, maybe sometimes the dad would smile, but there wasn't a lot of two-way conversation.</p> <p>The patient herself didn't really seem to be wanting to have conversation or a relationship with me as a nurse. It was almost like it was directed more towards me communicating through her father. I would talk to the father about how she's doing, how are her labs, how's she feeling.</p> <p>I liked going into her room. I liked taking care of her. Her whole family was very nice, but I did find myself almost even more focused on what the father's needs were because he was the one that was communicating with me and asking me questions, and so I felt like I could please him. She, I don't know if I could please her. Not that I couldn't please her, either, but she just didn't seem to give me that emotional response that I like being a nurse.</p> <p>I just felt more of a relationship with him. I like that aspect of nursing. That's the part of nursing that is not definable. You</p>
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	<p>having developed a relationship with him</p> <p>Towards the end when he wasn't doing very well, there wasn't a lot of family that came and saw him and things like that. It was different than sometimes what happens with other patients, where you have suddenly a lot of family show up</p> <p>I don't think that that's why this patient's [treatment] failed. I don't think that he went home and did anything wrong, but it was not surprising to a lot of us because of the fact that he didn't really put a lot of energy and effort into it...He was more like he had been fixed and he was going to go home and just resume his life. It wasn't that he was going to go home and there was going to be all these changes that went on in his life</p> <p>It's difficult to educate when you don't have people seeming to want to change or to adapt to the changes that you're telling them they have to</p> <p>When that gentleman died, she was like, "We were really good friends." That surprised me. I was like, "You're good friends with him?" Sort of like I didn't understand that...I can't even see how you could be good friends. I mean, you can be nice. You can have a good understanding, 'I'm the nurse, you're the patient' kind of relationship, but for her to say that. I didn't really ask her about</p>	<p>really quiet you don't feel threatened by them, sort of. Like if you have a patient that is a white person and they have a family member that stays with them, ninety percent of those people are going to be riding you like crazy about 'what are you doing' and 'how are you doing it'? 'Why are you doing that'? 'Can you talk to the doctor'? 'Could I talk to the doctor'? 'What were the patient's labs like'? Whereas when you have the Native American patient and the family member in there, no one asks any of that, they don't ask any of those questions and I think it makes you...it makes you not talk to them as much.</p> <p>If you feel like that person is not receiving a lot or asking questions then you are not as apt to spend time, you kind of go in, you do your tasks and you leave</p> <p>You don't develop that relationship or don't feel that connection that you do necessarily with a [non-AI] patient and their family</p> <p>There is less pressure on the nurse when you're taking care of a Native American patient. Do they want to know anything about what those medications are? Most of the time they don't. They're very thankful to just be there getting treatment and they're trusting in what you're doing for them but they don't really seem to want to know all those other details that other patients may want to know</p> <p>I think physically it's easier. Emotionally I feel disconnected as a nurse...I think that Native American people, they accept everything but</p>	<p>can't say, "What do you do as a nurse?" There's a big aspect of nursing that's hard to define, and that's the part that I like... To take care of patients that you don't make that connection with, or you don't have that reciprocation of that good feeling, it just doesn't make you feel happy about being a nurse</p> <p>You could tell it was uncomfortable for her, being there. Being in that situation</p> <p>She seemed educated as well. I mean, she wasn't someone that I thought didn't have any experiences in life or abilities or education</p> <p>If you go into a room and you're talking and you're trying to like bring someone out of their shell, and most of the time usually I'm pretty good at it. I can talk to them or I'll ask questions to try to get to know them. I think I get to know my patients more than other people do. I guess that's just maybe my style of being a nurse, because sometimes I'll say to people 'so and so did this' and they're surprised because they hadn't really talked to that person. But with her, it's very like you have to ask very pointed, direct questions. She'll answer them. She would answer them, but it was not any sort of mutual back and forth conversations</p> <p>Well, she wasn't really going through this. You know what I'm saying? Like</p>
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	<p>that. I guess I could've, but it was sort of surprising to me that that's how she felt</p> <p>I didn't really know him that well. I didn't feel really close to him.. Usually if you have a patient that's there for three months...I will have developed a relationship or at least know them pretty well... there was never a camaraderie or like a conversation that would exist between the two of us</p> <p>It makes you feel bad, though, as a nurse. Because you don't want to be like that with anybody. You don't want to feel that way. You don't want to have this patient die and think, "They just died." Because he was there so long. I feel like, how come I didn't get to know him better? How come I don't feel as touched? I mean, I've been a nurse for a long time, so I definitely have barriers up so that I don't get my heart broken every time someone dies...I can't have my soul touched by everybody, or I'll never continue being a nurse</p> <p>I think that's a hard thing to realize, but you just have to kind of keep up a barrier. Maybe that's why with him and I, if we have two people that kind of have those barriers, you're not going to have that connection where you feel like anyone's really putting their heart on their sleeve, as they say, or exposing themselves. That's why I say, maybe it's me. I don't mean that I'm a bad person. I</p>	<p>they don't give you a lot of feedback...my emotional feeling is that I'd rather take care of someone that that has more of an interaction with me than somebody I don't feel I have that connection with</p> <p>Not that I want Natives to tell me all their business but...I'm not a robot, right?</p> <p>I think that they respect nurses more than someone else might...they don't question what you're saying or asking them to do. They trust you.</p> <p>If I had to take care of three Native American patients in one shift I would probably leave frustrated... because I would've had no outlet. I would've just been there taking care of these patients and not doing much else. It's like taking care of a patient that speaks a different language. Yes, they speak English but their communication is just completely different</p> <p>I think it makes me feel angry. It makes me feel that I'm not being listened to, or maybe valued, that what I'm trying to explain or educate is not going anywhere. I get very frustrated. I think I do get angry. I just wish that they would at least acknowledge that what I'm saying is something that could happen, or something that they should be taking care of or watching for.</p> <p>If you do try talking, you're met with silence. Either they don't add to that conversation, or I guess maybe they feel like they don't know me, so why am I talking to them like that? I go in with a shut-down expectation, like, "I'm going</p>	<p>she was going through it, but she wasn't really the one who had to deal with all of this. Someone else was dealing with all the decision making and planning</p>
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	<p>just mean that I've been a nurse for 24 years. I'm going to protect myself. If I want to continue doing this for the next 15 years or 20 years, whatever it is until I retire, I can't sob and feel emotionally distraught when certain people die. I work in a high death area.</p>	<p>to be cordial. I'm going to be polite. I'm going to take care of what they need. I'm going to ask them if they need anything," but I'm not going to go in there and say, "How's your family? Where are you from? Oh, that's interesting" because I just don't seem to have any sort of way of making that connection, that spark.</p> <p>It's emotionally challenging—yeah, not fulfilling—because you feel like the patient is not really understanding what the journey of being an oncology patient is going to be like, so when you try to teach that patient, you feel like they're almost shut down, like they feel that they're not really interested in all those details. They just want to know how they're going to be fixed</p> <p>To them it's 'you're in the hospital, you get fixed, you go home and you're well'. I guess maybe I'm making biased, I'm like making biased opinions on something, but it seems almost like that's what happens</p> <p>I think that it's hard to teach someone or to educate someone if they believe that there's like a magic pill or some formula that's going to happen, that they're suddenly going to not have any problems</p> <p>They don't realize how different their life will be forever because of what their diagnosis was. Sometimes it seems like you can kind of chip away at that with people that maybe don't have as much education about medical conditions or people that haven't experienced someone else</p>	
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		<p>going through that, but with the Native American people, it just seems like that's something that they don't even want to talk about. Like they don't even look like they're interested or listening to what you're saying, sometimes</p> <p>They put faith in whatever we're doing for them...Anything that you do or anything that you do for them, I think they feel like they can trust. I don't know if it's trust, but they just feel like you're the one who takes care of that and that's something that you take care of and they don't have to really participate on their end. It's more of they've put their medical condition in your hands and you're going to take care of this. All these other things that you're trying to tell them don't really apply, because when they leave they're not going to have to worry about this illness or disease</p> <p>I think that I have a higher sense of compassion, an understanding for what they're going through. I think that sometimes when you have a relationship or a level of compassion or understanding of what they're kind of going through... it's sort of like you're a detective and you're peeling away at these different layers to try to get to know your patient better so that you can give better care...It just gives you insight as to how to handle the families and the patient and take good care of them, make them feel good</p> <p>Maybe asking questions makes them feel bad. Or not bad, makes them feel like uncomfortable or makes it even more so that</p>	
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		<p>they close down or don't want to communicate</p> <p>It feels really good when you have a connection, a really good connection with someone and you feel like you've made a difference, like you've really helped them in some way that maybe other people hadn't realized they needed that help. That always makes you feel really good... it makes me feel good, it's a positive thing, like you feel like you're really helping people</p> <p>It's almost like you're the authority figure and that they have that form of respect for you and they wouldn't even possibly think about telling you about any problems they have or anything that would add to your burden. I don't know if it's that reason or it's they're embarrassed by saying things, but I don't know exactly why. It just seems that sometimes those things aren't expressed. Like if they have symptoms and you don't pointedly ask them, they're not going to come open to you and say, "By the way, I feel like this." They just don't do that. You don't find that happening</p> <p>¾ WORDS/PHRASES; Respectful. Impersonal. Easy. Cold.</p> <p>Easy in the sense that when you take care of a patient that doesn't ask you very much, doesn't ask for PRNs, doesn't tell you that they have any problems, doesn't express to you that they have any needs</p> <p>I think sometimes maybe when you're doing an admission on an [AI] patient,, there maybe</p>	
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		<p>should be different questions that you can ask... We do some open-ended stuff, but it's almost as if there could be a better couple of questions in there, pinpoint especially for patients that not necessarily even just Native American but just patients that culturally are very different from us. Not that I even know what the questions should be</p>	
<p><b>Temporality:</b> "subjective time"; "appears to speed up...or slow down"; "temporal way of being in the world"; "past, present, and future constitute the horizons of a person's...landscape"; reinterpreting the past; "perspective on life to come"</p>	<p>He doesn't ask a lot of questions, he doesn't want to know about what the plan is going to be, what's going to happen next, what could happen...it's just kind of like living in the moment of his experience, what he's going through right then and there</p>	<p>I know that Native Americans are very present minded and so I don't think that they necessarily have a two year long plan to think of "ok I'm going to have to go through this treatment process for two years". It's more like a day to day existence and so maybe they don't think ahead as far as being able to have the resources or to plan ahead for staying in the program that long</p> <p>When you are talking to the patient or trying to talk to them about what the plan is, the sense is they want to know what you're immediately talking about but they don't want to necessarily talk to you about what's going to happen in the future or what they're going to look forward to. They just want to know what's going on right now</p> <p>Just looking at the this one little spot of time, it's difficult to do teaching because sometimes you know you're looking into the future, what could happen... And to them the side effects of what could happen aren't really reality until they actually happen</p> <p>I think that it's frustrating in a sense that they were in a "Hurry up and fix me," sort of mentality. They don't really want to hear all the</p>	<p>It was more like a Native American patient really seeming to want to know and see how she was going to do, like acknowledging that it was a long-term process, that it wasn't something that was going to just be fixed this one admission and that was it</p>

		<p>different points of what you're trying to explain to them</p> <p>I think that talking to them about what the future will bring, sometimes, is not something that they want to hear, or they understand, or it's not part of their lifestyle, thinking about that future. It's just a little bit frustrating from a nursing point of view that you're not able to feel confident that they're going to leave and they're going to understand how important it is to make their chemotherapy appointments, and that they're on time, or that they go on the scheduled day that they're supposed to be going on.</p> <p>Maybe it slows me down, or it makes me a little bit more aware of the present and just being in that time period, rather than thinking of all the different things that are going to be happening. I guess it probably slows me down... It makes me pause, makes me kind of more reflective as to trying to be in that moment, rather than going forward, thinking ahead</p> <p>They're very present-minded, and so they live in the present and thinking about the future or what could happen in the future is not something that [they do]. I mean, like I said, that's the foreign concept to me, is how do you not think about things for the future or how things are going to be in the future?</p> <p>I think that you slow down and you reflect, but I think it makes taking care of those patients quicker or easier because of the fact that you</p>	
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### Thematic Summary

**Theme #1:** She is *alienated* from her AI cancer patients, sensing a massive chasm between their respective worlds that she finds difficult to comprehend or traverse. These patients feel foreign, aloof, and like *others* to her. She does not recognize any piece of herself in them, and she doubts that they would even *want* to see any part of themselves in her as she is equally foreign to them. She obviously grasps that AIs are indigenous to these lands, but when they enter her cancer care world it feels uncomfortable and almost *uninvited*. This sensation is further compounded by her attestations of understanding very little about her AI patient's origins and present-day realities, leaving her grasping at intangible wisps of speculation and conjecture that color each caring occasion while contemplating her own biases and assumptions. Being so distant and unsettling in their presentation, she has no foundation in which to build a personal connection with these patients.

**Essence:** The *otherness* of AI patients leaves her stranded on the opposite side of a wide and insurmountable chasm where she feels *alone and alienated with nothing tangible to begin forging a relationship*.

**Theme #2:** She feels *inept* and as if her noble nursing efforts are in vain when her AI patients fail to respond in a recognizable or appreciative manner. They are stone-like and impenetrable, and her words ring vacant and hollow in the space between them, so she cuts them short. This is radically unfulfilling and degrading, and she has come to *dread* caring for some of these patients. At times their silence is interpreted as obedience and acquisition, which she translates into *respect and trust* for her as a nurse. They do not challenge or bargain with her interventions or implementations, and while this is physically easier, it is emotionally taxing, creating a peculiar *tension*. Still, she is nagged by the sense that even when her AI patients are quietly compliant, she has somehow failed to reach them as a cancer nurse, inciting feelings of *regret*.

**Essence:** Her words fall unacknowledged in the space between them, their meaning lost in her AI patient's impenetrable expressions and inciting sensations of tension, futility, and regret.

**Theme #3:** Occasionally, the *tiniest spark of connection* appears and she seizes this human warmth and attempts to cultivate it throughout the caring encounter. Often it appears in the form of a simple question or a fleeting smile on the part of the AI patient or family member; however brief or tentative, it is magnified by the void the way the smallest of sounds echoes in the silence. She finds these episodes pleasurable and fulfilling, and they are absolutely necessary for her to move beyond simply performing tasks to the space where authentic nursing care is delivered.

Interestingly, she seems to look to the patient and their family to create this spark instead of reaching out and establishing it from her end. It is they who must make the initial effort to link with her as her well-practiced reticence prevents her from doing so.

**Essence:** When they concede to her the smallest gesture of connection, she seizes this spark and cultivates it for the duration of the relationship, finding sustenance in the act but failing to recognize her own diffidence.

**Theme #4:** She experiences occasional sensations of being *slowed down* when she is caring for AI patients. They are in the present moment together, and that is all. Her inclination for living in and attempting to plan for the future is moderated by her AI patient's singular focus on the *here and now*. She feels some urgency in pressing upon them the seriousness and potential for harm that accompanies their cancer care treatment, but they seem to take this information "in stride" and to be unconcerned about anything other than the present moment. This causes her to question if there is indeed some value in living in the present that she fails to appreciate as a non-AI. During this type of slowed patient care scenario she is *forced to pause*, reflect, and question her own proclivities.

**Essence:** The sensation of *deceleration* and existing *exclusively in the present moment* is both disconcerting and intriguing, causing her to ponder the value and implications of this way of being in the world.

### **Participant #6** **Wholistic/Sententious Description**

This participant is a Caucasian woman in her mid-30s who has spent the bulk of her 12-year career in outpatient oncology where she both coordinates care and delivers chemotherapy. Married and with two young children, she feels that cancer care is “where I’m meant to be”, finding great satisfaction in caring for people during their most vulnerable time and in establishing long-term relationships with patients and their families. She sees a significant number of AI cancer patients, many of whom are sent to her urban facility from distant, rural areas for treatment. Friendly and open, she voluntarily shared at the end of the interview process that she feels “more aware” and “reflective” about her experiences as a whole after having participated in the study. She is glad that a nurse is conducting the study because “I can’t talk about these things with anyone else”, meaning the emotional challenges and rewards of this type of care might only be comprehended by a fellow nurse.

Overall, she feels that the AI patient-cancer care nurse relationship requires constant adjustment on her part in order to accommodate the cultural and situational nuances and complexities of caring for this particular population. She makes great effort to meet “in the middle respectfully”, meaning that she attempts to negotiate a plan of care that is collaborative, culturally sensitive, and medically appropriate. Including the AI patient is key to this strategy. “I hope that they know that we’re thinking of them as a whole...we’re trying to meet them halfway or we’re trying to compromise with them so that they can feel that they’re doing something for themselves as well.” Thus, the relationship required for care to occur is an exchange. “To build that relationship, meet them in the middle, and to earn their trust—that’s two ways. They have to show that they’re going to go in on their part, too.”

Establishing trust and patient participation, however, is not always easy. She is initially perplexed by many AI patients’ minimalistic body language and subdued demeanors, recalling many who “did not make eye contact” or did not appear to be following verbal instructions. She at times finds herself feeling impatient with this communicative pace saying, “you just feel frustration because, ‘Everybody else gets it. Why aren’t you? Why is it taking you longer?’” She tries to hide her feelings of frustration from the patient as a form of both professionalism and compassion:

The patient for the most part doesn’t know that I’m frustrated. It’s just all those feelings that you’re feeling inside. Not that we put ourselves in their shoes, but sometimes you want to treat others how you want to be treated. If I’m not getting something, I don’t want somebody to talk down to me...

Keeping empathy and compassion in mind, she has learned the value of silence and a slower pace of care when working with this group. She finds that “instead of to opening your mouth...sit back and listen” while building a relationship, adding that “you can add your two cents later. If you forgot about your two cents, it’ll probably be okay”. She also notices that “sometimes their perception of time and our perception of time aren’t the same thing”. This is apparent in in her many descriptions of a sense of urgency coming from the biomedical cancer care world colliding with a seemingly nonplussed response from the AI world. This has required adjustment on her part:

I think that over my years of experience that I’ve learned that you have to respect their timeline... They’re not a high maintenance people. They don’t expect things

to happen quickly, or they don't expect immediate results... [They are] culturally different, and so that urgency isn't in them. They'll come maybe, and they'll get treated, but all in their own time, which is okay—I think something that I've learned is that it is okay.

Not all of this deceleration is patient or culturally-directed, however, as she explicitly describes the systemic bureaucracy and delays that often thwart the trajectory of care. It's as if both she and the patients are at the mercy of a federal system that is “worse than it used to be” and “isn't managed well”. It's “like pulling teeth” to obtain patient records, requiring “a lot more energy” from her. This incites a sensation of paralysis as she explains, “as a nurse, you want to fix it. You want to make it the best experience for your patients so that they can move on, but I can't fix the IHS side of things”. She realizes that this scenario is deeply embedded and that her patients are just as powerless. “They've obviously learned that they just have to take it. I mean there's not a big uprising. It's not like you hear about picket lines or anything in front of the tribal councils...it seems like they just accept it”. She recognizes the historical roots of this apparent resignation, imagining from the AI perspective that it feels like “this is what we were dealt. This is how it is. The White man comes in, takes our land. We don't have a say in it”.

Marginalization manifests in a very observable and distressing way for her, admitting “it makes me sad because especially in the cancer business by the time it is figured out, it's a lot farther than it [should] have been”. This again reinforces her efforts to build relationships on a foundation of equality and even reconciliation, stating “it's almost like you're trying to make up for things that have happened in the past” during present-day caring encounters. “I think that maybe a little it's hard to establish [relationship] just because of their history.”

She speaks often of the geographic barriers that divide her from her AI patients, especially those who must return to the reservation after treatment. “It's like I'm just sending them to this abyss, this black hole,” she recounts. While the reservation represents a distant and unfamiliar place where “people disappear”, she is also impressed by her patient's ability to transcend this distance and seek cancer care far from home. “They're coming down out of their comfort zone to this big city, all things that are totally foreign to them,” she acknowledges. “When you realize whatever it took to get down here or what they've been through before, it's humbling for me”. Viewing the patient from a place of humility impacts the relationship by creating a sense of gratitude and equal interchange:

They are leery, and yet they're coming, and you get to care for them. In the end, they trust you enough to allow you to be with them in the vulnerable time, where they don't have a lot of control—to just walk that with them [is humbling]... I think sometimes as nurses we give, give, give, and we forget sometimes about what we get out of it, too.

She has come to recognize the strength and resiliency of this population; there is something enigmatic yet powerful to her about the ability of these patients to accept and even embrace the tribulations of cancer with “more inner strength, more inner peace”. She finds them more accepting of death than other patients she has cared for. “They're connected...spiritually or emotionally, they have their family around them. Now, they have cancer.... I feel sometimes the Native Americans see it more as a natural course. They know they're going to die of something” eventually. This has impacted her deeply, describing that she now attempts to “slow down and either enjoy the moment or take the time in the moment to realize that they might be on to

something” with this type of worldview. She reveals that she finds both professional and personal meaning in her experiences with AI patients and families:

I’m glad to care for them. I don’t think that you make this big mental sigh when you figure out that it’s a Native American coming to see you. I don’t dread it. I like to learn about them, and all of our patients shape us as we care for them. Each person you come in contact with, they probably take something from you, but you also get something from them in return. I’ve been glad to work with the Native American population. Life isn’t fair, and it hasn’t been fair for them just like it’s not fair for a lot of other different people. Not that I can make up for that, but I guess no matter who it is, to have them have the best experience, both to be able to treat them physically but also all of their aspects—the mental aspects, the whole person—is just part of what we aim to do as nurses.

She summarizes her experiences with AI cancer patients as “humbling”, “honored”, and “time consuming, both physically and mentally”.

**Sententious Formulation:** Nurses co-create a fulfilling relationship through humility, collaboration, and reciprocity while respecting the decelerated AI temporal continuum.

Level One Matrix

Interview #1; Interview #2; Interview #3

	<p><b>#1:</b> She briefly recounts a recent elderly AI female patient who required a significant amount of trust-building and reassurance from the nurse. She feels as if she is making up for the past mistakes of others, but this serves as a source of motivation and determination for her to prove to the patient and her son that she (and the cancer care system) are there to serve r in a morally just and caring way.</p>	<p><b>#2:</b> Generalized quotes about caring for AI cancer patients (potentially significant)</p>	<p><b>#3:</b> She develops a long-term relationship with the family members of an elderly AI female with a terminal prognosis who lives in a remote area. The nurse is initially baffled by their lack of urgency regarding the situation, but has come to respect the inherent right of this patient and her family to choose their own pace of care. Interestingly, the bulk of their relationship is over the telephone, so her voice serves as an instrument for fostering trust and guidance from afar, spanning the void between them.</p>	<p><b>#4:</b> She repeatedly revisits the case of a young AI female who she cares for over many visits. Her efforts to impart information to this patient, particularly time-sensitive forewarnings, seem to fall flat. She finds the patient difficult to “read” and detached, as if she is simply going through the motions out of a sense of obedience rather than empowerment. The nurse carefully weighs her images of ideal care against this patient’s reality and finds the comparison somewhat disheartening.</p>
<p><b>Corporeality:</b> “we are always bodily in the world”, we meet people “first of all through his or her body”; “when the body is the object of someone else’s gaze, it may lose its naturalness”, both revealing and concealing.</p>		<p>I mean, they think “okay, maybe you have caring eyes and you held my hand during the procedure so yes, you do care a little”</p> <p>Then I think whether it’s Native American or not, those different gestures or things can then span the gap of communication and trust and working together. If they already know that I’m coming in frustrated, they might take a step backwards. Then there’s a wall</p>	<p>They don’t know what we look like. They don’t have that face-to-face conversation with us</p> <p>I can judge by her voice how she’s taking it in and how’s she’s processing it, but I can’t see her face. There’s a difference there</p> <p>We just know each other by voice. There’s no face to go with the voice because I wasn’t there</p>	<p>Hoping she gets that, because there always is that blank look—there’s never that deep eye “yes, I’m with you, I’m tracking with you this whole conversation”. It’s never there</p> <p>She would follow commands, but there wasn’t a lot of eye contact</p> <p>It’s not a physical exhaustion. It’s more of a mental</p>

		<p>where it's even harder for us to get through</p> <p>They're already not making eye contact and doing things for one reason or the other, whether it's a cultural thing or because they know they're not getting it and so they're embarrassed or whatever the reason</p> <p>Sometimes I feel like they're so in touch with their body. Maybe they're not having symptoms, nausea and vomiting or whatever, but they know that there's something wrong</p> <p>I think the sense of what we need to do hasn't changed [with AI patients]. You still feel like you have to do it, but just that your stomach's in knots because it's not going as it should, as fast as it should—just to take that extra breath, I guess, I think is helpful for both us and them.</p> <p>When I realize, "Oh, this [AI] patient's from whatever," it's almost like you take a mental sigh even before you delve into it just because you have to gird your loins, get ready for the fight. Not the fight, just the time and the energy it takes to do whatever</p>	<p>for her initial visit. She just has to trust what I'm saying just through my voice and how I'm relaying the information and taking her questions and things, back and forth. There's a relationship there I can tell. She now knows me by voice</p>	<p>exhaustion. I'm just sitting in the chair, so it's not like I'm physically exhausted [educating her]</p>
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		<p>[Health] records you don't get [from IHS]. You get a referral, and you need A, B, and C. You only get A. Well, trying to get B and C is like pulling teeth</p>		
<p><b>Spatiality:</b> “felt space”; “inquiring into the ways we experience spatial dimensions of our day-to-day existence”; “we become that space that we are in”; “world or landscape in which human beings move and find themselves in”.</p>		<p>It's like I'm just sending them to this abyss, this black hole [the reservation]</p> <p>I hope that they know that we're thinking of them as a whole, not just from our perspective—we're trying to meet them halfway or we're trying to compromise with them so that they can feel that they're doing something for themselves as well.</p> <p>Again, meeting them where they're at and compromising. They're coming down from their tribe, their village—to the big city</p> <p>I think meeting in the middle respectfully and saying, “Okay, this is what we suggest. You need to go home and do this,” or, “You need to go talk to the medicine man,” or ceremonies or different things that you need to do culturally because that's what you believe you need to do. Then fitting our medicine into that [world] and making them interweave</p>		

		<p>They're coming down out of their comfort zone to this big city, all things that are totally foreign to them maybe</p> <p>You fax the orders to this black hole [on the reservation]. You hope that they get them</p> <p>[Losing an AI patient to follow-up] is a loop that's not closed. It's open ended... You think about them. At first we'll call and, "Can we reschedule your appointment?" You can't call forever. Our rule is three strikes and you're out. You call three times, and then you send a letter. Then the ball's in their court... Then you just have to let them go.</p> <p>They're already out of their element. We don't look like them. We don't have their customs</p> <p>Now she's back at the reservation. It's just a whole other step for her to get down here. It's not like somebody who's local or white</p> <p>Frequently Native Americans, they're not local for the most part...they're not familiar at all geographically of where they're going or what they're doing</p> <p>I've driven through there [the</p>		
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		<p>reservation], but just like they're not familiar with here, I'm not familiar with up there. For me to say, "Oh, I need you to go get labs," I don't know what that means for them as far as where they're driving to... There's a lot more steps, or just to get somebody on the phone in the clinic sometimes is just—it's hard</p> <p>It's just where I'm supposed to be. Being a cancer care nurse in general is what I'm supposed to be doing, the population I'm supposed to be helping care for. It's just where the Lord has put me at this point</p>		
<p><b>Relationality:</b> “relation we maintain with others in the interpersonal space that we share with them”; “develop a conversational relation which allows us to transcend ourselves”; “human beings have searched in this experience for the other, the communal, the social”</p>	<p>Just to make sure we formed a relationship where now I can call her, and she calls me. I don't have to go through her son anymore</p> <p>I think because there was that miscommunication in the team before us, she didn't necessarily in the beginning think that we knew what we were doing either. We had to show her that yes, we know. We will take care of you. We will call you. We will follow up with you. You're not out there by yourself... it's just a challenge to have to step into that role and say, 'we will follow through'</p> <p>The mother and the son didn't trust</p>	<p>It's nice to be able to have that trust because sometimes it is hard. I mean I feel sorry for them, just in general, because they don't get the care that they deserve</p> <p>It makes me sad because especially in the cancer business by the time it is figured out, it's a lot farther than it could have been if they were either going in regularly because they trusted the physicians that they had on the reservation, or if the physicians caught it [earlier]</p> <p>We don't live in a perfect world. For us to expect it to be perfect, whether they're Native American,</p>	<p>Because they hadn't come down to meet us, I don't know how much is lost over the phone between our office and them. Then, I also don't know what the communication is because we're not there between them and their physician up there. I mean it's hard to tell somebody that they have cancer over the phone. It's even harder to do that when you don't have a relationship with them. I know her name, and I know what her daughter sounds like on the phone, but that's all</p> <p>I mean and so there's a hard balance in between because obviously they [AIs] don't have</p>	<p>Well, the doctor didn't think she was savvy enough to remember to take her pill every day. So, she made the decision for her because she felt that the patient couldn't really grasp the concept</p> <p>I think especially in the beginning, she didn't get it. She knew she was here. She knew that somebody set up the appointment for her, but she didn't quite get why</p> <p>At the end of the day, reality, what's perfect for her and what's realistic for her are two different scenarios</p>

	<p>us in the beginning or didn't seem to because we didn't have that relationship</p>	<p>or Caucasian, or Black or whatever is not a realistic expectation. You have to balance what NCCN guidelines say versus the real world, real life stuff</p> <p>Look, hindsight's 20/20, but I'm a more experienced nurse. When you're right out of school, you want to change the world. This is what you were taught in school; this has got to be how it is. Then, to be out there and realize that it's not how it is...to get out in the real world and find out that it's not that way, it's hard. It really is. You just know that you do the best you can with Natives.</p> <p>it's like a hope and prayer because one of my mentors early on always said 'you can lead a horse to water, but you can't make them drink'. I mean no matter who it is, you can give them all the tools. You can education them 'till you're blue in the face, but at the end of the day, they're the ones that are going to have to follow through. However, when they don't have the tools to follow through [like AIs] then it's a lot harder</p> <p>I think that sometimes the patient is a lot more comfortable with the thought of dying in the Native</p>	<p>the resources they need up north. They're sending them down here. It's harder. It really is</p> <p>For her, if it happened, it happened. If it didn't, it didn't. Well, it needs to happen. This is what the doctor said. This is what our orders are. This is what we're trying to carry out for you. More frustrating on our part than hers</p> <p>Sometimes their accents are thick, so I have to really concentrate on what they're saying. I'm probably the same way to them. Then to think about, "Okay, I should slow down"</p>	<p>I would say each time we see each other, it might be for a little longer period of time, not because she's trying to be disrespectful. She's not uncomfortable. She comes. She does her thing. She knows us. We know her, but I don't know mentally if she can just hang on that long.</p> <p>It's frustrating. You worry...we don't want to miss the boat on anybody</p> <p>But you feel sorry for the patient. You have sympathy—empathy—just because it's not necessarily her fault that she doesn't get it. Whether it's because of her past...this is something that you just speculate on, [but] she just had that look of maybe being an alcoholic's baby. It's not her fault that all of her synapses aren't firing</p> <p>I think because of the multiple interactions and the re-education every time, I think she's getting it more. It just wasn't happening the first visit. Again, you just feel frustration because, "Everybody else gets it. Why aren't you? Why is it</p>
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		<p>American population. They're not as scared about it</p> <p>Whereas the Native American population, they're doing their thing. They're connected with whatever out there spiritually or emotionally. They have their family around them. Now, they have cancer.... I feel sometimes the Native Americans see it more as a natural course. They know they're going to die of something. They know that their time will come. This is just how it's going to happen. Instead of having a heart attack or whatever, they got cancer. This is just the path that they were chosen to take.</p> <p>Sometimes, you wonder if just because of the way their lives have gone, they just take it. Not that they couldn't fight for it, but because of how they've grown up. I might be stereotyping a little. Just how they've grown up where everything was taken from them so they just had to take it. "This is our lot. This is what we were dealt. This is how it is. The White man comes in. Takes our land. We don't have a say in it, so this is just how it is. We're going to conform to that." It doesn't upset them just because all of their life, it hasn't worked out</p>		<p>taking you longer?" I don't know if she didn't know she didn't get it. She was just there because somebody sent her because she had this mutation that she didn't know anything about. She was just doing as somebody told her to do. She knew she was following those instructions. It didn't necessarily bother her that she didn't understand it. It was kind of like, "Well, I'm here. You're talking to me. I don't quite get what all you're saying, but I will maybe do what you ask me to do."</p> <p>You feel frustrated and then sorry at the same time. There's a lot of different emotions because you know you can only get through so much. You know that you can only repeat yourself so much. You just hope that, "Okay. Well, she'll be back, so hopefully between now and then she won't have any cancer."</p> <p>But your brain's trying to work through being frustrated but at the same time thinking, "Well, you can't be frustrated with her because it's not her fault that she doesn't understand." Then berating yourself for being</p>
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		<p>They don't get so upset about [cancer]. It doesn't bother them like some of my other Caucasian patients...They're not disappointed. They're not as heartbroken</p> <p>It's frustrating because sometimes you're back in the office, you're reading the chart, you haven't even met her [an AI patient] yet. You know that she's going to be 300 pounds. You know that she's going to have diabetes. You know this huge road that's going to be ahead of you. It's just exhausting</p> <p>Or they look at you cross-eyed when you say, "Well, you should get [a high protein drink]," at 20 bucks a case where 20 bucks is their whole week's worth of money for their whole family. They're not going to use it for them. They're going to feed their family. That's the choice they're going to make</p> <p>It's hard because you're recommending these things that aren't realistic for them to get. They're looking at you thinking, 'all right, White girl, you have no idea what my home is like. You have no idea what my environment's like. You say these</p>		<p>frustrated, then turning the corner and saying, "Okay, well, then I need to try to meet her where she's at once the doctor leaves so hopefully five percent of what I need to get across to her can get across."</p>
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		<p>words, but you don't really want to help me because I can't do what you want me to do'</p> <p>[I feel like I say] 'Call me if you need me, but you know I can't do anything for you because I'm six hours away so that's just an empty promise'.</p> <p>As a nurse, you want to fix it. You want to make it the best experience for your patients so that they can move on, but I can't fix the IHS side of things. You can do everything up to a certain point. You just have to leave them unfortunately to the system...It's even worse now than it used to be</p> <p>They've obviously learned that they just have to take it. I mean there's not a big uprising. It's not like you hear about picket lines or anything in front of the tribal councils, whatever, because not that they don't know any better, because maybe they do, but it seems like they just accept it how it is</p> <p>Just different ways that you try to figure out things that can still help them, but it's not about the money or things. At the end of the day I think you just have to know that you did your best, that you gave</p>		
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		<p>them whatever information or education or maybe something that will just change just a little and make a difference for them.</p> <p>Then it's up to them to follow through to do it. Whereas that part you just have to just pray and hope that they take you to heart and listen.</p> <p>People disappear. Their phones often aren't in service or they don't have minutes...</p> <p>The patient for the most part doesn't know that I'm frustrated. It's just all those feelings that you're feeling inside. Not that we put ourselves in their shoes, but sometimes you want to treat others how you want to be treated. If I'm not getting something, I don't want somebody to talk down to me about it because it's not my fault that I'm not getting it. "You do this every day for a living, and I don't."</p> <p>As a patient I would want you to take your time and not be frustrated and to be patient with me so that maybe I can get it instead of just stomping out or rolling your eyes or doing things that I can pick up on</p>		
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		<p>So if I worked in an [Indian] clinic, it might be different because those are all the patients that I see every day. You learn about where your clinic is and who you're treating and more of those kinds of cultural nuances. But we're not an [Indian] clinic.... It's like you're learning as you're going. They're learning what we expect or what we ask them to do, and at the same time we're learning from them what they're bringing to the table. Native Americans, they're tough. They really are. I guess sometimes even if I don't know about it, they just suffer in silence, and then they come back again because they know that that's what they need to do.</p> <p>Just sometimes when we're having the hospice talk, the family is devastated, but the [AI] patient isn't. Why? Because the patient knows. Has she maybe not told her family because she doesn't want them to worry about her? I just think that sometimes they just know. Her kids maybe don't know because she doesn't want them to worry about her. She's already come to terms with where's she's at. She's ready, but then they're not. When they're 86 or 90, again culturally, that's when they're</p>		
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		<p>supposed to go anyway. This is just what is taking them. Whether we could do something about it or not is not part of the issue because they've already accepted it. They're not symptomatic, but they know something's wrong</p> <p>A lot of times the Native Americans don't have preconceived notions. They're just coming in and respect you as the expert. Respect you—maybe not trust you... I think out of respect they will listen to you—again, in their own time, maybe not in the week or two weeks that we think they should. They'll listen to you and respect you and then make their decision based on that. It's not that they're not intelligent. It's not that they can't decide on their own</p> <p>I think just the unknown is hard for anybody. To build that relationship, meet them in the middle, and to earn their trust—that's two ways. They have to show that they're going to go in on their part, too</p> <p>But most of the time with the Native population they're ready [to die]. Then you can meet them there and take them down that next path</p>		
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		<p>Sometimes Indian health does take a lot more energy because their system isn't as smooth because the person on the other end—whether it's for lack of resources, lack of people on their end, staff, whatever it is—is also trying to get through the day. I can't trust all the time that I'm going to call and [get through]</p> <p>I'm glad to care for them. I don't think that you make this big mental sigh when you figure out that it's a Native American coming to see you. I don't dread it. I like to learn about them and all of our patients shape us as we care for them. Each person you come in contact with, they probably take something from you, but you also get something from them in return. I've been glad to work with the Native American population. Life isn't fair, and it hasn't been fair for them just like it's not fair for a lot of other different people. Not that I can make up for that, but I guess no matter who it is, to have them have the best experience, both to be able to treat them physically but also all of their aspects—the mental aspects, the whole person—is just part of what we aim to do as nurses</p>		
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		<p>I guess I would say their strength, their inner strength... but just to see how they handle situations maybe differently with more inner strength, more inner peace, just more accepting instead of an, "Oh, why me," or to feel sorry for themselves, just to take it and do what they need to do with it</p> <p>Instead of to open your mouth, just to sit back and listen. Sometimes you find yourself wanting to jump in and say something, but, no, let them finish their thought. You can add your two cents later. If you forgot about your two cents, it'll probably be okay</p> <p>There are a lot of things that we as Caucasians could learn from them... I think they could learn things from us as far as screening or healthcare maintenance. Then, at the same time, I think we could learn things from them as well.</p> <p>Just taking that extra moment because when you take that extra time to teach, especially up front, and meet them where they're at. A lot of times they don't know medical jargon. Some people know more than others, but they usually don't know as much. To</p>		
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		<p>take that extra time to explain all of that so that when they come back they're either more compliant because they understand it more and why it needs to be done, or they understand what's coming so that side-effect-wise, they're not calling you for every little thing</p> <p>It's not their fault. They are where they are. For the most part, they're always appreciative of the effort you put forth. They never know how much work you put in, but they're always appreciative of what is there once they're here. I don't mind to put effort forth when you get appreciation back. It's just part of how it is. I can't change it...They don't need to feel badly because it took us twice the amount of effort to get their records. Just like it's not their fault they got cancer, it's not their fault that the system that they're in isn't managed well</p> <p>I think that maybe a little it's hard to establish [relationship] just because of their history. They're coming to the big city. They're not familiar with it. I think once you show them that "No, I'm here to help you and care for you, and I do have your best interest at heart," that then the give and take is good</p>		
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		<p>I think that it's rewarding to get the give and take. We had another [AI] patient who got chemo. Then at the end they brought us a beautiful blanket. Just ways to show their appreciation. That is not necessary, but I have been a nurse long enough to know that they want to show you how much you've given to them. Even though it's your job and this is what you do, it still is human nature to want to give back</p> <p>I think that they are a very humble people. They have their pride, but they don't gloat. Then at the same time, when you realize whatever it took to get down here or what they've been through before, it's humbling for me. Then you join on that together</p> <p>They are leery, and yet they're coming, and you get to care for them. In the end, they trust you enough to allow you to be with them in the vulnerable time, where they don't have a lot of control—to just walk that with them...I think sometimes as nurses we give, give, give, and we forget sometimes about what we get out of it, too</p>		
<p><b>Temporality:</b> “subjective time”; “appears to speed up...or slow</p>		<p>You feel bad because as [white] Americans, we want everything</p>	<p>Just because you say to a 90-year-old, “Hey, this is what you</p>	

<p>down”; “temporal way of being in the world”; “past, present, and future constitute the horizons of a person’s...landscape”; reinterpreting the past; “perspective on life to come”</p>		<p>done right away or yesterday. We want everything done as soon as we can get it done. It’s always a hurry up and wait kind of thing for us...They [AIs] didn’t have that same sense of urgency that we could feel</p> <p>It’s hard sometimes because you know if they put that little bit of effort forth, that you could give them a little bit more time. Not that you can cure them, most of the time there is no cure. It’s just time and good quality of time.</p> <p>Sometimes their perception of time and our perception of time aren’t the same thing. They have the clinic visit that I expect them to be there at 9:00 because there are ten patients after them, but they don’t come until 9:45....</p> <p>You’re frustrated with that because then your whole clinic gets thrown off. At the same time maybe it’s not their fault because it took everything they’ve got just to get there at all, no matter what time it was</p> <p>I think that over my years of experience that I’ve learned that you have to respect their timeline</p> <p>They’re not a high maintenance people. They don’t expect things</p>	<p>should do,” doesn’t mean that she jumps up and does it because they have their own timeline, which is fine. Then, instead of being diagnosed and treated, or diagnosed and choosing her own path because she has that choice, it was a two-month lag at least.</p> <p>The family obviously didn’t feel that urgency. When I talked to the family, she said, “Well, she’s doing pretty much the same that she has been doing.”</p> <p>Sometimes when the mom is quote/unquote “feeling well”, then they don’t feel that urgency because symptomatically there’s not something that they need to fix right away. They don’t see their mom suffering</p>	
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		<p>to happen quickly, or they don't expect immediate results...[they are] culturally different, and so that urgency isn't in them. They'll come maybe, and they'll get treated, but all in their own time, which is okay—I think something that I've learned is that it is okay</p> <p>It's almost like you're trying to make up for things that have happened in the past. I don't know how else to say it. Have them realize that that's not how we behave now. You know what I mean? That everybody makes mistakes, and we should learn from them and then hope to not repeat the mistakes that our forefathers have made</p> <p>Their timeline is different. You just have to work with that...Hopefully it still works out in the timeline because it doesn't necessarily have to be two days. It could be a week</p> <p>I think that it helps you no matter what you're doing to slow down and either enjoy the moment or take the time in the moment to realize that they might be on to something. [Laughter]. Obviously maybe not quite their timeline, but a nice compromise</p>		
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### Thematic Summary

**Theme #1:** She instinctively senses the complexity of her AI patients' lives, even when she is unable to directly observe them. She is acutely aware of an *unvoiced undercurrent* of historical oppression and marginalization. This context perpetuates a sense of distrust, hesitation, suspicion, and resignation on the patients' part and a carefully moderated (and repressed) level of frustration and impatience from her end as she struggles to deliver unbiased and kind nursing care to people who appear detached and uncomprehending. The tension is that even though she appreciates the origins of her patient's misgivings about her intentions (and cancer care as a whole), she must contend with the *unwanted remnants* of this painful legacy on a daily basis. It is as if she is expected to overcome four centuries of trauma and abuse in a single caring encounter. The impossibility and absurdity of this is not lost on her; it forms her view of the *imperfect and unjust world* in which she must provide cancer care and in which we all must live.

**Essence: Her awareness of history does little to ease the tension of present encounters. She is forced to contend with the *unwanted remnants* of a shared painful legacy while striving to deliver a more ideal version of care in an inherently unjust and imperfect world.**

**Theme #2:** The physical world in which her reservation-bound AI patients live feels exceptionally distant and empty. It is a "black hole" inhabited by confounding bureaucracy and systemic failures. Her patients have been *banished* to this isolated place, forcing her to exert an enormous amount of effort to *maintain contact* from her urban realm. Sometimes they never reappear, leaving her with a worrisome sense of loss and regret. At other times they amaze her with their return, and she is humbled by their ability to *navigate* between two worlds and *persist through barriers* in order to seek cancer care. Still, she is troubled by the fact that the journey is only occurring in one direction and that we as cancer care providers rarely make the effort to meet on middle ground, or better yet, to enter the AI world. To compensate, she attempts to adjust her expectations as much as can in order to accommodate and acquiesce.

**Essence: The reservation is an *abyss* in which her patients disappear, but while her efforts to reach them are hampered by complex obstacles, she is humbled by their ability to transcend barriers and seek care.**

**Theme #3:** She recognizes what she has learned from her patients: demonstrations of incredible resiliency; a healthy embrace of death as part of a life journey; bodily attunement; gratitude for other beings; and an unequivocal humility about our miniscule impact in this world as humans. Her patients gently remind her, *we are not in control*, and this is freeing for her. Through their eyes, she sees a bigger picture, one in which silence is a welcome respite and cancer is ordinary (and therefore less frightening). All that she can give in return to her AI patients is care provided in the same manner that she would also want it received. She sees the nurse-patient relationship as an *exchange* in the form of a temporary joining together of dissimilar people that leaves a lasting impression.

**Essence: Being in relationship is an exchange in which each learns from the other, creating admiration and gratitude between nurse and patient.**

**Theme #4:** She is accustomed to a sense of great urgency and determination regarding cancer care, yet this approach often abruptly collides with her AI patient's agendas. She feels pressured to act quickly and to facilitate an accelerated trajectory of care in response to the gravity of disease, but often her AI patients and their families are delayed in their responses or reactions, choosing instead to pursue and navigate treatment at their *own pace* and in their own way. Her AI patients have forced her to acknowledge that time and quality of life are not always interwoven. In response, she slows herself, becoming mindful and appreciative of the moment, and learns to walk beside her patients at a more gradual and restrained pace, engendering a sense of wonder and respect.

**Essence: Pulled between the values of the biomedical and AI worlds, she has learned to respect the autonomy of individual pacing and the inextricable intertwining of *time and quality of life*.**

### **Participant #7** **Wholistic/Sententious Description**

As an infusion nurse at an outpatient clinic in a mid-sized southwestern town, this nurse estimates that “probably 80%” of her cancer patients are AI from both the same town and the surrounding reservations. Originally from the southern United States and still retaining a distinctive accent, she is eager to share her experiences with me as they feel “hard”, “challenging”, and “frustrating” in many cases. Petite, blonde, and married with an infant child, the tone of her interviews seems to change significantly over the course of the study, something she also acknowledges as she reflects on her own personal growth as a nurse serving a complex population in which she has found “there’s more good than bad in it; it’s very fulfilling”.

Acutely aware of her outsider status, she initially struggles to build trusting relationships with her AI patients in an atmosphere of suspicion and uncertainty. Racism and oppression haunt their interactions, which is illustrated by an AI patient who somewhat jokingly tells her that he is afraid of “white people”. Although they laugh together, she is struck by this incident and realizes that “I can see their fear sometimes”. She relates it to her own upbringing, revealing “I guess I understand because where I come from there’s still a lot of racial issues... So even though it is a different population and we’re talking about two different racial things, when he said that it made me think”. In some cases, this racial tension manifests itself in AI patients not only coming across as recalcitrant with her, but also not wanting her to provide care to them (preferring instead an AI nurse):

A piece of me says, ‘I’m a good nurse, why wouldn’t you want me?’ But the bigger piece of me understands the bigger picture and why they feel more comfortable with a Native American because of the things that their ancestors and they themselves have been discriminated against. Their trust issues, I can understand that. So I don’t get offended necessarily, it makes me want to reach out that much more to say, ‘I’m here, let me help you, I’m just as good and it is not because I think I’m better than this one, it’s because I really want to help you’. So that part’s a little frustrating, [but] not hurtful. But the downside of it is you really do want to help and you are viewed as somebody who probably doesn’t.

She is forced to set aside her feelings of rejection and prove her altruistic intentions. It becomes a game of persistence for her, but a seemingly futile one in which she feels like “I hit a wall every time I try to do something to help. That is extremely frustrating, but only because...when do I cut it off or do I just keep trying?” She internally battles to prevent this sense of rejection from dampening her spirits and shutting down her emotions as “there are some instances where I cut off the relationship and I’m just a nurse”, a desperate act of self-preservation. She also depersonalizes the rejection, relaying “some Native patients don’t want me to touch them, and I think the reason...is not because they don’t like me as a person, it’s that I’m not part of their culture”.

The barrier between them is reinforced by her difficulty in reading many of her AI patient’s communication patterns, even when English is being spoken. “Sometimes it’s very hard to read them, and I’m usually a very observant person and it does trip me up sometimes”. At other times it is a combination of restrained bodily messaging and a language barrier that causes difficulty. “How do you even get from ‘hello’ to ‘I’m starting an IV’? How do you get to that when there’s a language barrier or there’s a straight face, no expression, there’s no personality or

anything?” During these times she relies on “jokes”, hand signals, and smiles to convey her caring intentions, recognizing that “it is probably more terrifying to them that...they are not understanding completely”. She also tries to place her patients’ realities at the forefront, reminding herself:

I don’t have cancer; I don’t understand what he’s feeling so I can’t relate enough to get upset with him because there’s probably a piece of the puzzle I’m missing, whether it is a language barrier, whether it is a cultural thing, whether it is just knowledge in general.

At other times, she “can feel the vibes from them, the tension. If it is tense then I know that they just don’t want to talk to me, I just need to let it go”. Widening the gap between them is her admitted lack of knowledge about both AI culture and life on the reservations that they are surrounded by. She is perplexed by a pattern she observes of patients being dropped off at the infusion center by family members who don’t return for long periods of time. “Maybe they’re very family oriented, but just in a different way,” she muses. Other patients come across as being non-compliant at first until she realizes that they lack cell phone service, mail delivery, and other amenities on the rural reservations. “That was like an eye-opener for me because I didn’t realize that people live like that”. She describes transitioning from feeling like she was going to great lengths to coordinate a patient’s care and thinking he was being unresponsive to realizing the constraints placed on him by his environment:

That was sort of frustrating because I felt like ‘I’m really trying to do this for you but your phone is always off’. I learned later that the phone is always off because he lives on the reservation and there’s no service out there. I was not aware of that at first so here I am thinking ‘he’s just not compliant, I’m busting my butt and he’s not helping me’. Then I was like, ‘whoa, okay, backtrack’. [Once] I understood that part and I finally got in touch with him, he was very compliant.

She is reflective about this experience now, admitting “I felt like ‘I care about your life but you don’t’. That was the wrong assumption... Now I have a better grasp on things so...now when things like that do come about I have a little bit more sympathy, empathy”. Still, she recalls a frustrating pattern where,

They might come the first two weeks then you don’t hear from them for two months, they don’t show, they don’t call, you don’t even know if they’re alive and then they show up or call two months later and want a medicine refilled or something... So you get them scheduled again and then you just go through the same cycle.

This remains challenging for her to contend with, but over time her perseverance and willingness to learn has paid off and she begins to form more satisfying relationships with AI patients as they come to recognize her and accept her care. “I’ve noticed several patients...that maybe treated me differently before are so open now and just loving and we have such a bond...they open up to talk to me a lot more”. Small moments of connection and honest conversation are infused with profound meaning for her, such as when she is able to share humor or recognize a patient struggling with depression and find the appropriate resources. She uses these fragments to sustain her through ongoing challenges and frustrations, but notices that as she bonds with individual patients, other AIs take note. “I can feel other Native Americans watching me and how I respond, and

that makes me want to reach out to them so...they'll develop that [same] trust". She has come out the other side of her lived experience a more aware person who is not only eager to learn about this population, but also willing to continue to adjust and develop as homage to what it means to be a nurse:

I don't know how to even describe it, but it's a very positive experience [caring for AIs]. It's definitely opened my eyes and any judgments that have ever come up in my mind are no longer there [regarding] any population... I think about all the judgment being passed to certain cultures and certain religions. Then I noticed that I had a few judgments of my own obviously when I first started working with the Native American population, not necessarily like racial, more of just like 'they're not listening to me, they don't like me', that kind of thing, but that's not the case. I mean I understand that now. It's just definitely opened my mind to see my blindness. Yeah, it's been a positive experience, that's for sure...I learn things about them along the way as well which kind of helps hold the relationship eventually.

She characterizes her relationships with AI cancer patients as being composed of "compassion", a challenging "language barrier", and finding herself "intrigued by the culture". After several years spent in this community, she now feels "more open" and "my patience level has just grown more and I don't get quite as frustrated as I normally would just because a piece of me does understand or can see why things went the way they did" during the provision of cancer care.

**Sententious Formulation:** When nurses persevere through emotional and communicative barriers in order to forge caring relationships, they gain a deep appreciation for small moments of connection that are immensely satisfying and sustaining.

Level One Matrix  
 Interview #1; Interview #2; Interview #3

	<p><b>#1:</b> She describes the exhausting, seemingly futile, yet ultimately rewarding process of tracking down an AI man to facilitate his oral chemo treatment. What first appears to be non-compliance is ultimately seen by the nurse to be a very typical situation for a reservation-dwelling patient. Still, she is troubled by the poor quality of life and limited ability to communicate with this patient and his family.</p>	<p><b>#2:</b> Generalized quotes or fragmented/undeveloped stories about caring for AI cancer patients (potentially significant)</p>	<p><b>#3:</b> She cares for an AI man with limited English, yet they somehow develop a bond and trust with one another, so much so that at the end of one visit in particular he makes a joke about being afraid of White people to her. The moment is simultaneously funny and awkward for her, and it stirs up a host of emotions and memories from her own childhood and family. His fear and distrust of Whites feels familiar and understandable, yet she feels the slightest twinge of discrimination being directed at her in the moment as well.</p>	<p><b>#5:</b> She tries every tactic in her arsenal to form a personal connection with an AI woman, to no avail. Then, suddenly, during a single moment she realizes that she has been “reading” this patient incorrectly all along; she immediately adjusts her approach and utilizes an AI nurse to assist her in caring for the patient more fully. The experience feels rewarding and productive, as if she has finally <i>nursed</i> this patient.</p>
<p><b>Corporeality:</b> “we are always bodily in the world”, we meet people “first of all through his or her body”; “when the body is the object of someone else’s gaze, it may lose its naturalness”, both revealing and concealing.</p>	<p>That was like an eye-opener for me because I didn’t realize that people live like that [on the reservation] but I didn’t realize that was a norm</p> <p>I feel like the norm for us is that we push, push, push to try to help this patient and I feel like there [on the reservation] the feet just get dragged, dragged, dragged and it is frustrating because you want to help the patient but you can’t make them go any faster</p>	<p>I honestly go home, change clothes and just sit down for five minutes or so and just turn it completely off...I’ve gotten really good at just letting stuff go</p> <p>That’s one thing I’ve learned along the ways with this population is that you do have to let go otherwise you take it home with you or you get too upset. You certainly don’t want a patient to see frustration whether they are compliant or not compliant or whatever the case may be</p> <p>He is so super sweet just in his</p>		<p>The last six months I've known her, she's definitely been detached from the whole treatment process, everything, she just doesn't hardly respond. You ask her her birthdate and she just mumbles it and her name, and it's just the minimal conversation possible, and she does speak English</p> <p>Maybe she's the breadwinner or the head of the house and she probably has the weight</p>

	<p>either</p>	<p>mannerisms and it always makes me want to take care of him every time he comes</p> <p>Sometimes I stick my foot in my mouth because I am so blunt about things and it comes out that way</p> <p>So if I'm helping someone in the Native American population, you can usually tell if you feel like somebody is not understanding versus they just don't want to talk to you. I can feel the vibes from them, the tension. If it is tense then I know that they just don't want to talk to me, I just need to let it go, hook them up, help them and take care of them like you are supposed to and you're not going to have any extra talk</p> <p>Then there's times I get an eerie feeling that they don't understand what I'm saying or they're not understanding what's happening here and then at that point if the Native American nurse is available I have her talk to them to let them know what I am doing, why I am doing it, so then they feel comfortable. A lot of times you get a 'sigh of relief' from them and they are willing to engage with you even if you don't speak the same language and they are willing to smile at you.</p> <p>When I did his teaching I could see that he even though he was trying to follow along he didn't really understand so he</p>		<p>of the world on her shoulders—I don't know, my mind was just going in so many different directions.</p> <p>She was smiling, like a light bulb went off between both of us...at least I feel like I hit the nail on the head and we can now help her</p> <p>She smiled at me a couple of times when I'd say something to her and again, this is someone with no expression ever [previously]</p> <p>I don't know, it just spoke to me. You know when somebody says something and they have their head down? That scared me off a little bit and then when I did say something to her at one point, she smiled at me, but it was one of those smiles that seemed like she didn't want to smile at me. It was a genuine smile, but a sad smile...It just didn't look genuinely happy</p>
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		<p>had that flat affect.... [later] he kind of opened up a little bit and by the end, it was the best feeling in the world</p> <p>I might not have physically saved him but he was so grateful and so happy when he said it and he was hugging everybody, it was just really sweet. It is sweet that other patients saw that too because then you have other patients in there who are not as open, who don't talk a lot or have that barrier up, that wall, then they hear something like that and they start to open up</p> <p>That's another thing I've noticed too with the Native American population: they watch how you treat each other...I can see somebody, I can feel somebody watching me doing a new teaching or a new start for this Native American patient. I can feel other Native Americans watching me and how I respond, and that makes me want to reach out to them so then I feel like if I get a good response, and even if I don't, I can really just be as nice as I can and they'll see that I mean no harm, I'm trying to help, and I want to help. Not that they think that I would harm them, but they trust me, they'll start to develop that trust</p> <p>I could see the concern in the son's eyes and I think he might have felt like, man I shouldn't have left, but I don't know as a nurse—you're an advocate for the</p>		
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		<p>patient, but do you overstep?</p> <p>Sometimes I can't read people in that population and sometimes it's very hard to read them. And I'm usually a very observant person and it does trip me up sometimes, but it's not anything I can't get through either or break that barrier...It's half and half. There's some I can easily read, it varies, the communication is great and then there's the other half that they're detached from the situation or from me</p> <p>I can feel the little bit of elevated heartbeat. I can feel my blood pressure and I just feel stressed out and on top of the stress, I'm a little bit emotionally drained from putting all my time and effort into something and it's just not working, or the person is not giving me the other half</p> <p>I just have to let it go at some point. If they don't care, I don't care and it's not necessarily that I don't care, it's just that I've decided that caring is putting too much negative on me and I'm not willing to accept that burden if you're not</p> <p>The minute I call them back, it's always, 'hey, how are you?' Greeting them with a smile and if they smile back and actually talk to me, then I feel normal...</p> <p>But I do get a presumptuous feeling when I call them back and there's just a straight face and there's no expression</p>		
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		<p>and it's like I'm not even here, but, I am here because I am hooking them up for treatment...this kind of stings a little bit, but I don't even try to understand it anymore. I just lighten my mind or it gets a little frustrating and then I just act numb. It's not my problem; I try to reach out them continuously, but eventually I've cut that off too if they don't respond, but most of the time they do and then we can change that relationship completely around and it seems like they trust me</p>		
<p><b>Spatiality:</b> “felt space”; “inquiring into the ways we experience spatial dimensions of our day-to-day existence”; “we become that space that we are in”; “world or landscape in which human beings move and find themselves in”.</p>	<p>‘How do you not have cell service or how do you not have access to these things?’ was my first thought. ‘How do people live like this?’ But at the same time I understood that things were different [on the reservation]. That was a learning curve for me to really learn what their norm is versus what my norm was</p>	<p>I haven't been out there [to the reservation] but just knowing that, getting feedback from other people about the living conditions, like some people don't have floors, or have dirt floors. I can't fathom that</p> <p>We're way off the map in these random towns...so I'm having to Google it and figure out, okay, where am I at, where is there a hospital near there, how can I set this up?</p>		
<p><b>Relationality:</b> “relation we maintain with others in the interpersonal space that we share with them”; “develop a conversational relation which allows us to transcend ourselves”; “human beings have searched in this experience for the other, the communal, the social”</p>	<p>That was sort of frustrating because I felt like ‘I'm really trying to do this for you but your phone is always off’. I learned later that the phone is always off because he lives on the reservation and there's no service out there. I was not aware of that at first so here I am thinking he's just not compliant, I'm busting my butt and he's not helping me. Then I was like, ‘whoa, okay,</p>	<p>It gives me an opportunity to try to communicate with him and I find new ways and then it makes me feel good when I can actually talk to him, but not with words. Like if I look at him and do a thumbs up he'll do a thumbs up back at me if he's good but he'll do a thumbs down if he wants something... it's not something that I was able to do with my first Native American patient, it is something that over time I am starting to develop ways to work around the barriers and communicate.</p>	<p>We had had a whole conversation with each other. He didn't speak English, I didn't speak [AI language] but we were still able to talk somehow. He understood some words and I understood what he was saying. I didn't understand words but I did understand where he was going with it so we were able to kind of have a conversation. When I got up to walk off I am like, ‘I have no</p>	<p>I asked the other nurses, “this lady, you guys, do you think she just doesn't like me, maybe I shouldn't take her, maybe she wants someone else to take care of her?” They're like, ‘no-no, she's like that with us.’</p> <p>I try to talk to her and it doesn't ever seem to get me anywhere until the other day, I noticed about her responses,</p>

	<p>backtrack'. [Once] I understood that part and I finally got in touch with him, he was very compliant</p> <p>I was pretty frustrated because I felt like 'I care about your life but you don't'. That was the wrong assumption in my head but at the same time, without having other previous knowledge, it was my first assumption because this is not working. Now I have a better grasp on things so even though I was frustrated then, now when things like that do come about I kind of have a little bit more sympathy, empathy, can kind of understand why the process is what it is...</p> <p>I called and the only two numbers we had were him and his daughter, and I'd call them both religiously for three months and then finally, I need to use this energy for people who want to get better. That's how my mind thought about it. I see so many people in here that genuinely really want to get better and maybe are never going to, and this person has a chance to and they're just throwing it away.</p>	<p>A lot of times I think what I am learning here is that most of the time they just don't understand what's going on. They don't want to ask for clarification, not entirely sure why, or maybe it's the language barrier</p> <p>I actually had some Native patients who don't want me to touch them. And I think the reason they don't want me to touch them is not because they don't like me as a person, it's that I'm not part of their culture. A lot of times they prefer her [the AI nurse] because then they don't have to get out of their norm to come into mine, even though we adapt to them too. I feel like sometimes you get a little backlash.</p> <p>A piece of me says, 'I'm a good nurse, why wouldn't you want me?' But the bigger piece of me understands the bigger picture and why they feel more comfortable with a Native American because of the things that their ancestors and they themselves have been discriminated against. Their trust issues, I can understand that. So I don't get offended necessarily, it makes me want to reach out that much more to say, 'I'm here, let me help you, I'm just as good and it is not because I think I'm better than this one, it's because I really want to help you'. So that part's a little frustrating, not hurtful. But the downside of it is you really do want to help and</p>	<p>idea what we just talked about but it felt good. I know what I said but I have no idea what he said and he knows what he said but he has no idea what I said'. But it was still a full conversation and it was a connecting moment, a moment that he felt comfortable around me and he was the one who previously just wanted a Native American nurse and not me.</p> <p>He's like, "Because I'm scared". He was being funny, and I'm, "Scared? What are you scared of?" He's like, "White people". We both just laughed about it and kind of laughed it off</p> <p>but that kind of stuck with me because I can see the fear sometimes</p> <p>My first response was to giggle because I knew that he was partially joking, but I didn't get upset or anything. I did understand his fear, I don't want to say his fear because I don't know that he's really afraid, but his reaction to Caucasian people I guess I understand it because where I come from there's still a lot of racial issues with African Americans and Whites...So I understand. So even though it is</p>	<p>it's not that she doesn't talk, she's sad. I got that from her and then I told our Native American nurse, 'when you get a chance I think she would be more receptive from you and I think maybe tell her about the support groups that happen here every Tuesday, that kind of thing' and I said 'I think she's really sad'. I thought at first that either she was just grumpy or she just was detached from the situation emotionally. I think it's a matter of depression...</p>
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	<p>That really bothers me because it's unfair in my mind. It's not fair that you have this cancer that can be cured and this person has this cancer that they wish they could have caught it when it could have been cured</p>	<p>you are viewed as somebody who probably doesn't</p> <p>A couple of times I just sat down and tried to talk to her and she didn't have it a few times, she was not interested in me talking to her, she would respond to me but short answers</p> <p>I try to make a joke or make small talk, "Hey how are you?" That goes a long way. Even if it takes 20 'hey, how are you's' it will get you somewhere. I've learned that, I've adapted based upon my responses I'm getting from the patients</p> <p>It's a little frustrating at times because you don't always get the response that you want. Then other times I don't have a reaction because I can just tell that they didn't understand a word I just said. At that point I usually get a Native American nurse because then she can help relay what I am trying to say</p> <p>I was getting frustrated with the daughter because she would bring her father and then she'd just leave him here knowing that he can't speak English and that we can't—our Native American speaking nurse was not here. I was like, "How could you just leave your father knowing that he can't tell anybody what he wants and we can't tell him what we want? Why would you do that?" I still don't understand that part of it, that's probably one of the most frustrating things, when</p>	<p>a different population and we're talking about two different racial things, when he said that all it made me think about back home, how people treat African Americans back home and then people think that's not real anymore and they think racism is not real. But if they think that they are either part of it or they never lived back there because it is very much still there</p> <p>I can't really have an opinion about discrimination, if that makes any sense. But in the same aspect, because of his fear of White people or even for an African American to say they have fear of a White person, in general it makes me—I'm not being discriminated against, but that kind of is discrimination in an aspect</p> <p>There was a strain of truth in there somewhere and it didn't offend me</p> <p>Because he actually taught me how to say 'White people' [in his language] because after that joke I was like, 'How do you say that in _____?' and he said it back to me and I was trying to say it and he was laughing at me because I couldn't get it and my</p>	
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		<p>outlook and my way of thinking and adapt to someone else if necessary but I can't change them. I've really understood that and at first I didn't, at first when I started here very frustrated...</p> <p>How do you even get from 'hello' to 'I'm starting an IV'? How do you get to that when there's a language barrier or there's a straight face, no expression, there's no personality or anything? That's when I started to think, 'okay. Let's use some tactics here, let's tell a joke'</p> <p>Most of the time it's like, 'Where's the Native American nurse?' That's the first thing that comes out of their mouth, so you know that you are not the person that they want</p> <p>I take a minute to recollect myself and remember that I don't have cancer but they do and whether or not they admit it or whether or not this is the case, they are probably scared</p> <p>It is probably more terrifying to them that there's a language barrier and they are not understanding completely everything that we're saying than it is for me to be frustrated. So I understand that...</p> <p>I don't have cancer; I don't understand what he's feeling so I can't relate enough to get upset with him because there's probably a piece of the puzzle I'm</p>		
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		<p>missing, whether it is a language barrier, whether it is a cultural thing, whether it is just knowledge in general. There are a lot of times that I catch myself, “How do they not know that drinking Gatorade would help them if they’re vomiting? I feel like everybody should know that, or hydrating, drinking lots of water is a good thing. How do people not know that?” But at the same time, if you are not in health care you don’t think about those things every day so I think about somebody with a language barrier, somebody who has a terminal illness or maybe not even terminal but whatever’s going on they have an illness or disease going on and I don’t have those factors in my life. So I can’t imagine what they feel like, so why am I stressing over me when their situation has to be a lot worse than mine? So a lot of times I just try to put it in perspective for myself so I don’t stay upset, I don’t hold a grudge</p> <p>You start to feel like a little family because you see the same people every few weeks, or every week, and you start to really feel like you got to know them, they feel like they know you</p> <p>He was like, “No, really, thank you for helping save my life”. That almost made me cry. I was like, ‘nobody’s every told me that’. People have told me ‘thank you’ but not ‘thank you for saving their life’... When he said that it was a really good feeling, I just felt really happy,</p>		
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		<p>really thankful that somebody noticed that we did help somehow. We played a part a little bit. Then I felt guilty because 'how did I save your life?' I just helped you, I just did my job. I didn't save your life, don't thank me, go thank the doctor. That thanks is deserved somewhere else, not with me.... That felt really genuine and really sweet but I don't feel like I did that, I feel like I did nothing, I feel like I just hung meds and charted on him and that was it. Even though there's much more to my job, that's the technical part of it so I felt like that was all I did</p> <p>I think there have been times where they've felt discriminated against, and they see you being nice to somebody else then they start to open up or trust you a little bit and then you're no longer a stranger, you're no longer a Caucasian, you're no longer anything but their nurse and that's what you should be</p> <p>I didn't know if it was disrespectful to speak to her in English knowing she can't speak English. You know what I mean? Or if it was disrespectful to pass it off to somebody else that can speak her language? I didn't want to be rude, but I didn't know [what to do]... I could have broken that barrier between us, but I don't know</p> <p>Maybe they're very family oriented, but just in a different way...</p>		
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		<p>It's like there's no relationship here, I'm just here to get my treatment and go home. Not that there has to be a personal relationship, but I do like to develop a relationship because I am taking care of you, but you will see me again next week</p> <p>I have other things that I could waste my mind and time on I feel like. I guess waste is not an appropriate term, but that's what it feels like, that frustration coming out when I get, not rejected, but just hit a wall every time I try to do something to help. That is extremely frustrating, but only because—I'm not really sure if that's why—I know I have a due diligence as a nurse to the patient and I'm doing my due diligence, but how do I—when do I cut it off or do I just keep trying?</p> <p>And then doctor by the end of the visit convinces them that they're supposed to be on it [medication] and they will maybe be supplied for another month or two and then we have the same problem again. For some people, it's a vicious cycle it seems, and then other people seem to learn their lesson. I don't want to say it like that, but it seems we're kind of babysitting a little bit at times in that area and maybe it's the lack of education too, as far as their knowledge with cancer itself and how to treat it and the fact that it may not be treatable at one point if you don't do it now</p>		
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		<p>I'm going to have to just turn this off and he's just going to be that guy never answers us back or doesn't comply and I just put him in that category, which sounds judgmental and bad in a way, but I don't know how else to channel it</p> <p>I feel like they don't trust me a lot of the time, and I don't know if that's because I'm Caucasian or if it's just because they don't know a whole lot about their cancer and everything that's going on? I get the impression of both sometimes</p> <p>In some instances I would say my relationship grows stronger with them, even through frustrating times, and then there are some instances where I cut off the relationship and I'm just a nurse</p> <p>It feels just like a relationship develops at that point when you can relate somehow because it feels like when you relate to people on a level with anything –it don't matter if it's the same interest in foods –it seems to develop a stronger relationship. Then you can really have conversations and communicate better and they're more compliant. But then there's times where I don't get a response and I eventually just say, 'okay'. I'm not going to walk away upset or offended</p> <p>I've just noticed several patients that have come to mind that maybe treated me differently before are so open now</p>		
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and just loving and we have such a bond...Now I notice the newer ones that are coming in, I'm getting introduced back to that old feeling where I don't know if I'm going to get a smile or just no words at all...it's not going to stop me from talking and maybe once they feel comfortable they'll talk to me

I just realized all the dynamics of it all and I just let it go and I guess when I say that I just continue to talk to the people and try to open up that type of relationship, whether they talk back or not, I just continue to do that. It doesn't hurt when they don't—I'm null and void there now. I understand the mindset and I don't blame anyone. Like I totally understand

I don't know how to even describe it, but it's a very positive experience [caring for AIs]. That's for sure. It's definitely opened my eyes and any judgments that have ever came up in my mind are no longer there [regarding] any population...I think about all the judgment being passed to certain cultures and certain religions. Then I noticed that I had a few judgments of my own obviously when I first started working with the Native American population, not necessarily like racial. More of just like 'they're not listening to me, they don't like me', that kind of thing, but that's not the case. I mean I understand that now. It's just definitely opened my

		<p>mind to see my blindness. Yeah, it's been a positive experience, that's for sure</p> <p>They don't talk a lot or they don't—I learn things about them along the way as well which kind of helps hold the relationship eventually</p> <p>She was extremely grateful. That part just kind of let it digest. I no longer felt the frustration. It was for that split second I was aggravated because I felt like I am doing everything but basically taking the scan for you...I care about you enough that I'm trying to do this—that's how I feel sometimes. I still occasionally will get wrapped up in that. I'm human, but then I just am reminded at some point that a lot of times it's a cultural thing, a lot of times its compliance. There's no knowledge. They don't understand why it is that important. Maybe in the doctor's visit when it was them and the doctor, the doctor doesn't realize that they don't speak great English. Just because they spoke a few words they think they understand everything. Maybe they need a translator. I mean it opens my eyes to a lot of different options that maybe [I didn't see] before and didn't open our mind to</p> <p>You just accept reality and you work around it...but it is challenging and it does get frustrating, but I also understand it at this same time. It's part of my job</p>		
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I care about people and I think that's what motivates me enough, and I'm intrigued a little bit about the culture. I like to learn, to know what that word means or how to say it, or the different spiritual things they do or the dances that are happening. Like the jewelry that they bring and just have us all look at. We [enjoy] stuff like that. It's a very unique culture...I would've never known any of this kind of stuff and I appreciate that and I think that motivates me more too as well to continue—it's not an easy field

There's a lot of cultural barriers when you start dealing with people one on one, but there's more things to learn and they learn about you and how you change each other. It's just motivating to do it every day...even though there are negative times there are—there's more good than bad in it. It's very fulfilling

THREE TO FOUR WORDS

DESCRIBING RELATIONSHIP: I would say 'compassion' being one of them. I'm 'intrigued by the culture'. I always want to talk more to the patients to figure out how their personalities are and what they do. I don't know, as like I said, sometimes even learning about meditation. I guess that falls into 'culture'. I do think about a 'language barrier'. It's not necessarily a bad thought. I just am reminded that it could be there

		<p>Probably before this interview process maybe I would've been more frustrated than I was. I was frustrated but I probably wouldn't have been so quick to understand that...I guess just talking about it and hearing some of my own judgments or my own just blindness I guess... [Now I] think outside of my box, like outside of me and how it's affecting them and I'm a little bit more open to what they feel, more than what just I feel. It's hard. It's human. You're me-me-me-me-me. I truly can think past me a little bit and understand why maybe something happened or why it didn't or why whatever. I don't know. I'm able to think through things a little bit more.</p> <p>Like on the outside of myself...I definitely have benefited from it for sure. Like I said, my patience level has just grown more and I don't get quite as frustrated as I normally would just because a piece of me does understand or can see why things went the way they did.</p>		
<p><b>Temporality:</b> “subjective time”; “appears to speed up...or slow down”; “temporal way of being in the world”; “past, present, and future constitute the horizons of a person's...landscape”; reinterpreting the past; “perspective on life to come”</p>		<p>We have several patients who just show up for treatment when they want to, meaning they might go two months, they might no-show to their appointments and they are supposed to get treatment every two weeks. They might come the first two weeks then you don't hear from them for two months, they don't show, they don't call, you don't even know if they're alive and then they show up or call two months later and want a</p>	<p>I know how ridiculous things are back there [where she is from] so it kind of seemed in the same instant two different cultures or two different areas [colliding]</p>	

		<p>medicine refilled or something...So you get them scheduled again and then you just go through the same cycle</p> <p>The longer I'm there, the more they see me. Some of the same people that's been there since I started are now getting used to me and they open up to talk to me a lot more</p> <p>I've noticed that my attitude has changed over the year too because I'm starting to understand and realize this is part of a cycle where I'm going to go through it with every new patient</p>		
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### Thematic Summary

**Theme #1:** In the beginning she was an *interloper* forced onto her patients by cancer. They eyed her skeptically, responding with silence and blank stares. Their cold retorts prompt a *persistence and determination* in her to *break down the barriers* between them. She saw their protectiveness as a personal challenge, something to be overcome with humor, cordiality, and kindness even when unrequited. Eventually, she exhausted herself with this endless game where she was the only player and she grew weary of constantly developing *new tactics* that seemed to lead nowhere. She withdrew and shut down, resorting to mindlessly completing tasks while *her heart hungered for more*.

More recently, she has come to *accept her patients unconditionally*, relinquishing any need for validation. Her persistence has paid off over time in the form of tentative connections and the comfort of familiarity.

**Essence:** *Initially an interloper forced onto her patients by cancer, she took on their guardedness as a personal challenge but found her caring overtones insufficient and unrequited. Over time, she began to embrace unconditional acceptance and finds comfort and connection in familiarity.*

**Theme#2:** She defines herself by what she is not (an AI nurse), and there are times when she feels *the sting of rejection* from her patients. She wears her otherness literally on her skin; it is inescapable and obvious. She experiences being a second-choice option in many instances. While her AI colleague has all of the right words and instantaneous connection, she is left to bumble her way through even the most basic interactions and to imagine relationships that may or may not be legitimate, calling into question her ability to bond when it matters most. But, the AI nurse is her comrade, her fellow sojourner on the emotionally erratic road of cancer; they are bonded together by their shared commitment to these patients regardless of the unfairness of it all. She does not blame her patients for their *overt preference*, knowing that she cannot change the course of history nor undo the past transgressions that hang in the air between them like smoke. She can, however, influence the present moment and she commits herself to changing their perceptions of her by using respect and diplomacy at all times.

**Essence:** *Feeling the painful and discouraging sting of rejection, she recognizes the historical origins of her second-choice status as a non-Native nurse while committing herself to changing their shared future.*

**Theme#3:** She is in a constant mode of adjusting, adapting, and learning. *Things are rarely what they initially appear to be* with her AI cancer patients, and this is an unsettling feeling that often leads to the abandonment of previously held convictions and assumptions. She was unprepared for this work and has had to create her own lessons, playing the role of teacher and student simultaneously. She is challenged by her patients' complex realities and is forced to reevaluate her own, questioning everything she thought she knew. She eventually *faces her own bias* and finds an incredible burden lifted from her shoulders. With her eyes, mind, and heart open, she is able to transcend differences and forge human-to-human connection. Her patients respond to this unencumbered approach and she has the sensation of things *falling into place* as her caring intentions as a nurse are finally received.

**Essence:** *As if she is delivering care on quicksand, she learns to constantly adjust, adapt, and reframe her expectations in order to face her own biases and deliver the kind of open and sincere care that she knows to be true.*

**Theme#4:** She spends an exorbitant amount of time *pursuing* her patients; this is back breaking yet necessary work.

Sometimes they disappear into the abyss of the reservation, leaving her standing with urgent prescriptions and unfilled orders. She can only reach out so far into the unknown; they must reach back to her, meeting in the middle ground where treatment occurs. Sometimes her patients reappear and she feels a visceral relief; other times they are all caught in a *never-ending cycle* of unanswered calls, missed appointments, and bureaucracy that feel *demanding and hopeless*. She is at the mercy of this inevitable cycle, unable to alter its perpetual motion. She takes protective measures against the personal disappointment that it generates, steeling herself against the physician's aggravation and the patient's unspoken complicity.

**Essence:** *Engaged in an endless cycle of dysfunction and powerlessness, she has come to terms with a constant, sometimes futile pursuit of time and hope.*

### **Participant #8** **Wholistic/Sententious Description**

As an AI woman in her mid-thirties, this nurse comes across as thoughtful and deliberate, often pausing before responding to queries during the interviewing process. She is married with a child, and began her professional life not in nursing but in social work, where she developed an appreciation for “the whole person” beyond the biomedical context. She is responsible for coordinating the care of AI cancer patients at a general health clinic located on a semi-rural reservation outside of a southwestern metropolitan area. Although this location is within twenty minutes of the city, it can feel like an entirely different world as evidenced by her stories of overcoming significant geographical, logistical, and communication barriers as she strives to connect her patients to the cancer care they need.

Overall, her relationships are comprised of security, trust, and dedication to AI people as an AI nurse. She is instantly recognizable to this population, although she acknowledges that “it took time for me to build rapport. It wasn’t as hard as for outsiders that aren’t Native who struggle to build the same relationship that I have in a shorter amount of time”, but her own AI identity “helps them feel more secure, more trusting”. This instant connection seems to be even more pronounced with her elderly patients:

Maybe not so much with the younger generation but with the elderly right away, they’ll appreciate that I’m Native. They ask me if I speak [AI language]. That kind of helps me...Right away you can see they open up more and more each time I see them. It starts with the initial contact...Sometimes they feel safe within their own people.

Although she serves a different tribe than her own (and speaks a different AI language), it seems to convey something meaningful and safe to AI patients when they know that she speaks her own language, too. Likewise, it sends a message to her reservation-dwelling patients that she, too, comes from the reservation and understands the context. “I understand the hardships... I think letting them know that I come also from the reservation and that I understand [is helpful].” She seems to straddle two worlds, the biomedical one and the AI one, and instinctively appreciates her patients’ struggles to do the same. “You think about these patients who come from the reservation and they come to the cancer center and it’s a whole new environment. It helps me in that I understand both worlds and I don’t take anything for granted”. She recognizes that her “patients need me to be the mediator, the middle person” in many situations.

Her familiarity and comfort with this role is especially poignant when she points out a history of previous nurses in her position abandoning the community. “That [high] turnover rate—I’m almost certain that it impacted their ability to trust certain nurses, to trust the health care they were getting”. In the beginning, she found many of her patients to be “hesitant” or unforthcoming, reminding herself “not to take it personally... When I did start to feel a little overwhelmed I had to remind myself that it probably isn’t directed at me directly. It’s just a lot of frustrations with the whole care [system]”. As a result, she takes her work very seriously, feeling especially compelled to ensure that they receive proper and compassionate care, and that “things go full circle”.

This sense of dedication, however, comes at a cost in the form of “burn out”. “My level of commitment to these patients is what is exhausting at times,” she admits. This sensation manifests in sensations of being “overwhelmed”, “frustrated”, “physically drained”, and

“emotionally exhausted”. When this occurs she rests, seeks support from family and colleagues, and participates in traditional ceremonies. Although she describes burn out as “a complete cycle...I guess more like a roller coaster”, she recognizes the importance of self-care as a nurse working in the AI cancer field:

I think it’s important that I can stay mentally and physically intact to be able to continue to do my job. I think it’s important to realize that we’re human too. We can reach that point. We have to take care of ourselves so that we can help take care of other people.

Contributing to her frustration is her exposure to often preventable poor outcomes among her AI patients, such as insufficient wound care related to transportation limitations or post-operative patients who live in primitive conditions being sent home with wheelchairs. These scenarios hang over her as she works to navigate present-day systemic bureaucracy and communicate with often culturally insensitive or ignorant cancer care providers. The upside to this complex navigation is that “working with these patients and talking to them, and helping them, and dealing with all their circumstances, and helping them to navigate through their care, I think they've learned to appreciate the relationship we have”. She feels motivated by and connected to her patients, stating “there is no way I can’t be tied to these patients...I think that’s probably why I do what I do, because I feel for patients.” These intricate ties to one another foster a feeling of being *part of a community* and *at home*:

I think ‘home’, for me, is being able to be part of a community that’s bigger than just you. You have this tie to people who are not necessarily family, but you have this connection to them. You have this feeling that you’re not alone... that you belong somewhere, that you’re not the outcast or you’re not the outsider, in terms of the emotional connection to your surroundings.

She is both compelled and honored to serve AI people knowing that even as one individual nurse, she serves a much greater cause –“who you are is bigger than you”. She bears witness to their resiliency in the face of cancer, observing “a lot of patients don’t realize that they are strong. They think that the cancer is taking their life away... [but] they got from the day of the diagnosis to this far.” Having an open, trusting relationship “improves their participation in their care”, but she is reluctant to take credit for fostering such a positive patient-nurse dynamic. “I don’t know if ‘humble’ is the word... It feels good. I just leave it [at that]. I don’t pride myself on it.”

**Sententious Formulation:** AI nurses foster patient relationships grounded in servitude, honor, and security, contributing to a sense of being *at home* in AI communities.

Level One Matrix  
 Interview #1; Interview #2

<p>#1: Generalized quotes about providing cancer care to AI patients (potentially significant)</p>	<p>#2: She experienced total exhaustion (physical, mental, emotional, and spiritual) after attempting to locate and then facilitate treatment for an AI woman who had been lost to follow-up. This scenario seems to have been precipitated by high staff turn-over before her arrival and general systemic failures, which she finds frustrating and fatiguing to contend with day in and day out.</p>	<p>#3: She describes an early experience shortly after arriving on this reservation when she began caring for an AI woman with a serious complication from a cancer surgery. Slowly, she developed a caring relationship with the woman, but the experience brought forth a host of ethical and professional dilemmas as the nurse was thrust into relentless advocacy for the patient. She found this to ultimately be a rewarding experience that seems to have instilled a sense of purpose and belonging for her.</p>	<p>#4: In the interim between interviews, she cared for and counseled a patient and her family regarding the patient’s recent terminal diagnosis. While the news was somewhat of a shock, she quickly moved into the role of patient advocate, care coordinator, and unequivocal supporter. Although rewarding, this scenario is tinged with grief for the impending loss.</p>	
<p><b>Corporeality:</b> “we are always bodily in the world”, we meet people “first of all through his or her body”; “when the body is the object of someone else’s gaze, it may lose its naturalness”, both revealing and concealing.</p>	<p>They’re reaching back to me whereas before I was hitting almost a brick wall. Leaving a message, nothing, nothing. Now I do get the response back. They do keep me in the loop</p> <p style="text-align: center;">Cancer is not a light word</p> <p>I have to learn how to juggle...you get bombarded with everything, phone calls, your patients in the treatment room...It can be pure exhaustion. You’re just constantly juggling</p>			<p>Helping them to realize that even though they feel alone in all of this situation, even though...everything is heavy, a heavy burden, that we have each other. We have family. We have other means to provide support. They're not alone</p>

	<p>I sit down—I like to sit down with the patient.</p> <p>Now I see the patients, maybe they give me a hug. It's like, okay, I'm doing okay. That's my reward I guess. That's when I know I've done what I needed to do</p> <p>I could easily not pay too much attention to what needs to be done, because I'm too busy focusing on myself or focusing on the burdens that I carry I have to learn to juggle it so that I'm there for the patients and doing the best I can for them</p> <p>I think it's personal—I feel a personal fulfillment. It's nothing like your salary. I think physically, it's <i>in</i> me. I feel the reward... It's internal. All the reward for me is internal</p> <p>I just get so exhausted. I feel that I don't have the energy. Then I experience it enough that I know I [can] get myself out of it. It's a complete cycle... I guess more like a roller coaster. There's high moments when you feel like you've done what you can. You feel this self-fulfillment. Then there are always the lows. You feel exhausted. You feel drained</p> <p>I can feel when I'm getting</p>			
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	<p>exhausted. I don't let myself get under all the pressures of everything. Sometimes I take a couple days off</p>			
<p><b>Spatiality:</b> “felt space”; “inquiring into the ways we experience spatial dimensions of our day-to-day existence”; “we become that space that we are in”; “world or landscape in which human beings move and find themselves in”.</p>	<p>I think it’s just important that you understand that there are those layers [to cancer care] and try to address it in that manner versus not trying to pull through or not trying to follow through with these patients. That’s where a lot of the care doesn’t happen. That’s where they get lost [to follow-up]</p> <p>You think about these patients who come from the reservation and they come to the cancer center and it’s a whole new environment. It helps me in that I understand both worlds and I don’t take anything for granted. I learn. It just keeps my eyes open...</p> <p>This is like home for me. It’s not going to be a big adjustment for me [to work on this reservation]</p> <p>It didn't start off that way. I had to work with the patients, remind them, call them a lot. I think we've reached good ground</p> <p>I think now that I've worked there as long as I have and working with these patients, I think we're both reaching this ground where the patient will call me to remind me</p>		<p>I just had to learn that if I know the right places to look, I can find the answers that I need... I've learned you don't have to find all the answers in one place</p>	

	<p>Talking to them and letting them know their messages aren't going into [outer] space. It's coming to me. I'm hearing them. I'm doing something about it</p> <p>I think 'home', for me, is being able to be part of a community that's bigger than just you. You have this tie to people who are not necessarily family, but you have this connection to them. You have this feeling that you're not alone. Feeling that you belong somewhere. That you're not the outcast or you're not the outsider, in terms of the emotional connection to your surroundings</p> <p>Growing up on the reservation, you're around people like you. You're around the community. You develop a bond with the community members, which are not all family, but you feel that way. You're all family. I think that's why I say it feels like home</p> <p>You feel that connection—right away you go there, you'll feel the community sense within the clinic. Then you don't automatically become part, because you're new there. You slowly get let into the circle. You slowly get included</p> <p>...feeling like I'm at home is that you sense a community. You sense a closeness within the little clinic</p>			
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	<p>there... They were inviting me to stuff. It took a while for me to get there, but that was home to me because that's what home is like</p> <p>You learn immediately that it's not just you. Who you are is bigger than just you... It's not just you. It's everybody. Your neighbors. It's your whole community</p>			
<p><b>Relationality:</b> “relation we maintain with others in the interpersonal space that we share with them”; “develop a conversational relation which allows us to transcend ourselves”; “human beings have searched in this experience for the other, the communal, the social”</p>	<p>How do I build a good relationship to where the patient lets you know, “This is how I’m feeling. This is what I need”? I know when I first started I didn’t have that trust immediately, of course, because I’m new to the facility and new to the patients. I think what did help me a lot in dealing with this population is that I’m [AI]. Right away they say, “Are you [AI]? What tribe are you from?” It was easier for me to build relationships. I’m not going to say the barriers weren’t there, but that was my ‘in’ to letting the patients relate to me, talk to me</p> <p>It took time for me to build rapport. It wasn’t as hard as for outsiders that aren’t Native who struggle to build the same relationship that I have in a shorter amount of time. I think that a lot of it has to do with me being [AI]. I don’t know if it helps them feel more secure, more trusting</p> <p>I think the patient population is so</p>	<p>She didn’t have a stable home to where she went from family members to family members. It made it difficult for me to locate, to track her down...It was exhausting to actively to that—not that I didn’t actively try to seek her out, I did</p> <p>I don’t know if it was more that she was tired from the treatments, tired from the whole thing, or that she didn’t want the help that we were trying to give her</p> <p>I was physically, emotionally exhausted, drained...I felt myself getting so exhausted and almost, not irritable, but frustrated. I can sense it in myself when I reach that total burnout</p>	<p>When I first started I was still learning, and building a relationship with her. I would do a dressing change, I would talk to her</p> <p>I had to get her back on track [with her treatment]. I think it was just picking up the pieces with different patients and trying to figure out ‘where are we at?’ or ‘are you keeping up with your care? Do we need to make sure that we start you back up?’</p> <p>I was overwhelmed thinking ‘is this something I should be doing?’ I’m like, ‘is this something that I’m supposed to be doing? Do I just call the cancer center and then hopefully they call her and let her know? What am I supposed to do? What do I do? Somebody help me’</p>	<p>We didn't see her for a while. It turned out she has a cancer that has metastasized. That's a new diagnosis... that was a shock, because it was like at random...</p> <p>My provider and myself are more attentive to what the patient desires, because she's had a long road</p> <p>I was very shocked. Very saddened for her. The daughter is very emotional. She let me know what was happening. It was something that brought me down within that conversation with the daughter</p> <p>For myself, it's very difficult. I think that's one of my biggest downfalls is that I get very emotionally involved in a lot of my patient care. In schooling, you learn that you can't. You have to be careful. You get burnt out. For me, there's no off and on switch. There never has been. I don't think there ever will be. [Laughs] These patients, because I</p>

	<p>unique and there are so many areas to focus on that some of them get lost in the shuffle</p> <p>I think I kind of found myself a little frustrated because I was getting calls from the cancer center...Getting feedback on what was keeping them from scheduling these appointments. They [patients] weren't very open</p> <p>I would tell them, "I know where I am from there's a lot of traditional families. Not all homes have electricity. I understand the hardships..." Slowly they'll start telling me [their situation]...I think letting them know that I come also from the reservation and that I understand [was helpful]</p> <p>Now that I've been there for as long as I have, I have built this relationship with the patients...They are keeping open communication with me. I hear a lot more from them. It's always a good feeling when they call me...</p> <p>It's very rewarding. I see where I started, where I've come to now. Where I am now, I see the big change. Some might be little changes, some might be big changes, but I see it</p> <p>I think it's important that I can stay</p>	<p>I was overwhelmed and frustrated because coming from the cancer center it was like, why isn't this being done? I also understand that there are reasons why the appointments aren't being kept, the appointments are being missed. I've learned that even though the appointment is two or three weeks ahead I have to start planning for the patient now</p>	<p>[Taking care of her made me feel] that I could do something. That I was in the right place. That it was in the scope of my clinical description there at that facility to do something about it, to talk to her, to make sure this was happening. I didn't know if I was overstepping boundaries. I didn't know if that was not what I'm supposed to be doing. It was just an interesting, new environment that I didn't know anything about</p> <p>I've learned it's not just me trying to figure out what I need to do. I had to learn my resources. Talk to my provider. Talk to sometimes even just the members of the [tribe] themselves...</p>	<p>see them all the time, they become almost like family. Because they do their care, they follow up with me. They call me. They bring us cookies. They bring us cards. All the holidays, they'll bring things to us. It's hard not to be emotionally tied to them</p>
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	<p>mentally and physically intact to be able to continue to do my job. I think it's important to realize that we're human too. We can reach that point. We have to take care of ourselves so that we can help take care of other people</p> <p>They let you know [they appreciate you]. That lets me know that I'm not losing my mind for nothing. I'm doing what I can. It's, I guess, just being able to know that you're doing something, little or small, or big</p> <p>I don't know if it's because of the level of care I like to see for my patients get that I burn myself out. I don't know if we all reach that in the clinic, we all reach that same level of exhaustion. It could be a different level of wanting to ensure that the patients are okay...I want to know that I contacted the patient. I want to know that I've done everything I possibly could, not leave that one voicemail and be done</p> <p>Maybe just my level of commitment to these patients is what is exhausting at times</p> <p>I let the patients know that I'm following up, let them know that I care so in return I don't have the resistance or difficulty as when I first started</p>			
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	<p>It was like, “Okay, she left. You’re taking her spot. She just got here, now when are you going to leave?” That was kind of the tone of what my interaction with them was from the very beginning. I don’t know if that turnover rate—I’m almost certain that it impacted their ability to trust certain nurses, to trust the health care they were getting because they finally [shared] their story to the person and the person is gone. Now it’s another person and another person and another person</p> <p>I think I had to step back and realize, try to understand why they were very hesitant to jump on board right away with my nurse visits, to come talk to me. I had to step back and realize they’re going through probably one of the hardest things they’ve ever been in in their entire lives...I had to remind myself not to take it personally. At times when I did start to feel a little overwhelmed I had to remind myself that it probably isn’t directed at me directly. It’s just a lot of frustrations with the whole care [system]</p> <p>It gets redundant [chasing patients]— I mean, you just try to find what works. Then once you find something that works that’s where you keep going until you need to find</p>			
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	<p>something else that works better</p> <p>I know that there are a lot of times that they do not understand how serious what they are going through is. They do not understand or they feel more overwhelmed with each appointment that they're keeping</p> <p>They call the patient but I take it a step further and call the patient myself...It works well for me to know that the patient is getting that follow-up phone call. If I call them myself I know that it's done, not somebody telling me it's done and the patient saying, "They didn't call me." It makes me feel good in knowing that I followed it through all the way to as far as I could possibly follow it through</p> <p>I don't know if it's just a lot of the extra things that I do is for me to feel like I've done what I can, for me to have that feeling of I've done what I can</p> <p>Sometimes I don't know if I'm just enabling them just to feel like somebody is managing their care enough to actively make sure these things are happening on their own. I feel like if I don't take that step in helping them in the way that I do then the care—I'm not saying they won't follow up with their care but</p>			
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	<p>the chance of them not is higher than if I didn't...I feel like if I don't follow up then I don't know if it's being done. I like to stay in the loop so I know what's happening. I think that's my way 'in'</p> <p>Even though it can be exhausting, it comes down to who else is going to do it [care for these patients]? Who else is going to do it?</p> <p>It makes me feel good [to be hugged or thanked]. It makes me feel that I've done the best that I could. It makes me feel accomplished. It lets me know that everything that I put into making sure everything was in the work flow, that it was not done for nothing, that it was appreciated, that it has a good outcome</p> <p>[Being AI] helped me build relationships with them a lot, I don't want to say easier, but I was able to build a better rapport with them. That was always their first question. "Are you Native? What tribe are you from?" Right away.</p> <p>Maybe not so much with the younger generation but with the elderly right away. They'll appreciate that I'm Native. They ask me if I speak [AI language]. That kind of helps me...Right away you can see they open up more and more each time I</p>			
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	<p>see them. It starts with the initial contact... Sometimes they feel safe within their own people</p> <p>I feel like if I'm not fully intact, my patients don't get 100 percent of my care, because I'm lacking those areas. I feel like I'm able to perform best to my abilities when I feel like I'm at a good place myself</p> <p>I feel like that hinders my ability to look at the whole situation and be able to help the patient better, because I am frustrated, or I am overwhelmed, or stuck in another patient's situation. I have to be able to gather myself</p> <p>Sometimes a patient [or] the family, all they need is somebody to listen to them. Somebody to hear their anger or their frustration. They don't really need me to physically do something for them, just be their mental ventilator just for them to talk to me. Sometimes that's all they need. I think that I can do that better when I know how to keep myself intact.... sometimes all they need is just somebody to hear them out, all the frustration that happens with cancer, with the sadness</p> <p>Sometimes being the mediator can be a little [exhausting]—if there's so much disagreement in the families,</p>			
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being the middle person can sometimes be exhausting, because you're trying to relay what is important... I think my goal in those kind of situations is to help the family understand the patient's the one that is experiencing all of that

Knowing that our relationship is strong enough for them to say, "I need you to listen to me. I need you to help me understand this. I need you."

There is no way I can't be tied to these patients. There's no way that they can experience what they're going through without me having some kind of tie to what the family is experiencing. I learned that early on. I think that's probably why I do what I do, because I feel for patients. I like to help patients

Cancer, to me, is a big, loaded word.

For myself, I see what it can physically, emotionally, spiritually do to a patient, the impact it has on that individual themselves. Then I see what it's doing to loved ones. It's something that takes, I think, a lot of strength. You have to have strength to carry through it and out of it. It's not always a bad outcome. It's just getting through it... A lot of patients don't realize that they are strong. They think that the cancer is taking

	<p>their life away, in a sense. You think about it, they got from the day of the diagnosis to this far. They're going through the treatment. They're going day to day, whether they realize it or not</p> <p>I see it as, "Okay. I may be tired, but I'm helping a patient understand what they were being told that they didn't understand at the cancer center." I'm seeing that my bouncing back and forth is an important component in the whole thing for everybody involved...to make sure that the things that they are requesting, their follow-up care is being done</p> <p>I know that the patients need me to be the mediator, the middle person...I think when I start to feel overwhelmed, I remind myself it has to happen. It has to for the patients to follow up with their care. It's key. It's key to the whole concept</p> <p>I like to see things go full circle. Make sure that the patients are getting the care that they need</p> <p>A lot of times, I know how frustrating that is. What if it were me? I think a lot of my work habits are self-created</p> <p>Sometimes, I do feel like I'm enabling the patient, but then again,</p>			
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	<p>there's that self-gratification knowing that I'm doing it. If I don't do it and leave it up to the patient, sometimes I'm afraid that those things will be missed. I think that just falls back to the kind of person I am</p> <p>There is a lot more appreciation in return for what I do. The patients are very grateful. "Thank you." Before, I don't want to say it was expected, but that appreciation wasn't felt half of the time. It was more for me. I think working with these patients and talking to them, and helping them, and dealing with all their circumstances, and helping them to navigate through their care, I think they've learned to appreciate the relationship we have a lot more</p> <p>Yes, it improves their participation in their care. It improves and you start to feel the positive—it just makes the relationship—I don't want to say better, but it brightens the relationship a lot more. You don't see a patient come in sad like they were before... I take it as a compliment. I think I just smile. I don't know if humble is the word... It feels good. I just leave it. I don't pride myself on it</p> <p>I try to draw the line there with my patient care. My colleagues, for my team, there's another RN and myself. We do a lot of picking each other up</p>			
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	<p>between the two of us. She'll sense when I'm getting irritable and getting a little exhausted... Just encouraging each other. We practically sit—our desks are connected. We do sense when it gets a little overwhelming, when we're starting to feel a little irritable</p>			
<p><b>Temporality:</b> “subjective time”; “appears to speed up...or slow down”; “temporal way of being in the world”; “past, present, and future constitute the horizons of a person’s...landscape”; reinterpreting the past; “perspective on life to come”</p>	<p>It can be time consuming [chasing patients]. It can take your time. The patient tells you one thing, ‘let the doctor know this’. You tell the doctor, ‘this is what needs to be done or this is what she needs to do’. You’re bouncing back and forth</p> <p>It almost takes me back to when I first started there. The nurse that was there prior to me had left. There was a time lapse between when she left and when I started. In the middle, within that time period, patients were frustrated, were angry... Going from there to where I'm at with my patients is night and day. It wasn't something that happened overnight</p>			

### Thematic Summary

**Theme #1:** She is *at home* in the community, a place that is familiar, comforting, and approachable. Although she had to work to gain entry in the beginning, her ability to transcend her patients' wariness and atone for previous disappointments was made exponentially easier by their shared heritage and her gentle persistence during the delivery of cancer care. She is instantaneously relatable to her patients, *one of them*, and they are eternally grateful for her presence. She fosters and protects their alliance, sensitive to the tenuous threads that bind them together during these vulnerable times.

**Essence:** **Transcending past abandonments through gentle persistence, she is *at home* and *deeply connected* to her patients and community as they are bound together by their shared heritage.**

**Theme #2:** To abandon this community would be betrayal to them, and also to herself. Her unfettered obligation towards them is clear and feels *intrinsically right* having arisen from her own deeply ingrained culture. She sees herself as a very small part of a much larger, more powerful universe; this creates an *unpretentious sense of responsibility* and commitment to those around her, particularly her own people. These sensations are so embedded into her very being that she sees no other way of existing as a nurse or as a human being, as she is first and foremost an AI person.

**Essence:** **Although spurred by an overarching sense of responsibility and commitment to nursing AI people, the duty is embedded in her own being so deeply that it feels *intrinsically right* and as natural as breathing air.**

**Theme #3:** Providing cancer care to the AI community is akin to 'juggling', an *exhausting routine* rife with competing demands, systemic complications, and cultural complexities. She is often overwhelmed and drained by this performance. Although accustomed to her patient's multilayered lives, she struggles to wade through numerous bureaucratic and contextual obstacles in order to connect them with the level of care they deserve. At times, she grows so weary of this work (and this unmerited world) that she must physically step away, taking time and space to replenish her emotional and mental energy. But, she knows that this level of attention and exertion are both inevitable and necessary in order to facilitate sufficient care, and there is *honor in her struggle* to do so. Moments of exhaustion are countered by moments of deep fulfillment and gratification.

**Essence:** **Although a convoluted and often personally depleting process of juggling the multiple layers of demands and needs, she finds *honor and meaning* in the struggle to deliver sufficient cancer care to AI patients.**

**Theme #4:** She is a *mediator and peacemaker*, serving as a *conduit* between the allopathic and Native worlds. She comprehends two realities, two languages, and two ways of being. This dyad is seen as a gift that belongs not to her, but to the patients that she serves. When conflict between the two worlds arises, she calls upon her wisdom and skill to broker resolution and inspire empowerment. Often this entails *simply being* with the patient and family, silently listening as they struggle to reconcile the grief, pain, and injustice of cancer. At other times, she is the voice of AI people rising up amidst the indifferent din of the healthcare system. In her role as supportive observer and advocate, she sees *strength and resiliency* in her patients that they fail to recognize in themselves. Even when death is imminent, she sees the awesome power found in persevering another day. Straddling these two worlds allows her the unique vantage point of witnessing what it means to *truly live*.

**Essence:** **As a mediator and broker between two worlds, she *gives voice* to her patients while bearing witness to their resilient ability to *thrive against the odds*.**

### **Participant #9** **Wholistic/Sententious Description**

As the most experienced nurse in the group, this participant has over three decades of both inpatient and outpatient oncology experience. She currently works on an inpatient medical-surgical unit in a large southwestern city, but has travelled extensively as a nurse, exposing her to AIs from several different regions and tribes. She is exuberant, animated, and confident, and is divorced with adult children. When contacted for the study, she replied enthusiastically and assured me that she had “many” stories to share about caring for AI cancer patients, including regular encounters at her current place of employment. Despite her extensive nursing experience, she acknowledges “I felt I didn’t have enough tools, I was learning along the way. We have almost no training” in caring for the AI population in either school or in the post-graduate setting.

She begins with explaining that nurse-patient relationships are built on both an invisible yet sensed interchange between patient and nurse, requiring that each set aside their barriers and preconceived notions and allow one another into their world:

There’s always an interchange if we allow it. There are some people who keep up their boundaries pretty high and won’t allow it, but I think if we allow it, there’s learning [and] lessons on both sides. I sometimes really look at cancer as nothing more than a vehicle to get you together.

She admits that neither she nor every patient is always capable of this equal exchange, especially with AI patients “because very oftentimes, they don’t trust you.” She finds this distrust to be historically placed, imagining that many AIs feel “I’ve been abandoned. I’ve been rejected. I’ve been scorned. Why should I trust you? Your culture has done this to us”. Their reserve and caution is no more apparent than in the way they resist bodily contact from her:

When you have a culture that does not look at you, and doesn’t trust what you’re doing, and they’re always questioning, it’s difficult to touch someone in an atmosphere of distrust, and try to bring healing. It’s very difficult... because you have to touch them to do [clinical] things.

When her caring advances are thwarted, it “feels burdensome” and inhibits her clinical judgement. “Maybe because of my culture, I like people to look at me when I’m talking to them. I can tell more when I look in a person’s eyes.” When patients don’t look at her, “I feel like they’re absent from their body”. She instead tries to use a more deferential approach with AI patients by offering “whatever other kind of touch that you can help to make them feel better. You respect that boundary, and you ask first.”

In addition to a physical boundary, she recalls several AI patients who seemed emotionally distant despite her best efforts to establish connection. With a particularly difficult AI patient she was left feeling, “I can’t reach you! I want to reach you, and I can’t reach you. It was very frustrating for me”. She felt herself withdrawing from this patient. “Every time you walked in the room, it was an [emotional] encounter. Then you have a tendency not to go in the room”. When she is unable to reach an AI patient, whether due to their resistance or her own obstructions, she is wracked with feelings of regret and failure. She examines these instances with great scrutiny in an effort to understand their meaning but realizes that the emotional openness she craves often takes time to develop. “I think building that confidence and trust in the relationship [comes first], and then they feel like they can open up and explain things to you.”

She feels like trust should be earned and that “consistency is real important” with the AI population, recalling one patient where “I believe the trust in getting what he needed when he asked for it [helped]”. With other patients, she finds an almost instantaneous connection and a deep sense of *knowing* one another. She describes in great detail her experience of providing long-term care to an AI traditional healer with whom she became very close:

When I began to care for her, when I opened up this to understanding of who she was and what she came from, and how she believed, and what her faith base was, and what her struggle was at the point when she was dealing with cancer, I think in my listening, my ability to care for her at several different times... we just connected because of my openness in wanting to learn, and then wanting to care for her however she wanted to be cared for...

She describes this as a “wonderful learning experience” and marvels at “how much self-control she had and how little [pain] appeared to affect her”. After several impactful events and being invited to participate in a ceremony with the patient’s family, “it was just that reaffirmation of ‘you’re being led [by a higher power]. Trust and do, and you will see the results’. I think it’s all part of nursing.” This experience reinforces her perception that “Native Americans have spirituality that we don’t even understand. I just really think there’s a lack of understanding on their culture”. She finds her belief system congruent with many AI belief systems, instilling a sense of compatibility that helps to foster connection. Our misunderstanding or neglect of spirituality in the biomedical world is especially apparent to her in the “crisp, clean, and regimented” cancer care setting where most AIs are far from home and separated from not only loved ones, but also from nature. “They need the earth, they believe in the earth. They need to touch ground, and they’re not touching the ground [in the hospital]”. She longs for a more integrated, culturally attuned, and reverent cancer care system, lamenting “I wish we could treat them in a different way” or at least “keep them at home more [where] I think they’ll do better”. Overall, her characterizations of her relationships with AIs feel like “your privilege is to walk alongside of them in their journey” and a continuous lesson in restraint and maintaining both distance and closeness: “I think we have to remember as nurses that, yes, we wish to change things, but we have to back off and remember that maybe sometimes we just need to hold their hand.”

**Sententious Formulation:** Nurses desire an emotionally fulfilling relationship where reciprocal learning can take place, but this yearning is sometimes fraught with both individual and shared barriers unique to AIs that are historically situated.

Level One Matrix  
 Interview #1; Interview #2

	<p><b>#1:</b> She shares the profoundly moving experience of caring for an AI woman with a terminal prognosis. Very quickly in their relationship, she felt closely connected with this patient on a spiritual level, which was later reaffirmed by a series of events that are nothing short of mystical. This patient continues to have a powerful impact on the nurse many years later, and she thinks of her often, both fondly and with great reverence.</p>	<p><b>#2:</b> General quotes about caring for AI cancer patients [potentially significant]</p>	<p><b>#3:</b> She experienced complete exhaustion when caring for a challenging and often oppositional young AI female cancer patient. Although cognizant of the patient’s difficult contextual circumstances, the relationship was especially emotionally draining as the nurse attempted to deeply care for the patient only to find her overtures falling short. The patient eventually passes away, and the nurse is still haunted by what could have been.</p>	<p><b>#4:</b> Initially, she finds an AI gentleman to be demanding and defensive, but over time, she and the other nurses manage to ‘break through’ to him and earn his trust; in return, he ‘opens up’ and becomes significantly less burdensome. At one point, she demands that he stop ‘manipulating’ her and take responsibility for his actions, which he appears to respond positively to.</p>
<p><b>Corporeality:</b> “we are always bodily in the world”, we meet people “first of all through his or her body”; “when the body is the object of someone else’s gaze, it may lose its naturalness”, both revealing and concealing.</p>	<p>You wouldn’t have known she was in pain until she grimaced, because, I think, of her years of being in the sweat lodges, and doing her meditational practices. I believe she had a lot of great self-control of her body and toward her senses, so it was very difficult, sometimes, to get her to admit that she had a lot of pain</p> <p>I guess I want to say I was amazed at how much self-control she had and how little it appeared to affect her</p> <p>We did the dance around, and then when I took the shawl off, it felt differently. It was lighter.</p>	<p>I do believe in accumulative grief, and I do believe that nurses, especially cancer nurses, do accumulate grief, and it’ll hit you out of nowhere, as it did me. I actually burned out...I had to actually leave. I knew I was done</p> <p>In fact, when I walked into my boss’ office and handed her my resignation, she said, “I’m not surprised. I bet you feel better?” I said, “Oh, it’s like everything thing’s been lifted off of me.”</p> <p>{Cumulative grief feels} dark, heavy, burdensome, no joy, you can’t smile about anything... It feels like you become bitter, a</p>	<p>I think that you’re very tired after days like that [taking care of her] on the floor. You’re physically tired, you’re emotionally tired, and you’re spiritually tired. That’s why you need the days off, because you just don’t want to deal with her again</p> <p>Everybody had a bad taste in their mouth when it was over with.</p> <p>We were trying to get people down from the reservation to give her support, and—oh, my gosh, it was just one thing after another. I felt really sorry for</p>	<p>Once he felt we weren’t judging him on anything, we were just treating, he started to relax with us, and talk to us more. That’s unusual for that tribe. They don’t look at you. They don’t trust you, they won’t look at you in the eye, so you have to really work around that</p> <p>Towards the end, he’d look at us. In the beginning, he wouldn’t... when I first experienced it, it was difficult, because I [thought], “Well, come on, look, at me. What are you? What’s the problem here?”</p>

	<p>There was something that was real heavy with it when I would put it over my shoulders, and when I was done, the dance was finished, it was light; it was very, very light</p> <p>I tried to pray with it, and my elbow was so big! And then the next day, I was able to pray with it. My elbow didn't hurt. My elbow went down. I was like, "What the heck is that about?" It was, I think, a physical manifestation for me that said, "No, it's not time yet for you to have this [the prayer shawl]. It's not time yet." Then after I danced with it, it was fine</p> <p>She'd sit there in the bed and just meditate. I would very calmly go into the room and put my hand either on her shoulder or on her arm. "Is there anything you need?" There were times when she would come out of her meditation. There were times when she wouldn't. If she didn't, you left her alone and you walked away. I learned through her that when she needed something, she would let us know</p>	<p>little bitter. You become cynical</p> <p>I know they [AIs] don't like to be touched sometimes. Then just to offer, "May I offer a warm blanket?" Whatever other kind of touch that you can help to make them feel better. You respect that boundary, and you ask first</p> <p>It feels very burdensome at times, when you can't do anything about it...When you have a culture that does not look at you, and doesn't trust what you're doing, and they're always questioning, it's difficult to touch someone in an atmosphere of distrust, and try to bring healing. It's very difficult... because you have to touch them to do things</p> <p>It causes an energy that's very negative and, for me, touch should be about positive energy. I think that's the most difficult part</p> <p>She would not look at us. Writhing in pain, wouldn't look at us...Frustrating, again. It's like, "Look at me!" She wanted to, but she knew in her own culture, she couldn't, you know what I'm saying? Maybe because of my culture, I like people to look at me when I'm talking to them. I can tell more when I look in a</p>	<p>her. I felt, "Oh, my goodness. I'm so sorry that this is your journey"</p> <p>Emotionally, physically, and mentally tired. I was extremely exhausted</p> <p>Because lesson-wise, I really don't think I learned anything different, other than I needed to back off. I needed to back off when I needed to back off. I needed to move forward when I needed to move forward. I think I needed to learn a different kind of dance, maybe a little more detailed with her than I did with other patients. "Oh, now's the time to approach. Oh, now's not the time to approach."</p>	<p>He had a little smirk on his face. I said, "Are you trying to manipulate me?" He didn't say anything</p> <p>I would ask him things like, "Are you comfortable with your relationships? Have people deserted you?" so that he would talk about it. Once he started opening that box, you could just see this kind of light come back to his face...That's emotional healing. Doesn't matter whether it's a right or wrong answer. That's emotional healing</p> <p>I think the first thing is frustration. Physically, it feels heavy and itchy. It almost feels itchy. Heavy. I don't like that feeling. Heaviness, of all the things I can think about. It's just heavy. I don't want it anymore</p>
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		<p>person's eyes</p> <p>I feel like they're absent from their body. Because I think [AIs] can do that, just be kind of absent. It's almost like when they don't look at you, they're denying the spiritual part of, you know? They're denying that soul connection, because the eyes are the windows to the soul. When you can't look at people, I have a difficult time sensing what's going on... You're reading other signs. That can be challenging</p>		
<p><b>Spatiality:</b> "felt space"; "inquiring into the ways we experience spatial dimensions of our day-to-day existence"; "we become that space that we are in"; "world or landscape in which human beings move and find themselves in".</p>	<p>That was a very good example of her journey, and what she needed to do to show her family what it was to do the dying process</p> <p>I really believe the whole drive was for her, and especially for her life, the circle of life, as they describe it</p>	<p>I really believe that cancer nurses in particular have a sense of the bigger picture anyway. When you incorporate their profession with their family life, with their spiritual life, with their emotional life, you can really get healing</p> <p>[AIs] need the ground. They need the earth. They believe in the earth. They need to touch ground, and they're not touching the ground [in the hospital]</p> <p>Because it's not good for their spirit or their emotions, just to focus on only their physical. We've got to stop shutting them up in a room, and saying, "No, you can't [go outside]. You can just walk around the hospital."</p>	<p>It was just really difficult. I still can see her today [after death]. Again, the thing I learned through some of this, it's their journey. Your privilege is to walk alongside of them in their journey</p> <p>Sitting down, not standing up. Sitting down next to the bed. Getting into her life, what she was into. Letting her see that you're interested in that, which builds trust, then letting that flow into conversation in regards to her care. If you don't have that foundation and the time to create that foundation, you're not going to get anywhere</p> <p>Every time you walked in the room, it was an encounter. Then</p>	<p>Then the fact that he kept saying to me he just needs to be home, "I just want to be home." He was far from home. I think it was he just needed the familiarity of home</p>

		<p>I wish we could treat them [AIs] in a different way...I believe we're going to be able to at least educate them on how their living will change a little in their own environment. Yeah, keep them at home more. I think they'll do better. I really do...It seems as though if the patient has some control, they do better</p> <p>I have been in situations where it's manipulative, where they want something, but yet they won't allow you to do it, so then you say, "Well, you've got me between a rock and hard place. I can't—you're asking for it, but you won't allow me to do what I can do, and what is accessible to me to help you."</p> <p>I really feel that because we've been given privileges to enter into people's lives at a time when they're very vulnerable, that we have the gift and privilege of walking alongside of them on a journey, or helping to guide their journey</p> <p>The separation from their loved ones and their community, because they can't afford to come down [to the hospital]. When you're not in your own environment...I just think it</p>	<p>you have a tendency not to go in the room</p>	
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		<p style="text-align: center;">makes it more difficult to do treatment and be in the midst of a disease</p> <p style="text-align: center;">I think the Native Americans in particular just have difficulty with that whole part. They walk into a strange environment. It's like going into a foreign land...They walk into this hospital, where it's crisp, clean, and regimented, then have to acclimate to our process instead of theirs</p>		
<p><b>Relationality:</b> “relation we maintain with others in the interpersonal space that we share with them”; “develop a conversational relation which allows us to transcend ourselves”; “human beings have searched in this experience for the other, the communal, the social”</p>	<p>I really began to ask a lot of questions about her tribe, her family, her religious beliefs, because I didn't understand their culture. She began to train me...she began to explain a lot of things to me about the cultural—the belief system. They pray to a sacred tree, they are very earthy. For some reason, [she] and I began to really connect</p> <p>Just a lot of things that she was struggling with, as far as socioeconomic, the alcoholism that's on the reservations, and she had family members that were alcoholic. They tried to come and visit her, and they were pretty abusive, and so we had to kick them out. We literally had to call security and have the brother leave, because he was upsetting her...She said, “I want him out of</p>	<p>When I walk into a room, it's not about what I'm going to do to you, it's about who you are. What I try to do when I walk in a room is I ask “So, tell me, what do you do as a profession?” and, “Can you tell me a little bit about yourself?”, while I'm hanging IVs... It helps me then to put together a plan of care where I can communicate with them really well</p> <p>I think building that confidence and trust in the relationship, then they feel like they can open up and explain things to you</p> <p>There's always an interchange if we allow it. There are some people who keep up their boundaries pretty high and won't allow it, but I think if we allow it, there's learning lessons on both</p>	<p>[She had a] very complicated socioeconomic situation. She had no foundation, she had none whatsoever. She had no morals—I mean it was just awful. The aunt was trying to get her to do what we needed for her health, and this was in the hospital</p> <p>Social work involvement, case management involvement, physicians involved, nursing involved. Those [patients] are so difficult, because you can't educate them...that part has been difficult. She actually went through a series of in and out of the hospitals, then after the transplant, and she died</p> <p>It was hard for me. I wanted to love her, and she didn't know what healthy love was</p>	<p>He had a lot of anxiety. Oh, my gosh. Medicine doesn't fix that</p> <p>He didn't do well either, and it was because he needed to be out of the hospital</p> <p>He was very afraid, very afraid of what was going to occur</p> <p>His mom was very, very good with him. I mean him and his mom had a great relationship. His mom tried to do as much as she could for him to help alleviate it, but I think the anxiety was what was going to happen for him, disease wise</p> <p>Nature things [on TV] helped a little bit for him. Then I do believe once we got the disease starting to get under control, the anxiety got a little better, and I</p>

	<p>here.” Because he was berating her for not doing her traditional medicine</p> <p>[My dog] was looking up into this tree, and I thought he was looking for a squirrel, and he was barking. I looked up there, and I couldn’t really see anything, then all of a sudden, it was almost like an outline of a Native American woman’s face, that you could see in the tree and the leaves of the tree...I was praying for her at the time I was walking. “Put [her] in the river, I will wash her clean.” I heard this. I imagined her figure in the river and washing clean...so I go back to work, and I had to [care for her] again, and I walk in the room, and she’s doing pretty well. I said, “You look really good.” She goes, “I don’t have any pain”</p> <p>Between her sisters and everybody, I was able to develop a really good relationship with the whole family that was there and with her. I told her the story, and she looked at me with just this twinkle in her eye that I can’t even explain, and she said, “I know.” [also corporeality]</p> <p>They said, “We want you to come to her giveaway.” I said, “Oh, my</p>	<p>sides. I sometimes really look at cancer as nothing more than a vehicle to get you together</p> <p>No matter what life throws you, be who you are in it. I don’t know how else to word it, because we should never place an expectation on a patient to not be who they are. I think we have to adjust, instead of making them [AIs] adjust to us. In the medical profession we need to adjust to them</p> <p>I just feel that when you gain the trust of a patient, you do what you say you’re going to do. You alleviate as best you can whatever situation they’re in. You go to bat for them, they begin to look at you like, “I can trust this person.” I think that was the best part because, very oftentimes, they don’t trust you</p> <p>I believe it’s because they don’t trust Caucasians any. I mean, look at what we’ve done to them. Oh, my goodness... It’s that, “I’ve been abandoned. I’ve been rejected. I’ve been scorned. Why should I trust you? Your culture has done this to us “</p> <p>Consistency is real important, I think, for them. Then being open</p>	<p>Being an older nurse, she did look at me as a mother image at one point, but I couldn’t get through to her. I tried several different avenues. I tried the directness, I tried the laying down the boundaries, then I tried the compassion side. It would just seem like she was so mentally ill, as well as physically ill</p> <p>I think we have to remember as nurses that, yes, we wish to change things, but we have to back off and remember that maybe sometimes we just need to hold their hand. That was the education for me on her: you just have to do what you can at the time</p> <p>After you do oncology for as many years as I’ve done it, you understand the journey. You’re like, ‘darn it, I wish we could have helped’. You just continue to try. Every time that she came in there were other social issues... It was just compounded</p> <p>It’s very disheartening. Then you have to respect where that person is. When you accept that, you begin to mentally process that, then you begin to understand that</p>	<p>think just trust. I think he needed to trust us that we were going to help him</p> <p>I believe the trust in getting what he needed when he asked for it [helped]. It was the call light, it was that constant, “Hey, what you need? What can I do for you?” I think then he began to relax more and more with us. With each admission that we had with him, it got better. He was like, “Okay, I have to do this.” His anxiety was not as bad</p> <p>As you begin to care for them and you understand their culture, and then their needs, then you begin to back up and say, well, there’s other ways I can gain his trust. That of which is to come in when the call light is put on. To get what he needs at the time he needs it, if you can... to just address all of the needs, physically, emotionally, and spiritually</p> <p>You sometimes have to put that responsibility back on them, and I had to with this gentleman when I first met him, because it started him thinking, “I do have to take responsibility, I do have to say something. I do have to</p>
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	<p>gosh, I'll be there." I went. I was sitting talking to the cousins and the sisters, and the two older sisters that I had the best relationship with came and put her prayer shawl over my shoulders, and they gave me the shell that she brings sage in, and they said, "You have to have this." I cried. I was like, "Why?" I didn't understand...I took it home. It's beautiful; I still have it, [but I] couldn't pray with it</p> <p>I take the shawl in my trunk of my car with me to the pow wow. I just felt like I should. The first Indian I meet is Lakota. I explain the story to him, and he goes, "Oh, my." He takes me by my hand... "No, you have to understand. The reason you were given the shawl is because you have to complete her circle of life. She was unable to. You can't pray with it, because it's not time for you to pray with it."</p> <p>The whole time, I really felt privileged. I really felt that it was just such a privilege to finish her job that she was unable to finish in this life</p> <p>To me, it was just one of the most beautiful experiences I've ever—and she had died, of course...It</p>	<p>and honest and saying, "I can't do that right now."</p> <p>We need, as nurses, tools to understand each tribe's culture, and then approaches to the tribes, so that we can handle it better. I felt I didn't have enough tools, I was learning along the way. We have almost no training in that</p> <p>I really believe the Native Americans have spirituality that we don't even understand. I just really think there's a lack of understanding on their culture</p> <p>I think in that regard, they're [AIs] no different than anybody else. You want to find out what their learning style is, where they are, what's their disease—do they understand? What do they want to know from you?</p> <p>I asked him about his tribe and what belief systems he had. Is there anything we need to do culturally or religiously for you? He goes, "I'm good." You leave it alone</p> <p>I think the Natives have even one more strike against them: very poor. Poverty is the great divider. It brings up all kinds of psychosocial issues</p>	<p>maybe the way to love her is to allow what she needs at this point. Then at that point, it gets easier on them, and easier on you, because not everybody wants what you want, and you have to learn to assess. Part of that process was trying to find a way to get into her, I think</p> <p>That was the most discouraging situation we were ever in. It was really hard</p> <p>I really believe that in her case, she was unreachable because of her distrust of humans and what they had done to her...I think for me, it was like I can't reach you. I can't reach you! I want to reach you, and I can't reach you. It was very frustrating for me...</p> <p>For her, it was just the innocence of her that got stolen away, literally then by the disease</p> <p>You feel like you can't accomplish anything. Like you can't make progress. Like you can't help. Like you don't see any end to the needs</p> <p>"There's a lot of us nurses here, but we're all busy right now." That's just one more rejection. That's the hard thing. It's one</p>	<p>allow them to do things for me."</p> <p>I found it difficult at first, to really take care of him, because I didn't want to take care of him. I was like, "I can't do anything to help this guy. Why do I have to be his nurse today?"</p> <p>With him, it got a lot better over time. I almost, towards the end, got the feeling that he felt like we were part of his family</p> <p>I think with him, it was he got to be a lot better towards the end. I have to add that I think what helped with the trust issue with him and I is I said, "Well, you know, I have taken care of [infectious] patients for over ten years...I'm not concerned about my well-being". Then he started relaxing</p> <p>Towards his last treatment, I think we brought him a cake in or something. We were celebrating with him, "Oh, it's your last treatment!" We were trying to help him celebrate things</p> <p>We had to repeat to him. It just seems like, "He's not getting</p>
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	<p>was just gorgeous. I felt really, really honored that the spirit had given us a connection</p> <p>For me, it was beautiful. I was grateful to see that there is that out in our community, that there—that people take responsibility, I think, for the situation they’re in. She seemed to do that very well...</p> <p>I was a little leery, knowing she was the sacred pipe carrier of the tribe. That just blew me away, and I thought, “Oh, how do I approach this?” Well, my own sense is to go inwardly because I meditate and pray a lot myself. I just went in there inwardly and said, “Please make my words your words.” It just happens, usually. I can usually sense the moment to ask the question</p> <p>I think it got me deeper into what they struggle with. The emotional part, the spiritual part... She explained her struggle about going to traditional medicine, and how she felt failure in not being able to heal herself</p> <p>I knew I was in not in control of any of it, that I was just being a messenger, if you will, or a facilitator of something that I had</p>	<p>It doesn’t have to be an algorithm, but it certainly could be something general about the tribe. Have a way better concept on how to manage, or approach [AIs]</p>	<p>more rejection for her, and one more abandonment for her</p>	<p>this. Why is he not getting this?”</p>
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	<p>no understanding of at the time. I think there was fear in there, thinking that I needed to pray for the tribe. Was I doing that for them? Was I truly responsible?</p> <p>When I began to care for her, when I opened up this to understanding who she was and what she came from, and how she believed, and what her faith base was, and what her struggle was at the point when she was dealing with cancer, I think in my listening, my ability to care for her at several different times... we just connected because of my openness in wanting to learn, and then wanting to care for her however she wanted to be cared for</p> <p>She was open, being the teacher and an educator that she was. She was open to sharing that so that we would understand what she was going through</p> <p>For my journey with her, it was just that reaffirmation of 'you're being led. Trust and do, and you will see the results'. I think it's all part of nursing. I really believe it's all part of nursing</p> <p>It was a wonderful learning experience for me, because I</p>			
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	<p>really believe it was one of those experiences where you begin to understand that you're only a facilitator. You aren't one who is doing anything considered a change. You're helping them process. That's all it is. The medicine was actually minimal compared to all the other things she talked about</p>			
<p><b>Temporality:</b> "subjective time"; "appears to speed up...or slow down"; "temporal way of being in the world"; "past, present, and future constitute the horizons of a person's...landscape"; reinterpreting the past; "perspective on life to come"</p>		<p>I'm in and out of the room a lot because I want to give them time, and I want those brief moments to be like, "I'm here if you need me. I'm here if you need me."</p> <p>I think we sometimes have too quick of interactions when they're [AIs] in a hospital setting, don't you? The great divider: time... Time to accomplish the goal that the administration has set out for you in our healthcare system</p>	<p>The 12 hours that you take care of her was all I wanted to take care of her, because I couldn't go back the next day and do it again</p>	

### Thematic Summary

**Theme #1:** She finds *human touch to be a powerful messenger* and implement for healing, but it must be used wisely and judiciously, and always with the patient's assent. This is especially so among her AI patients, with many carrying the scars of violence and invasion. Her vocation as a nurse demands that she touch patients, but she finds many AIs to be leery of physical encounters and all of the emotional, cultural, and historical connotations that they carry. They turn their eyes from her, refusing entry. So, she sets aside her tactile urges and *waits for permission* to enter into the physical space where vulnerability resides, making gradual yet persistent progress until *the boundaries between them recede* and patient and nurse join together in caring moments.

**Essence:** **Waiting for the boundaries between them to recede, she uses *deferential touch* to create a receptive landscape where she can convey her healing intentions as a nurse.**

**Theme #2:** Cancer has *displaced* her AI patients by tearing them from their homes, families, culture, and communities to seek care in an unfamiliar environment in which she comfortably resides. They arrive disoriented and cautious, and although she is sensitive to their plight, there is little she can do to ease the transition. All she can offer in this foreign land is kindness and respect within their burgeoning relationship, a small gesture to comfort and console in the midst of isolation and fear. She uses her familiarity with the terrain to navigate between the patient's desires and the constraints of the system. She *wishes for a different place*, one where her AI patients could feel the earth and be cared for wholly and expansively. But in the interim, both patient and nurse are *utterly human* within this sterile, fixed, and unfeeling environment. There is no other way for them to be.

**Essence:** **Unable (and unwilling) to deny their humanness, she guides her AI patients through a sterile and rigid cancer care environment, offering kindness and respect to atone for the impersonal.**

**Theme #3:** She must carefully calculate each exchange, each word, each touch; it is an *exhausting choreography*. She is highly alert to her AI patients' individual variations, yet often finds a *disappointing inability to impact* them.

They seem so far away, unaffected by her caring intentions. She feels as if she is gaping open while they remain tightly closed. She wants desperately to give them love as a method of facilitating healing, yet is unsure of her next move. Many of her AI patients feel impervious, disjointed, and detached from her and the present situation. She is burdened by this distancing negative energy and her *failure to connect*, and it weighs on her to the point where she can no longer continue her work.

**Essence:** **She carefully choreographs her care of AI patients but finds that her intentions are often unreceived or rejected, leaving her burdened and stymied with disappointment.**

**Theme #4:** She has learned to *relinquish control*, to surrender to a much higher power that directs life and death; disease and healing; patient and nurse. She is merely a facilitator, a *channel for transitioning* to occur exactly when it is meant to. She accepts this role, although often humbled and awed by these outside forces that so mysteriously unfold, yet always with intention. She finds that her AI patients inherently grasp the gravity of these phases; it is they who have taught her how to live and to embrace life's cosmic wonders. She sees her own spiritual awakenings shared by her AI patients, and this internal quest unites them on an otherworldly plane that is both striking and reaffirming.

**Essence:** **She sees her AI cancer patient's innate understanding of life's cosmic mysteries as an affirmation of her own spiritual journey and the transient nature of life, death, disease, and healing.**

APPENDIX N:

SHARED THEMES AND THEMATIC DESCRIPTIONS IN LEVEL-TWO MATRIX

	Corporeality	Spatiality	Relationality	Temporality
P. #1	<p><b>#1:</b> AI patients' body language and physical responses feel flat, subdued, and vexing. She feels an <i>unsettling sense of uncertainty</i> about if they are listening to her or absorbing the information adequately because there is so little physical reaction. She is less adept at reading their physical symptoms, increasing her anxiety about potentially mismanaging a complication or issue and hampering her ability to effectively advocate on the patient's behalf. She in turn tries to suppress or hide her pent up frustration over this lack of bodily engagement by maintaining a professional and calm appearance even if internally she is aggravated. She experiences increased connection and comprehension when she is allowed into their physical space, which is sometimes triggered by an unavoidable caregiving act inherent to nursing.</p> <p><b>Essence:</b> A <i>vexing inability to "read" bodily messaging</i> negatively impacts her ability to connect emotionally with her AI patients, but it is through deep contact with the physical body that she is sometimes able to transcend that void.</p>		<p><b>#2:</b> A lack of reciprocity on a relational level is experienced by her as a <i>distancing</i> and <i>closing off</i> between herself and the patient. She describes an emotional void and inability to form an immediate bond related to her lack of understanding about AI culture, stilted communication patterns, opposing expectations, and perplexing behavior. Having her patients "open up" is a significant event for her; this seems to be a requirement for progression of the relationship to occur and signals that she has adequately reached them. However, at no point does she reveal her own opening up to the patient. The emotional "work" and exposed vulnerability seems to be one-sided. Yet, she is often left feeling <i>apart</i> and <i>separated</i> from AI patients despite considering <i>closeness</i> to be essential for developing a caring nursing relationship. <b>Essence:</b> <b>Her primary way of gauging the success and depth of her caring relationships with AIs is through the patient-directed act of being 'open' or 'closed'. When 'opening' does not occur, her expectations are dashed and she is left feeling ineffective and inadequate.</b></p> <p><b>#3:</b> Despite the barriers between them, she experiences pronounced feelings of protectiveness and concern while striving to ensure her AI patient's physical and emotional comfort. She often characterizes her patients' demeanor as</p>	<p><b>#5:</b> Her relationships with AI patients tend to improve and become more positive and fulfilling over time. Collectively, she characterizes her initial suppositions, interactions, and perceptions rather negatively, but her trepidation about caring for AI patients' lessens over time and several relationships evolve into dynamics that feel openly communicative and containing more parity. When she becomes the preferred nurse of an AI patient, it signals a <i>major transformation</i> in their nurse-patient dynamic and brings great joy and fulfillment. She has learned that a crucial component of improving these relationships is to <i>spend time</i> with her AI patients in order to build rapport, increase understanding, and establish trust. Occasionally, she finds herself wishing for <i>more time</i> –both in the sense that many of these cancer patients have terminal prognoses and also longing for the opportunity to engage in a long-term nursing relationship that is mutually benefitting.</p> <p><b>Essence:</b> <b>Over time, she learns to adjust to her patients; her own growth and flexibility leads to personal insight while altering the way she approaches care in future interactions with AI patients.</b></p>

			<p>“childlike” regardless of their chronological age, symbolizing her maternal role within the dynamic. She does not view this characteristic negatively, instead associating it with safety, advocacy, and fulfilling the patient’s needs during times of extreme vulnerability. Her relationships with patients are highly individualized, personal, and of a one-on-one nature. She makes very little mention of family members, external spiritual sensations, or any other entities. In her eyes, they are coupled together in the cancer care scenario with very distinct parts to play.</p> <p><b>Essence: Her relationships with AI cancer patients are highly exclusionary, strictly coupled, and sometimes characterized by maternalistic inclinations.</b></p> <p><b>#4:</b> She is baffled when her well-known AI patients fail to recognize her or call her by name, referring to her only as ‘nurse’. Although she questions the meaning of this <i>impersonal interaction</i>, it seems to symbolize the doubt she has about her ability to establish the deeply emotional relationships that she expects to occur in order for “good” nursing care to be provided. She initially feels wounded, but perhaps as a measure of self-protection, she attributes this tendency to an AI-specific cultural oddity that she does not comprehend. The painful alternative is that her patients value their relationship in an</p>	
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			<p>entirely different manner than she does, causing her to feel disoriented about her assumptions and expectations.</p> <p><b>Essence: Feeling nameless and faceless to her AI cancer patients is alienating and disappointing, calling into question her impact and identity as a cancer care nurse.</b></p>	
<p><b>P. #2</b></p>	<p><b>#3:</b> She uses multiple methods to convey her caring intentions to patients: non-verbal techniques (specifically, light touch and eye contact), humor, and presence. All play significant roles in conveying meaning, clarifying confusion, establishing rapport, and building a sense of collaboration and togetherness. She found one patient’s own sense of humor despite his terminal circumstances to be healing <i>for her</i>. She intuitively senses when to apply any of these approaches within gender and age-specific cultural confines; they are tools that make her better at the “work” of building trusting relationships within cancer care as well as garnering her patient’s attention when something crucial needs to be conveyed.</p> <p>These tactics also involve and integrate the entire family into the patient’s journey.</p> <p><b>Essence: Connecting through touch, eye contact, and presence builds trust and collaboration, allowing her to convey deeper</b></p>		<p><b>#1:</b> Her perceptions of her relationships with AI cancer patients are almost completely defined by their shared ethnicity. Her approach to communication (verbal and non-verbal), methods of delivering education and care, and understanding of her patients on both a day-to-day and deeply existential level is completely viewed through her own “Native lens”. Just as she is inseparable from her own identity and heritage, so are her experiences and subsequent relationships with this particular patient group. She uses this “sameness” to her advantage, seeing it as a significant benefit to building a mutually open, trusting, and even rewarding relationship. She observes that many AI patients open up and are less guarded with her compared to other non-AI nurses/staff; this reinforces for her that despite the challenges inherent in this type of work, she is in “the right place” not just as a nurse, but as an <i>AI nurse</i>.</p> <p><b>Essence: She is beholden to this community, tapping into their sameness and shared identity to forge connection and create a feeling of</b></p>	

	<p>meaning and to create fleeting moments of healing for herself.</p>		<p><b>being <i>at home</i> for both her and the patients. She intrinsically understands their collective (traumatic?) pasts and the communal present moment at a level that transcends explanation but gives her great purpose. [ALSO SPATIALITY]</b></p> <p><b>#2:</b> The centrality and embedded meaning within indigenous language plays a prominent and profound role in her relationships. It is a connector, an immediate and identifiable sign of a shared history and a common ground. It facilitates trust through its very use, but also has its limitations in the biomedical world. She experiences difficulty in bridging that gap, having to repeat and redefine terms and procedures. Her colleagues and even herself sometimes make false assumptions about an AI patient's level of comprehension. At times, she uses metaphor and story to convey meaning in either language, which can be an extremely satisfying and fulfilling experience as expressions of comprehension and trust appear on her patients' faces. At times there is an increased burden placed on her time and workload as the only bi-lingual nurse on staff, but she does not seem to resent this added responsibility, choosing instead to embrace her skills.</p> <p><b>Essence: Indigenous language creates a literal and symbolic <i>bridge</i> between nurse and patient, which is both a gift and an accepted burden. Providing</b></p>	
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P. #3		#1: She describes strong spatial sensations of her AI patients’ worlds integrating and intermingling with her own, often in	#2: She looks into her patients’ eyes and sees herself; reversely, she supposes that when they look into hers they see	

		<p>profoundly meaningful and spiritual ways. She is deeply cognizant of the distinctive nature of life on the rural reservation and how this physical and cultural space shapes and isolates her cancer patient's experiences or "journeys" as well as her own. She has the sensation of being a "visitor" on Indian lands, yet found it "easy" to integrate AI beliefs, traditions, and preferences with her own as she finds them inherently compatible. This is hugely comforting, causing her to feel a sense of belonging and sameness. When asked what happens when the two worlds collide or are found to be incompatible she was largely unable to articulate any response, choosing instead to hyper-focus on the ideal "fit" between herself and this community.</p> <p><b>Essence: She seamlessly meshes her world with that of her AI patients on a spiritual level, creating a "middle ground" where caring occurs while finding this experience to be deeply satisfying and comforting.</b></p>	<p><i>themselves</i>. This act of conscientious mirroring is tied to her spiritual foundation and resides at the center of her way of being in the world.</p> <p>Pragmatically, she relies on this perspective to guide her care delivery, striving to deliver the type and quality of care that she would want for herself if placed in her patient's shoes. She recognizes her own vulnerabilities in her patients and this is somehow reassuring to her, especially when she observes them thriving and remaining hopeful despite their terminal prognoses. This is especially poignant as she completes her own cancer journey, heightening her awareness and deepening her ability to empathize to the point where words are no longer needed to describe their shared suffering and joy.</p> <p><b>Essence: Through a shared intrinsic sacred humanness, the boundaries and differences between individuals are erased while calling forth our inescapable bond to one another, particularly during times of illness and vulnerability that transcend words and are simply felt with the heart.</b></p> <p><b>#3:</b> She develops long-term relationships with patients and families to the point where they began to "give back" to her, offering support (prayer, laughter) and even physical connection (embracing) during her own difficult health diagnosis. She readily and eagerly accepts this sustenance, finding it uplifting and</p>	
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			<p>engendering a sense of belonging to both place and community. Rarely do nurses acknowledge their reliance on patients for emotional, mental, spiritual, and even physical support, preferring instead to focus on what we <i>give</i> to patients with no expectation of anything in return. Her reality is that the “return” has been both welcome and even a natural progression of the nurse-patient relationship, and she even assumes that it brings joy to her patients to be able to give back to her as the nurse.</p> <p><b>Essence: She finds community, comfort, and belonging as patients and their families provide support to her during her own health crisis; this role reversal is not foreign but instead perceived as an organic progression of the altruistic nurse-patient relationship.</b></p>	
P. #4			<p><b>#1:</b> Compelled by a strong duty to be a <i>good nurse</i>, she has high expectations for the completeness and sensitivity of cancer care. Her altruistic intentions are sometimes thwarted by the cultural and situational complexities of her AI cancer patients and families, resulting in increasing frustration as she <i>wades through the many layers</i> of bureaucracy and physical distance separating them. These barricades are both tangible and symbolic, serving as a point of dissonance that stands out amongst the otherwise highly fulfilling nature of her work. When she is unable to <i>break through</i> these barriers and <i>close the loop</i>,</p>	<p><b>#2:</b> She uses <i>time as an intervention</i>, creating space for openness, understanding, and trust building. She views time as a powerful tool for accessing and connecting with this particular patient group. During these decelerated moments, she senses that spending time in physical proximity to the patient facilitates <i>presence</i> and sends a message that she is dedicated and can be depended upon throughout their cancer journey. This is a learned approach that took years to cultivate and is in opposition to the typical nature of her care delivery with other patients. She has been forced to slow</p>

			<p>she is overcome by a sense of unsettling failure that lacks closure and totality. She protects herself against these feelings to avoid burn out and carry on.</p> <p><b>Essence: Challenged by the layered complexities of caring for AI patients, she conscientiously evades burnout through persistence and by seeking closure in order to find peace and fulfillment within the relationship.</b></p> <p><b>#3:</b> As with time, her embrace of <i>silence</i> as a form of connection is an approach that she distinctly associates with AIs. She feels very little need to be silent with non-AIs, but embracing silence has cultivated a level of patience and tolerance in her that is sometimes surprising. While sitting silently beside a patient immediately after he receives distressing news, she overcomes the urge to speak and instead <i>becomes attuned through silence</i> to what he needs in that exact moment. In an instant, they become enjoined. She senses that her willingness to suspend words is somehow meaningful and encourages tendrils of deep trust between patient and nurse.</p> <p><b>Essence: Embracing silence, she finds rare moments of attunement and meaning, in turn intensifying, strengthening, and cultivating connection and trust.</b></p> <p><b>#4:</b> She is committed to maintaining a sense of openness and broad-mindedness</p>	<p>down, yet is not resentful of this altered pace, and has even come to relish it.</p> <p><b>Essence: She has come to appreciate a slowed pace in which she uses time as an intervention to convey dependability, reassurance, and presence.</b></p>
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<p>P. #5</p>		<p><b>#1:</b> She is <i>alienated</i> from her AI cancer patients, sensing a massive chasm between their respective worlds that she finds difficult to comprehend or traverse. They are foreign, aloof, and feel like <i>others</i> to her. She does not recognize any piece of herself in them, and she doubts that they would even <i>want</i> to see any part of themselves in her as she is equally foreign to them. She grasps that AIs are indigenous to these lands, but when they enter her cancer care world it feels uncomfortable and almost <i>uninvited</i>. This sensation is further compounded by her attestations of understanding very little about her AI patient’s origins and present-day realities, leaving her grasping at intangible wisps of speculation and conjecture that color each caring occasion while</p>	<p><b>#2:</b> She feels <i>inept</i> and as if her noble nursing efforts are in vain when her AI patients fail to respond in a recognizable or appreciative manner. They are stone-like and impenetrable, and her words ring vacant and hollow in the space between them, so she cuts them short.</p> <p>This is radically unfulfilling and degrading, and she has come to <i>dread</i> caring for some of these patients. At times their silence is interpreted as obedience and acquiescence, which she translates into <i>respect and trust</i> for her as a nurse. They do not challenge or bargain with her interventions or implementations, and while this is physically easier, it is emotionally taxing, creating a peculiar <i>tension</i>. Still,</p>	<p><b>#4:</b> She experiences occasional sensations of being <i>slowed down</i> when she is caring for AI patients. They are in the present moment together, and that is all. Her inclination for living in and attempting to plan for the future is moderated by her AI patient’s singular focus on the <i>here and now</i>. She feels some urgency in pressing upon them the seriousness and potential for harm that accompanies their cancer care treatment, but they seem to take this information “in stride” and to be unconcerned about anything other than the present moment. This causes her to question if there is indeed some value in living in the present that she fails to appreciate as a non-AI. During this</p>

		<p>contemplating her own biases and assumptions. Being so distant and unsettling in their presentation, she has no foundation in which to build a personal connection with these patients.</p> <p><b>Essence: The <i>otherness</i> of AI patients leaves her stranded on the opposite side of a wide and insurmountable chasm where she feels <i>alone and alienated</i> with nothing tangible to begin forging a relationship.</b></p>	<p>she is nagged by the sense that even when her AI patients are quietly compliant, she has somehow failed to reach them as a cancer nurse, inciting feelings of <i>regret</i>.</p> <p><b>Essence: Her words fall unacknowledged in the space between them, their meaning lost in her AI patient's impenetrable expressions and inciting sensations of tension, futility, and regret.</b></p> <p><b>#3:</b> Occasionally, the <i>tiniest spark of connection</i> appears and she seizes this human warmth and attempts to cultivate it throughout the caring encounter. Often it appears in the form of a simple question or a fleeting smile on the part of the AI patient or family member; however brief or tentative, it is magnified by the void the way the smallest of sounds echoes in the silence. She finds these episodes pleasurable and fulfilling, and they are absolutely necessary for her to move beyond simply performing tasks to the space where authentic nursing care is delivered. Interestingly, she seems to look to the patient and their family to create this spark instead of reaching out and establishing it from her end. It is they who must make the initial effort to link with her as her well-practiced reticence prevents her from doing so.</p> <p><b>Essence: When they concede to her the smallest gesture of connection, she seizes this spark and cultivates it for the duration of the relationship,</b></p>	<p>type of slowed patient care scenario she is <i>forced to pause</i>, reflect, and question her own proclivities.</p> <p><b>Essence: The sensation of <i>deceleration and existing exclusively in the present moment</i> is both disconcerting and intriguing, causing her to ponder the value and implications of this way of being in the world.</b></p>
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			<b>finding sustenance in the act but failing to recognize her own diffidence.</b>	
P. #6		<p><b>#1:</b> She instinctively senses the complexity of her AI patients' lives, even when she is unable to directly observe them. She is acutely aware of an <i>unvoiced undercurrent</i> of historical oppression and marginalization. This context perpetuates a sense of distrust, hesitation, suspicion, and resignation on the patients' part and a carefully moderated (and repressed) level of frustration and impatience from her end as she struggles to deliver unbiased and kind nursing care to people who appear detached and uncomprehending.</p> <p>The tension is that even though she appreciates the origins of her patient's misgivings about her intentions (and cancer care as a whole), she must contend with the <i>unwanted remnants</i> of this painful legacy on a daily basis. It is as if she is expected to overcome four centuries of trauma and abuse in a single caring encounter. The impossibility and absurdity of this is not lost on her; it forms her view of the <i>imperfect and unjust world</i> in which she must provide cancer care and in which we all must live.</p> <p><b>Essence: Her awareness of history does little to ease the tension of present encounters, forcing her to contend with the unwanted remnants of a shared painful legacy while striving to deliver a more ideal version of care in an inherently unjust and imperfect world. [ALSO RELATIONALITY]</b></p> <p><b>#2:</b> The physical world in which her reservation-bound AI patients live feels</p>	<p><b>#3:</b> She recognizes what she has learned from her patients: demonstrations of incredible resiliency; a healthy embrace of death as part of a life journey; bodily attunement; gratitude for other beings; and an unequivocal humility about our miniscule impact in this world as humans. Her patients gently remind her, <i>we are not in control</i>, and this is freeing for her. Through their eyes, she sees a bigger picture, one in which silence is a welcome respite and cancer is ordinary (and therefore less frightening). All that she can give in return to her AI patients is care provided in the same manner that she would also want it received. She sees the nurse-patient relationship as an <i>exchange</i> in the form of a temporary joining together of dissimilar people that leaves a lasting impression.</p> <p><b>Essence: Being in relationship is an exchange in which each learns from the other, creating admiration and gratitude between nurse and patient.</b></p>	<p><b>#4:</b> She is accustomed to a sense of great urgency and determination regarding cancer care, yet this approach often abruptly collides with her AI patient's agendas. She feels pressured to act quickly and to facilitate an accelerated trajectory of care in response to the gravity of disease, but often her AI patients and their families are delayed in their responses or reactions, choosing instead to pursue and navigate treatment at their <i>own pace</i> and in their own way. They have forced her to acknowledge that time and quality of life are interwoven yet unparalleled. In response, she slows herself, becoming mindful and appreciative of the moment, and learns to walk beside her patients at a more gradual and restrained pace, engendering a sense of wonder and respect.</p> <p><b>Essence: Pulled between the values of the biomedical and AI worlds, she has learned to respect the autonomy of individual pacing and the inextricable intertwining of time and quality of life.</b></p>

		<p>exceptionally distant and empty. It is a “black hole” inhabited by confounding bureaucracy and systemic failures. Her patients have been <i>banished</i> to this isolated place, forcing her to exert an enormous amount of effort to <i>maintain contact</i> from her urban realm. Sometimes they never reappear, leaving her with a worrisome sense of loss and regret. At other times they amaze her with their return, and she is humbled by their ability to <i>navigate</i> between two worlds and <i>persist through barriers</i> in order to seek cancer care. Still, she is troubled by the fact that the journey is only occurring in one direction and that we as cancer care providers rarely make the effort to meet on middle ground, or better yet, to enter the AI world. To compensate, she attempts to adjust her expectations as much as can in order to accommodate and acquiesce.</p> <p><b>Essence: The reservation is an <i>abyss</i> in which her patients disappear, but while her efforts to reach them are hampered by complex obstacles, she is humbled by their ability to transcend barriers and seek care.</b></p>		
<p>P. #7</p>			<p><b>#1:</b> In the beginning she was an <i>interloper</i> forced onto her patients by cancer. They eyed her skeptically, responding with silence and blank stares. Their cold retorts prompt a <i>persistence and determination</i> in her to <i>break down the barriers</i> between them. She saw their protectiveness as a personal challenge, something to be overcome with humor, cordiality, and kindness even when unrequited. Eventually, she exhausted</p>	<p>personal disappointment that it generates, steeling herself against the physician’s aggravation and the patient’s unspoken complicity.</p> <p><b>Essence: Engaged in an endless cycle of dysfunction and powerlessness, she has come to terms with a constant, sometimes futile pursuit of time and hope. [ALSO SPATIALITY]</b></p>

			<p>herself with this endless game where she was the only player and she grew weary of constantly developing <i>new tactics</i> that seemed to lead nowhere. She withdrew and shut down, resorting to mindlessly completing tasks while <i>her heart hungered for more</i>. More recently, she has come to <i>accept her patients unconditionally</i>, relinquishing any need for validation. Her persistence has paid off over time in the form of tentative connections and the comfort of familiarity.</p> <p><b>Essence: Initially an <i>interloper</i> forced onto her patients by cancer, she took on their guardedness as a personal challenge but found her caring overtones <i>insufficient and unrequited</i>. Over time, she began to embrace <i>unconditional acceptance</i> and now finds comfort and <i>connection in familiarity</i>.</b></p> <p><b>#2:</b> She defines herself by what she is not (an AI nurse), and there are times when she feels <i>the sting of rejection</i> from her patients. She wears her otherness literally on her skin; it is inescapable and obvious. She experiences being a second-choice option in many instances. While her AI colleague has all of the right words and instantaneous connection, she is left to bumble her way through even the most basic interactions and to imagine relationships that may or may not be legitimate, calling into question her ability to bond when it</p>	
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			<p>matters most. She does not blame her patients for their <i>overt preference</i>, knowing that she cannot change the course of history nor undo the past transgressions that hang in the air between them like smoke. She can, however, influence the present moment and she commits herself to changing their perceptions of her by using respect and diplomacy at all times.</p> <p><b>Essence: Feeling the painful and discouraging <i>sting of rejection</i>, she recognizes the historical origins of her second-choice status as a non-Native nurse while committing herself to changing their shared future.</b></p> <p><b>#3:</b> She is in a constant mode of adjusting, adapting, and learning. <i>Things are rarely what they initially appear to be</i> with her AI cancer patients, and this is an unsettling feeling that often leads to the abandonment of previously held convictions and assumptions. She was unprepared for this work and has had to create her own lessons, playing the role of teacher and student simultaneously. She is challenged by her patients' complex realities and is forced to reevaluate her own, questioning everything she thought she knew. She eventually <i>faces her own bias</i> and finds an incredible burden lifted from her shoulders. With her eyes, mind, and heart open, she is able to transcend differences and forge human-to-human connection. Her patients respond to this</p>	
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			<p>unencumbered approach and she has the sensation of things <i>falling into place</i> as her caring intentions as a nurse are finally received.</p> <p><b>Essence: As if she is delivering care on quicksand, she learns to constantly adjust, adapt, and reframe her expectations in order to face her own biases and deliver the kind of open and sincere care that she knows to be true.</b></p>	
<p>P. #8</p>		<p><b>#2:</b> To abandon this community would be betrayal to them, and also to herself. Her unfettered obligation towards them is clear and feels <i>intrinsically right</i> having arisen from her own deeply ingrained culture. She sees herself as a very small part of a much larger, more powerful universe; this creates an <i>unpretentious sense of responsibility</i> and commitment to those around her, particularly her own people. These sensations are so embedded into her very being that she sees no other way of existing as a nurse or as a human being, as she is first and foremost an AI person.</p> <p><b>Essence: Although spurred by an overarching sense of responsibility and commitment to nursing AI people, the duty is embedded in her own being so deeply that it feels <i>intrinsically right</i> and as natural as breathing air. [ALSO RELATIONALITY]</b></p> <p><b>#4:</b> She is a <i>mediator and peacemaker</i>, serving as a <i>conduit</i> between the allopathic and Native worlds. She comprehends two realities, two languages, and two ways of being. This dyad is seen as a gift that belongs</p>	<p><b>#1:</b> She is <i>at home</i> in the community, a place that is familiar, comforting, and approachable. Although she had to work to gain entry in the beginning, her ability to transcend her patients' wariness and atone for previous disappointments was made exponentially easier by their shared heritage and her gentle persistence during the delivery of cancer care. She is instantaneously relatable to her patients, <i>one of them</i>, and they are eternally grateful for her presence. She fosters and protects their alliance, sensitive to the tenuous threads that bind them together during these vulnerable times.</p> <p><b>Essence: Transcending past abandonments through gentle persistence, she is <i>at home</i> and deeply connected to her patients and community as they are bound together by their shared heritage. [ALSO SPATIALITY]</b></p> <p><b>#3:</b> Providing cancer care to the AI community is akin to 'juggling', an <i>exhausting routine</i> rife with competing demands, systemic complications, and</p>	

		<p>not to her, but to the patients that she serves. When conflict between the two worlds arises, she calls upon her wisdom and skill to broker resolution and inspire empowerment. Often this entails <i>simply being</i> with the patient and family, silently listening as they struggle to reconcile the grief, pain, and injustice of cancer. At other times, she is the voice of AI people rising up amidst the indifferent din of the healthcare system. In her role as supportive observer and advocate, she sees <i>strength and resiliency</i> in her patients that they fail to recognize in themselves. Even when death is imminent, she sees the awesome power found in persevering another day. Straddling these two worlds allows her the unique vantage point of witnessing what it means to <i>truly live</i>.</p> <p><b>Essence: As a mediator and broker between two worlds, she gives voice to her patients while bearing witness to their resilient ability to thrive against the odds.</b></p>	<p>cultural complexities. She is often overwhelmed and drained by this performance. Although accustomed to her patient's multilayered lives, she struggles to wade through numerous bureaucratic and contextual obstacles in order to connect them with the level of care they deserve. At times, she grows so weary of this work (and this unmerited world) that she must physically step away, taking time and space to replenish her emotional and mental energy. But, she knows that this level of attention and exertion are both inevitable and necessary in order to facilitate sufficient care, and there is <i>honor in her struggle</i> to do so. Moments of exhaustion are countered by moments of deep fulfillment and gratification.</p> <p><b>Essence: Although a convoluted and often personally depleting process of juggling the multiple layers of demands and needs, she finds honor and meaning in the struggle to deliver sufficient cancer care to AI patients.</b></p>	
<p>P. #9</p>	<p><b>#1:</b> She finds <i>human touch to be a powerful messenger</i> and implement for healing, but it must be used wisely and judiciously, and always with the patient's assent. This is especially so among her AI patients, with many carrying the scars of violence and invasion. Her vocation as a nurse demands that she touch patients, but she finds many AIs to be leery of physical encounters and all of</p>	<p><b>#2:</b> Cancer has <i>displaced</i> her AI patients, tearing them from their homes, families, culture, and communities to seek care in an unfamiliar environment in which she comfortably resides. They arrive disoriented and cautious, and although she is sensitive to their plight, there is little she can do to ease the transition. All she can offer in this foreign land is kindness and respect within their burgeoning relationship, a small gesture to comfort and console in the midst of isolation and fear. She uses her familiarity</p>	<p><b>#3:</b> She must carefully calculate each exchange, each word, each touch; it is an <i>exhausting choreography</i>. She is highly alert to her AI patients' individual variations, yet often finds a <i>disappointing inability to impact</i> them. They seem so far away and unaffected by her caring intentions. She feels as if she is gaping open while they remain tightly closed. She wants desperately to give them love as a method of facilitating healing, yet is unsure of her next move.</p>	

	<p>the emotional, cultural, and historical connotations that they carry. They turn their eyes from her, refusing entry. So, she sets aside her tactile urges and <i>waits for permission</i> to enter into the physical space where vulnerability resides, making gradual yet persistent progress until <i>the boundaries between them recede</i> and patient and nurse join together in caring moments.</p> <p><b>Essence: Waiting for the boundaries between them to recede, she uses deferential touch to create a receptive landscape where she can convey her healing intentions as a nurse.</b></p>	<p>with the terrain to navigate between the patient's desires and the constraints of the system. She <i>wishes for a different place</i>, one where her AI patients could feel the earth and be cared for wholly and expansively. But in the interim, both patient and nurse are <i>utterly human</i> within this sterile, fixed, and unfeeling environment. There is no other way for them to be.</p> <p><b>Essence: Unable (and unwilling) to deny their humanness, she guides her AI patients through a sterile and rigid cancer care environment, offering kindness and respect to atone for the impersonal.</b></p> <p><b>#4:</b> She has learned to <i>relinquish control</i>, to surrender to a much higher power that directs life and death; disease and healing; patient and nurse. She is merely a facilitator, a <i>channel for transitioning</i> to occur exactly when it is meant to. She accepts this role, although often humbled and awed by these outside forces that so mysteriously unfold yet always with intention. She finds that her AI patients inherently grasp the gravity of these events; it is they who have taught her how to live and to embrace life's cosmic wonders. She sees her own spiritual awakenings shared by her AI patients, and this internal quest unites them on an otherworldly plane that is both striking and reaffirming.</p> <p><b>Essence: She sees her AI cancer patient's innate understanding of life's cosmic mysteries as an affirmation of her own spiritual journey and the transient nature of life, death, disease, and healing.</b></p>	<p>Many of her AI patients feel impervious, disjointed, and detached from her and the present situation. She is burdened by this distancing negative energy and her <i>failure to connect</i>, and it weighs on her to the point where she can no longer continue her work.</p> <p><b>Essence: She carefully choreographs her care of AI patients but finds that her intentions are often unreceived or rejected, leaving her burdened and stymied with disappointment.</b></p>	
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**Cross-Participant Thematic Descriptions with Metathemes**

1. Relationship is paramount for nurses to transform nursing care into authentic caring. (From Task to Connection)
2. Relationship is thwarted by an inability to read verbal and nonverbal cues expressed by AI patients. (Unnerving Messaging)
3. Relationship is deepened by recognizing self in the other (and other in self) regardless of contextual differences. (We Are One)
4. Relationship is facilitated by removing bias, assumption, and judgement and finding neutral ground for caring to take place. (The Freedom of Unconditional Acceptance)
5. Relationship is a process of attuning to the AI patient in every dimension and becoming receptive to a new way of being. (Attuning and Opening)
6. Relationship is a means for honoring the struggles of AI peoples through the easing of suffering, even if only momentarily. (Atoning for the Past, One Moment at a Time)
7. Relationship is a mediator between the biomedical cancer care and AI worlds. (Humanizing the Inhumane)