



# Identifying Strengths and Challenges in Cancer Care Delivery on Navajo Nation: A Qualitative Study

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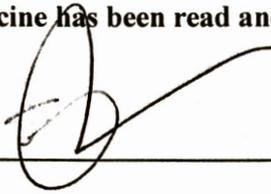
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**This Thesis, Identifying the Strengths and Challenges in Cancer Care Delivery on Navajo Nation: A Qualitative Study, presented by Hannah Sehn, and Submitted to the Faculty of The Harvard Medical School in Partial Fulfillment of the Requirements for the Master of Medical Sciences in Global Health Delivery in the Department of Global Health and Social Medicine has been read and approved by:**



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IDENTIFYING STRENGTHS AND CHALLENGES IN CANCER CARE DELIVERY ON  
NAVAJO NATION: A QUALITATIVE STUDY

HANNAH SEHN

A Thesis Submitted to the Faculty of

The Harvard Medical School

in Partial Fulfillment of the Requirements

for the Degree of Master of Medical Sciences in Global Health Delivery

in the Department of Global Health and Social Medicine

Harvard University

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May, 2018

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## **Identifying Strengths and Challenges in Cancer Care Delivery on Navajo Nation: A Qualitative Study**

### *Abstract*

**Background:** On Navajo Nation, cancer is the second leading cause of mortality and a leading cause of premature death. Multiple preventable cancers are diagnosed at later stages than in non-Hispanic Whites (NHWs). Preventable cancers, such as cervical cancer, have higher prevalence than with NHWs (Yazzie, 2018). The healthcare system serving Navajo Nation is complex and fragmented. Although health facilities and health programs are actors along the cancer care continuum, little is understood about cancer care delivery and care coordination from a systemic perspective. This study sought to understand structural barriers and opportunities to improve cancer care delivery on Navajo Nation.

**Methods:** We collected qualitative data through semi-structured interviews with health sector workers who provide care and services along the cancer care continuum regarding what they viewed as the strengths, barriers, and opportunities for improving cancer care for individuals on Navajo Nation. We open coded a subset of the interviews and used content analysis method with the grounded theory approach (Pope & Mays, 2006) through an iterative process to come up constituent categories that describe the themes that emerged from the dataset.

**Results:** On the basis of category construction and interpretation of the data, we organized the findings from the interviews into several thematic categories represented below: 1) Patient access to care and resources, 2) Communication, 3) Care coordination, and 4) Larger systemic challenges. Together, these are understood through the larger category of the interrelatedness across the cancer care continuum.

**Conclusion:** Although there are significant systemic challenges in providing cancer treatment to individuals living on Navajo Nation, there are also important opportunities to improve cancer care that can be addressed at the health facility level. To relieve the care coordination burden placed on patients, certified mentored Navajo translators and cancer care coordinators could help ensure equitable access to cancer treatment and resources by transforming a champion-based model into a system level change that addresses the challenges in continuity of care, provision of culturally appropriate care, and timely referral, especially in departments that have a higher staffing of short-term providers such as the emergency department and urgent care.



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## **Part 1. Political economy/background**

American Indians and Alaska Natives (AI/ANs) experience some of the most pronounced cancer disparities in the United States (US), even though cancer treatment centers in the US, such as the Dana Farber Cancer Institute and MD Anderson Cancer Center offer the most cutting-edge cancer treatment in the world. Specifically, on Navajo Nation, cancer is currently the second leading cause of mortality and a leading cause of premature death. Many cancers that are preventable are diagnosed at later stages than in non-Hispanic Whites (NHWs) in the southwest (Arizona and New Mexico). Additionally, preventable cancers, such as cervical cancer, have a higher prevalence than in NHWs (Yazzie, 2018).

Why is it that these health disparities exist in AI/AN communities? The question has been posed before. In response, some have tried to explain these health disparities through differences in genetics, speculating that specific genomes must be more susceptible to disease. Others argue that indigenous communities were in an ill state of health before European contact and have continued to experience poor health that has only been exacerbated by the legacy of US policy and history. However, both of these explanations fall starkly short of the poignant truths that can be obtained by looking at this question through a biosocial lens, taking into account the global and local perspective and recognizing the causal relationship between US history and corresponding policy and health disparities in AI/AN communities today.

Global health means eliminating health disparities wherever they may be found, but all too often, global health can be used as a means of diverting our attention from the challenges individuals face in our own back yard; disparities do not only exist in distant places. In the US, we have the most cutting-edge medical care, yet we also have communities without access to care, let alone well-coordinated care. The further removed we are from these inequities, the stronger our feeling of exoneration is from the role our own US government has played in the creation of disparity and their intentional propagation of these disparities throughout the centuries. If we excuse genocide with concepts like “Manifest Destiny,” then we transform it from a blatant human rights violation to a “God given right”.

In this way, we can sabotage the transfer of the truth by erasing American Indians and Alaska Natives from the history books, thereby removing them from mainstream discourse. Most Americans only know what history books have insinuated – that AI/ANs were “all wiped out” hundreds of years ago. Despite a population of 5.2 million (Humes, Jones, & Ramirez, 2011), representing over 573 distinct, federally recognized nations (Schilling, 2018), the existence of American Indians and Alaska Natives in the US is often only acknowledged on Halloween when countless individuals don “Indian costumes” thereby desecrating sacred war bonnets, or on Thanksgiving, when Americans demonstrate their thankfulness for the salvation of the Pilgrims. Sports mascots such as the Washington Redskins are the only image many have of indigenous peoples, and these mascots have been shown to have a significant negative impact on Native communities, especially on youth (Fryberg, Markus, Oyserman, & Stone, 2008). If a person no longer exists in the consciousness of the country and in its recorded history, they have become the perpetual tree falling in a forest.

## Applying the Lens of Biopower to Understand AI/AN Health Disparities

Michel Foucault's theory of "biopower" is an apt lens through which we can explore the previously-posed question – why do health disparities still exist in American Indian and Alaska Native communities? According to Foucault, biopower arises from the progression of power over life and death exercised historically to modern day (Foucault, 1988). He traces the origin to *Patria Potestas*, a concept in ancient Rome whereby men had the power to decide whether their children and slaves lived or died. According to Foucault, in moving forward to the classical age, this concept transitioned to a sovereign's power "to *take* life or *let* live," which eventually gave rise to a fundamentally different form of power that focused on "generating forces, making them grow, and ordering them, rather than one dedicated to impeding them, making them submit, or destroying them" (Foucault, 1988).

However, this construction of biopower not only leaves out the majority of the world by focusing on only Western perspective, but also excludes those most affected by biopower in Western societies, where governments have exerted power over indigenous peoples through subjugation and destruction. A continued complexity to biopower lies in the past and present of colonization in the US. The scale of World War II's death and destruction seems to have strongly influenced Foucault in this volume. However, in the United States, prior to and after WWII, biopower and the "power of life and death" (Foucault, 1988) existed simultaneously and reflect a complex and sordid history quite unique from the broader Western context.

The Navajo leveraged the Spanish arrival to obtain livestock such as horses and sheep, choosing to incorporate them into their culture. Although there was animosity between these two nations during this time, it was the rise of the American government that worked to undermine Navajo sovereignty during the 19<sup>th</sup> century (Calloway, 2012; Denetdale, 2007). Believing it was their divine right to push west to take and control the land, resources, and people they encountered, the U.S. exercised *Patria Potestas* under the auspices of Manifest Destiny.

Death was a travelling companion of Manifest Destiny. For the indigenous peoples living in the United States, "the power of life and death" was manifested in army massacres and land seizure. Killing women, children, and destroying sources of food such as cornfields and buffalo was at the heart of the "scorched earth policy" the US army employed when their military prowess was not sufficient to assert control. Honor never had its place in these actions. In 1863, Christopher "Kit" Carson, a commander in the US army led multiple campaigns burning Navajo cornfields and fruit groves (Gorman, 1973). In Gallup, New Mexico, a town surrounded by Navajo Nation, vestiges of this time in US history remain as a street called "Kit Carson" is an unwelcome reminder its namesake's actions. Following these campaigns, Carson, led the US effort in 1964 to forcibly remove and intern over 9,000 Navajo people over 300 miles away at Fort Sumner (2016, "Native Voices").

Resilience is knowing the odds are stacked against you, knowing that history does repeat itself, but still working to create a different outcome. Perhaps this is the most important, the key social theory that no one talks about. Navajo people have changed the course of history many times over because of their resilience. The US army marched the Navajo people to Fort Sumner in Bosque Redondo over the course of about three weeks (2016, "Native Voices"). Having brought seeds with them, many tried to plant, but season after season nothing would grow (Gorman, 1973), many were starving and only had meager government rations of lard, sugar, flour, and at times spoiled meat to sustain them (Iverson,

2002). They knew the seeds were not growing because they were outside the four sacred mountains. The people came together and insisted that they return to Dinéétah (Navajo land), as that was the only way the people would prosper once again (Denetdale, 2007).

In 1868, after over 2,000 Navajo individuals passed away during the four years at Fort Sumner (2016, “Native Voices”), the impossible happened. The Navajo people signed a treaty with the United States that provided for their return to some of their ancestral lands. Once the US government had determined a Native community would go through the process of removal, never before had the exact opposite taken place. It had been planned for the Navajo people to be removed to Oklahoma like many other Native nations had been. Not only did the Navajo people return to their ancestral lands, but over the following several decades, they were able to expand the area within the allocated reservation. Today, that area covers over 27,000 square miles and is the biggest land base of any Federally Recognized Native Nation in the US (Gerke, 2008).

However, during this same time, biopower was at play in a new US government strategy of seizing Native children and placing them in boarding schools to “Kill the Indian, Save the Man.” In these schools, children were sexually assaulted, abused, starved; their traditional clothes were burnt, their hair cut, and their language and traditional names forbidden. Administrators at these schools, many of which were run by the U.S. Government, issued uniforms and white-man names to the thousands of children at these schools (Child, 1998; Lomawaima, Child, Archuleta, & Heard, 2000). There is more than one way to kill and destroy.

Nearly a century later, in the 1970s, while Foucault’s *The History of Sexuality* was being published, the legacy of biopower continued: the health facilities whose purpose should have been to provide healthcare were controlling American Indian women’s bodies by sterilizing them without their consent (Lawrence, 2000; Torpy, 2000). The US government still decides “to take life or let live” for over 5.2 million American Indians and Alaska Natives (“Profile America”, 2011) living in over 573 distinct communities in areas across the United States. Biopower is manifested in resource extraction and its legacy (Brugge, Benally, & Yazzie-Lewis, 2006; Roscoe, Deddens, Salvan, & Schnorr, 1995; United States. Congress. House. Committee on, Government Reform. United States. Congress. House. Committee on, & Government, 2008), underfunded Indian Health Service facilities (Goodkind et al., 2010), contaminated water (United States. Environmental Protection Agency, 2015), and control over food and land (Robert, 2004).

### **Cancer Epidemiology in Navajo Nation**

In Navajo traditional culture, the goal has always been to reach old age – 102 years old, in fact. Today, you can find elders in the community who are well over 102 years old, and more still who are welcoming old age. However, today, community members affected by cancer are often not able to achieve this goal of reaching old age, as cancer is the second leading cause of mortality, with breast, colorectal, and prostate being the most common diagnosed cancers (Yazzie, 2018).

Inferences from case series informed early knowledge about cancer epidemiology on Navajo Nation. Smith, Salsbury, and Gilliam at Sage Memorial Hospital located in Ganado, Arizona, looked at

cancer related mortality data from 1948-1952. They found only a total of 74 deaths from cancer during this time, roughly 3.5 times less than expected when compared to rates of whites and non-whites. They thought this “consistent with the belief that the Navajo experience a deficit of cancer as a whole and, more specifically, of cancer of the breast, prostate, and lung,” (Smith, Salsbury, & Gilliam, 1956, p. 77-89). What has changed since the 1950s that the “deficit” is now some of the most commonly diagnosed cancers on Navajo Nation today?

A simple search in google for “causes of cancer” yields over 191 million results. The American Cancer Society’s informational page “Learn About Cancer: What Causes Cancer?” rises to the top of the list. To answer this question, they state, “the known causes of cancer are: genetic factors; lifestyle factors such as tobacco use, diet, and physical activity; certain types of infections; and environmental exposures to different types of chemicals and radiation,” (“Learn about cancer”, 2016).

Gallup, New Mexico, located an hour drive from Ganado, AZ, and surrounded by the southeast part of Navajo Nation, elucidates some of the influential factors that have changed history. The Rio Puerco, a small wash dubbed the “Perky” by locals, runs through Gallup. Far from the connotation its nickname elicits, the Perky holds the dark legacy of uranium mining on Navajo Nation. Most of the year, it is just a dry wash. Seeing people walking through its sandy path is not uncommon in the dry season. In the wet season, the Rio Puerco, stretching about 230 miles fills with water and connects to the Little Colorado River in Arizona. On July 16, 1979, during the typical dry season, the Perky was overflowing, but not with rainwater. The largest nuclear waste spill in history, larger than Three Mile Island or Chernobyl, took place in the Churchrock mine, washing over 94 million gallons of nuclear waste down the Perky (“United Nuclear”, 1979, p. 16; Thorn, 1987, p. A22). Like other uranium mines, the mine at Churchrock released toxic byproducts into the ground water, but this spill was different. In her book, *Yellow Dirt: A Poisoned Land and the Betrayal of the Navajos*, Judy Pasternak, tells how this yellow nuclear waste snaked its way through Navajo Nation – scorching the skin of children playing in the Perky, and killing livestock who dared drink from its pools (2010).

Only five short years earlier in 1974, the US Congress had passed the Navajo-Hopi Land Settlement Act – aimed at moving Hopi and Navajo families out of their communities and off the land in order to access the mineral resources the land held (Lacerenza, 1988, p. 3-6). Despite the 1979 spill, in 1987, thousands of Navajo people were forced to leave their ancestral homelands in Arizona and were placed on lands adjacent to the Perky (Thorn, 1987). As if the US leasing Navajo land to developers who extracted resources such as uranium and then left without ever cleaning up the toxic waste in their wake were not offensive enough, forcibly relocating whole communities to this toxic waste area only to extract additional resources from their homelands is egregious. What’s worse remains the fact that while most people have heard of Three Mile Island or Chernobyl, not many know about the mine in Churchrock, NM, that filled the Perky in dry season. Just like not many know the 1974 Navajo-Hopi Land Settlement Act was not a result of a land dispute, but instead is viewed by many as merely the US government’s insatiable greed for natural resources. Today, as a result of extracting over 30 million tons of uranium ore, there are over 500 abandoned uranium mines across Navajo Nation (“Navajo Nation”, 2016). Spanning the area within the four sacred mountains, as Figure 1 demonstrates, these abandoned mines affect everyone on Navajo Nation.

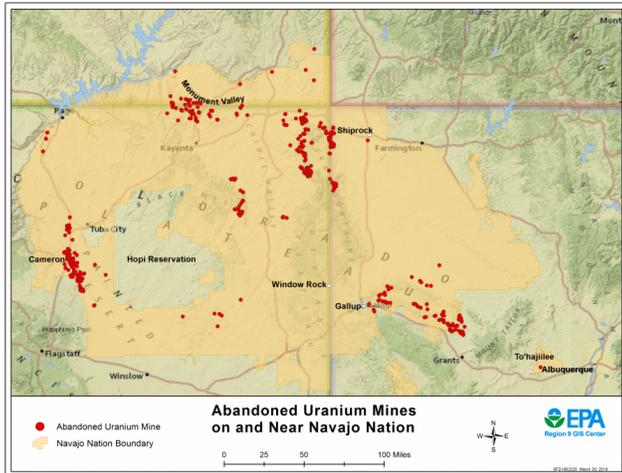


Figure 1: Abandoned Uranium Mines on and Near Navajo Nation (“Navajo Nation”, 2016)

Native communities have been advocating for control over natural resources in their own communities. This has continued to be challenging and complex, with the US still asserting ultimate control over all resource extraction. Perhaps this can be explained by the fact that reservation geographic areas as part of Native communities only cover 2.3% of the U.S., but these Native lands are estimated to contain over 50 percent of uranium, 20 percent of natural gas and oil reserves, and about 30 percent of the nation’s coal reserves in the western half of the US (Grogen, Morse, & Youpee-Roll, 2011, p. 3, 6). Perhaps this is also elucidated by the fact that the Bureau of Indian Affairs (BIA) is currently housed in the Department of the Interior, the entity that manages all natural resources across the US. Equally as poignant is the fact that the predecessor to the BIA was housed in the War Department.

Biopower, manifested in US-controlled resource extraction and other US policies, has drastically impacted access to healthy foods and clean water on Navajo Nation. Through many conversations with Navajo elders, I feel honored to have had the opportunity to learn from their first-hand experience how these changes have impacted the community. The relationship with food has traditionally been one of respect and reciprocity. Elders often mention the many cornfields and sheep that dotted the landscape. However, in the 1930s, the US implemented the Livestock Reduction Policy, slaughtering thousands of Navajo sheep and livestock without Navajo community members’ consent, in some cases herds were doused in gasoline and burned alive in front of their herders (Roessel, 1974).

According to the United States Department of Agriculture, the Navajo Nation is a food desert (Figure 2). Additionally, efforts to grow food on Navajo Nation have confronted new, unforeseen challenges. In the summer of 2015, only 36 years after the Churchrock spill, the Environmental Protection Agency triggered a toxic spill from the Gold King mine into the San Juan River, which runs through the northern part of Navajo Nation. This river had been a source of water for animals, crops, and even a water source for many people, as about half of Navajo community members have no running water (RPI Consulting, The Jones Payne Group, Native Home Capital, & Alternative Marketing Solutions, 2011). Like the Perky, the San Juan River was filled with yellow toxic waste. In “Cancer Among the Navajo,” the Navajo Epidemiology Center found that the prevalence of cancers such as kidney, liver, and stomach are higher on Navajo Nation (Yazzie, 2018) compared to other areas in the southwest (AZ, NM). What role do US actions related to food and water insecurity play in these prevalent cancers?

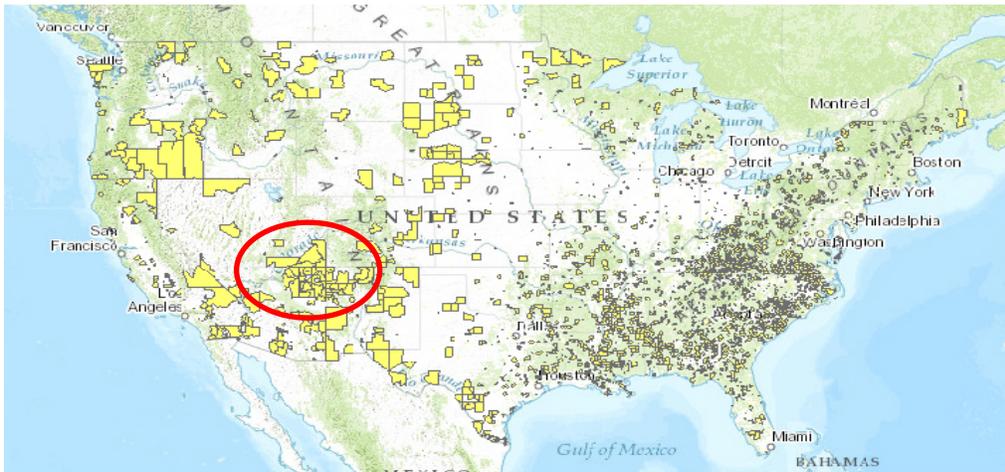


Figure 2: Map of Food Deserts in the United States (“USDA Economic”, 2016)

In Navajo traditional culture, living a long, healthy life and reaching old age is reflected in maintaining balance and the relationship with the land, water, plants, and animals. With resource extraction, contaminated land and water sources as well as access to healthy foods hundreds of miles away, how much of the cancer we see today on Navajo Nation is a reflection of this legacy of uranium mining and resource extraction and other detrimental US policies?

**The Health System Serving Navajo Nation**

The health system serving Navajo Nation is complex and fragmented. Covering over 27,000 square miles, parts of New Mexico, Arizona, and Utah, the Navajo Nation is at the heart of a quandary – it lies at the epicenter of many sovereigns, but also where resources are scarce. For health services, Navajo Nation is divided into eight service areas. Within each of these service areas, there is no one standard for health care delivery – although five of these main health facilities are federal and run by the Indian Health Service, three are self-determined and locally run, and others are private health facilities (“About IHS,” 2018).

Furthermore, because Indian Health Service (IHS) Hospitals are often understaffed, underfunded, and rural, they have trouble with longevity of providers. Stemming from past experience, such as occurred with sterilization at health facilities, some individuals have lost trust in their health facility. Since often times providers are not from the community or are only working on Navajo Nation in a short-term engagement, having a provider who understands the unique community context is a daily challenge for those seeking care.

Some of the Navajo Nation health service geographic areas encompass areas within different states. Medicaid and Medicare are administered differently and services provided through each state department of health vary. Six counties – two in New Mexico, three in Arizona, and one in Utah have jurisdiction across Navajo Nation, therefore services in each of these counties also differ. Moreover, the

Navajo Nation has its own newly formed Department of Health (NNDOH) where health programs, such as the Community Health Representative (CHR) Outreach program, provide services to community members. Some NNDOH programs, such as the Breast and Cervical Cancer Prevention Program (NNBCCPP) can only provide services in Arizona, due to certain funding allocation and related stipulations. Those who are referred for cancer regimens such as chemotherapy, radiation, certain types of surgery must, etc. travel to cancer treatment centers in Gallup, NM, Albuquerque, NM, Farmington, NM, Flagstaff, AZ, Phoenix, AZ, or even Salt Lake City, UT, which could be as far away as an eight-hour drive in some cases.

An additional complicating factor is the turnover in providers. The promise of loan repayment or being part of a locums staffing agency often brings providers to health facilities serving Navajo Nation, but patients can lose trust in the health facility because they have a different provider every time they seek care, especially in the urgent care setting. Because of the frequent provider turnover, where two providers from the same health facility decide to refer their patients for cancer specific treatment could vary significantly, even when patients have the same cancer diagnosis.

Patients have detailed their experience accessing care that was different from others in their area who have been diagnosed with the same cancer and cancer stage. Maybe they got sent for treatment eight hours away, while their neighbor was sent just an hour away. Maybe their neighbor was linked to transportation services while they had to sell their family heirlooms or one of their vehicles just to have the gas money to go to appointments. Although the geography of Navajo Nation is vast, the resources are not. The coordination of resources could be the key to leverage these resources, but care is often fragmented and good coordination is more a reflection of champion providers than the system itself.

### **The Legacy of Research in Native Communities and Navajo Nation**

While it is true that a search in any university database will yield a plethora of information in academia about Navajo people, what is also true is that most research has not been community driven or guided. Much of the research that took place in the past, similar to US environmental dealings on Navajo Nation, has been extractive by nature. This history of exploitation has caused distrust in many American Indian and Alaska Native communities around research. Ruth Roessel, Director of the “Navajo and Indian Studies Department” at Diné College in the 1970s, explained that the main challenge she observed was that researchers including anthropologists, historians, and social scientists, came to the Navajo Nation to do research for their own professional gain, driven by their own agendas, and in this way, they overlooked what was important to the communities themselves (Roessel, 1974). Additionally, instances of mistreatment and misrepresentation have led to loss of trust in researchers within these communities (Sahota, 2007). Researchers are often characterized as being unwilling to genuinely seek to understand the problems community members face, stereotyping community members in their publications, conducting research without having proper respect for cultural and traditional beliefs, and failing to create systems for research that is community driven in order to be sustainable and inform change (Herbert, 1996).

Unfortunately, the Navajo people share this sordid research history. For example, uranium mining took place on Navajo Nation from the 1940s through the 1980s (Brugge et al., 2006). Starting in the

1950s, as the U.S. advanced its atomic nuclear interests, Navajo communities were subjected to five decades of research on the health effects of uranium mining, particularly regarding occupational risk of lung cancer. These studies have been widely criticized as being unethical for a number of reasons, especially given the fact that they were conducted without informed consent (Panikkar, 2007). Thereby despite these initial studies concluding that miners faced serious risks, information was never shared with miners or their families. Miners continued to leave work in the mines, covered in uranium dust, and go home to their families, transferring the dust to their children and family members.

Decades passed before safety measures were adopted and a compensation system providing reparations to these miners was established. Although some thought the prevalence of smoking was the cause of cancer and often cited it as a way of discrediting the association between uranium exposure and lung cancer (Brugge & Goble, 2002). It was not until the 1980s that research demonstrated that this assertion fell starkly short of the truth. The majority of lung cancer incidence among former Navajo uranium miners was solely attributable to their occupational exposure (Gilliland, Hunt, Pardia, & Key, 2000; Gottlieb & Husen, 1982). These types of research abuses didn't come to an end decades ago, with the end of uranium mining. In a more contemporary example, research findings resulting from a Hantavirus Pulmonary Syndrome epidemic in 1993 unjustly and discriminatorily characterized the epidemic as a "Navajo disease", leading to severe backlash from the community (Brugge, 2006).

Providers on Navajo Nation have observed, among their patients, several cases of Lynch Syndrome, a genetic mutation whereby an individual's risk for cancers such as colorectal, endometrial, and ovary cancer are increased especially at earlier ages. Resulting from an autosomal dominant mutation, those affected pass this gene mutation to their children. Some of these providers want to start research to identify how Lynch Syndrome is affecting the Navajo community as a whole.

However, although providers may be well meaning in trying to understand the impact on the community, many community members still remember a supposed diabetes study on the Havasupai Nation that took a devastating turn. In 1989, with diabetes on the rise among its roughly 650 members, the Havasupai Nation wanted to understand if there was genetic link. Over 100 community members provided a sample of their blood, believing it would only be used to test whether there was any genetic link with diabetes and its increased prevalence (Sterling, 2011).

Although the researchers found no genetic link to diabetes, other researchers utilized the blood samples for their own topics of research. Soon they used these additional analyses to publish papers on topics such as inbreeding, alcoholism, and what they believed to be the origin of the Havasupai people. The Havasupai Nation took the university to court. However, after seven long years, the only compensation awarded to the community was \$700,000, offers of university scholarships, and help with a health clinic (Sterling, 2011). This legacy of exploitative research in Native communities has significantly impacted the community's trust of researchers and projects proposed on Navajo Nation as well as other American Indian and Alaska Native communities.

## **A Model Committed to Community-driven Initiatives and Research: Community Outreach & Patient Empowerment (COPE)**

Community Outreach & Patient Empowerment (COPE) began in 2009, with the goal of addressing AIAN disparities by partnering with Navajo Nation Community Health Representatives (CHRs) and health facilities serving Navajo community members to innovate the way health care is delivered for Navajo people. Building trust with the community over the past seven years, we have worked in close collaboration with the community and other local stakeholders to inform program needs, design, and implementation. Their feedback and guidance has led to the formation of COPE's mission to eliminate health disparities and improve the wellbeing of American Indians and Alaska Natives, as we believe the power to overturn long-standing health inequities lies within the communities themselves.

In the past four years, we have worked to bring together several advisory groups representing the community and stakeholders with whom we partner. We started the first Patient and Family Advisory Council (PFAC) of its kind on Navajo Nation for individuals affected by cancer. These individuals have been our compass, our true north as we work to identify how we can support others living with cancer on Navajo Nation.

Over my nearly eight years working with COPE, I have had the opportunity to learn from the community and build strong relationships. In conversations with patients and family members, I have come understand some of the challenges they face accessing cancer treatment, and their stories have been the catalyst for this type of community-driven research. Their journeys have always been in the direction of wellness and balance. However, the difficulties they have encountered make this journey an arduous, if not an impossible one at times. Our conversations and their guidance informed the direction in collaborating to improve cancer disparities experienced on Navajo Nation through community-based research.

I often feel that stories are what link us through time. In the moment I heard patients and family members sharing their experiences, I thought back to my own memories related to cancer. It was hard for me to think about cancer without thinking about the way cancer could take your best memories of a person and leave you with the exact memories that person would never want you to have – a cold hospital room, where the person you loved, now in a coma, had left a long time ago. You are forced to stand by and witness the person in that reticent, sterile bed slip away ever so slowly. Each day that passes by seems to take with it one of the good days you spent with them before the word cancer was even spoken. Those last memories seem to stick with you better than all those that came before, as if they entered bound in a book, while those that came before were fleeting pages on a windy day.

But it was those same bound memories that had motivated me to work to bring balance back – to tip the scale in favor of those affected by cancer. In hearing these stories, I realized that stories give you back that power. I believe if stories connect us across time, then stories themselves can change the course of time, change the future. Resilience is knowing the past, what has brought us to where we are today, but believing that despite the odds, we can change the course of history. It is believing that we have the power to do so.

Many exciting research projects aimed at having a better understanding of what is causing cancer on Navajo Nation from a biologic perspective are finally taking place. Responding to community

advocacy around the need to understand how uranium is affecting people living on Navajo Nation, the Navajo Birth Cohort Study began in 2013 with the aim of understanding the effects of uranium on babies that are born on Navajo Nation. This study is collaborating closely with the Navajo Nation CHR Program and health facilities across Navajo Nation.

Far too long overdue, these types of positive research that respond to the community's needs and desires are encouraging. Still, little is being done to understand how to best provide support to individuals who are living with cancer on Navajo Nation. What needs to be done to fill the gaps in care and resources for those affected by cancer on Navajo Nation? The structural barriers that prevent a person from being able to access cancer care are not well documented.

Understanding the structural barriers to cancer care delivery on Navajo Nation will not only help to improve cancer outcomes on Navajo Nation but will also provide insight that can benefit other American Indian/Alaska Native communities, as well as other communities affected by cancer disparities. In general, there is not a lot of published research about cancer care delivery and cancer management in Native communities in the United States; there is even less that the community itself has been a part of or guided. Working in close collaboration with the community and local partners and stakeholders, this thesis has endeavored to remedy that.

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## Part 2. One publishable research paper

### 1. Introduction

American Indians and Alaska Natives (AI/ANs) experience some of the most pronounced cancer disparities in the United States (US). On Navajo Nation, cancer is currently the second leading cause of mortality and a leading cause of premature death. Certain types of preventable cancers, such as colorectal and breast cancer, are diagnosed at later stages. Other cancers such as stomach, liver, kidney, and gallbladder have a higher incidence on Navajo Nation than in Non-Hispanic Whites (NHWs) in the southwest (Arizona and New Mexico) (Yazzie, 2018).

The Indian Health Service (IHS) is responsible for providing care to 2.2 million American Indians and Alaska Natives ("About IHS"). The healthcare system serving Navajo Nation is complex and disjointed and even more so for individuals affected by cancer. Cancer treatment is only available outside of the IHS system at regional cancer centers located off the Navajo Nation, often hundreds of miles away from a patient's community. There are no cancer treatment centers on Navajo Nation, even though it spans three states (New Mexico, Arizona, and Utah), covers over 27,000 square miles (roughly the size of Vermont, New Hampshire, and Massachusetts combined), and has 332,129 members according to the 2010 census (U.S. Census Bureau, 2011). The resulting cancer care delivery system with its numerous actors across the cancer care continuum is siloed and therefore has a negative impact on health outcomes, especially among older AI/AN patients with cancer (Wilson et al., 2007). Although health facilities and health programs on Navajo Nation provide supportive care along the cancer care continuum, little is understood about cancer care delivery and care coordination for individuals diagnosed with cancer from the first-hand perspective of front-line care providers. The goal of this study was to understand the barriers to cancer care on Navajo Nation in order to identify opportunities to improve cancer coordination, diagnosis, treatment, and outcomes.

### 2. Methods

Study setting: Navajo Nation is divided into eight geographic Indian Health Service (IHS) Areas, called service units. Each of these service units has a main health facility or hospital and clinics that correspond to it. These facilities provide primary care and varying degrees of specialty care depending on the size of the facility. This study took place in the service unit that serves the largest population of Navajo individuals, with 250,000 outpatient encounters and 5,800 inpatient admissions annually ("Gallup Indian Health Center"). The main hospital for this IHS service unit is located in a city that borders Navajo Nation. As one of the largest hospitals in IHS, it provides some surgical care and laboratory diagnostic testing. However, beyond these services, individuals have to be referred to a specialized center for chemotherapy, radiation, and other types of cancer treatment. One such cancer center is located down the street from this IHS hospital. Because of the large area Navajo Nation encompasses, individuals often still have to travel long distances to receive cancer treatment at this cancer treatment center and others which are located in the larger cities that border Navajo Nation (i.e. Farmington, Gallup, Albuquerque, Flagstaff, Phoenix, etc.).

Data collection: We collected qualitative data with the purpose of learning from health sector workers who provide care and services along the cancer care continuum regarding what they

viewed as the strengths, barriers, and opportunities for improving cancer care for individuals on Navajo Nation.

Two interviewers (HS, OM) conducted the interviews with the health sector workers. HS did nineteen interviews and OM did three interviews. These individuals had prior experience working on research initiatives on Navajo Nation. The qualitative semi-structured interview guide had sixteen open-ended questions to give respondents the opportunity to share their thoughts and feedback without the interviewer swaying their responses. A patient and family advisory council (PFAC) provided significant feedback on the development of the interview guide. Through this process, the study team incorporated feedback from the PFAC and also incorporated general input from providers regarding important points to include in the interview guide as well as which perspectives would be vital to understanding cancer care delivery in this health service unit. The interview guide was piloted and then finalized for use in this research study.

From January 2018 to April 2018, we obtained written informed consent to conduct the interviews and to audio-record them. Each interview lasted between 45 to 120 minutes. Both OM and HS transcribed the interviews they conducted for analysis. We purposefully sampled health sector workers to obtain a diverse perspective across the continuum of cancer care using maximal variation sampling (Creswell & Clark, 2018), from physicians, case managers, surgeons, oncologists, to outreach workers across facilities in this service unit, both IHS and private, which provide services to Navajo individuals diagnosed with cancer. These key perspectives were identified in collaboration with the PFAC as well as respondents who could recommend an individual whose feedback they believed to be vital to the research.

Data Analysis: We open coded a subset of the interviews. OM and HS created the codebook, and HS directly coded all the interviews using the content analysis method with the grounded theory approach (Pope & Mays, 2006). HS and OM reviewed the coded transcripts and employed an iterative process to come up with an initial set of constituent categories that describe the themes that emerged from the data set (Pope & Mays, 2006). The iterative process continued by returning to the data to further develop and refine the categories into a set of final themes that are represented in the results.

The study was approved by the local Navajo Nation Human Research Review Board NNR-17.287T as well as the Harvard Medical School Institutional Review Board IRB17-1361.

### **3. Results**

A total of 33 health sector workers were invited, 29 accepted, and 22 completed an interview within the timeframe. Encompassing IHS and private facilities, health sector worker categories were as follows: primary care providers in family medicine, internal medicine, pediatrics; specialty physicians in surgery, oncology, radiology, and emergency medicine departments; pharmacists, nurses, and health facility patient support staff including case managers, care coordinators, receptionists, social workers, Navajo language translators, patient advocates, patient benefit coordinators, hospice staff,

and nonprofit service providers. We were successful in sampling all the categories we wanted to include from the outset, and the feedback from participants enabled us to include additional categories of participants. There were seven male and fifteen female participants.

On the basis of category construction and interpretation of the data, we organized the findings from the interviews into several thematic categories represented below: 1) Patient access to care and resources, 2) Communication, 3) Care coordination, and 4) Larger systemic challenges. Together, these are understood through the larger category of the interrelatedness across the cancer care continuum.

*Patient Access to Care and Resources:*

*Transportation:*

Physical challenges in getting to the health facility including transportation and long distances were repeatedly mentioned as significant barriers for patients in accessing care; as shown in the narrative below:

I think the biggest challenge from the patient's standpoint is getting here – resources. Believe it or not, and it's terrible, they'll hitchhike. They'll hitchhike for a procedure for breast cancer. We here, if they are late for their appointment, we'll actually spend the time, the overtime to accommodate the patient, because we know if they leave, they aren't coming back. We can't allow that, it's just unacceptable in our book. That's our biggest challenge, trying to get the patient here. – *Specialty physician*

*Primary care: provider shortages, short-term staff, turnover*

In describing barriers to cancer treatment, respondents discussed the challenges that patients had in accessing care and resources across the cancer care continuum including screening, treatment, and survivorship. They indicated that insufficient staffing, for example, being waitlisted to receive a primary care provider, accessing care through the emergency department or urgent care, and staff turnover of short-term providers impacted the cancer outcomes. Therefore, not having primary care drives patients to urgent care for sporadic, symptom-focused treatment rather than any attention to primary cancer screening and prevention. Interviews revealed that because of the shortage of primary care providers, individuals trying to access reliable continuous care in a primary care setting are triaged, with only those most in need, such as those who are elderly or those who have a medical condition being assigned a primary care provider.

He [IHS staff member who empanels new patients] sees a lot of the new patients who need to establish care, and he was complaining the other day that he's been getting all of these young, healthy patients who presented to the urgent care with like a cough or something minor and he's like, "We have so many people who need primary care, why are we getting all these young people?" It would be great if people were used to being in the medical system starting young and having a primary care doctor so when you turn 40 or 50 and you're thinking about cancer screening, then you're already going. I think that is one of the reasons why early diagnosis isn't happening. – *Primary care provider*

Our data demonstrated some challenges exist within the health care delivery structure due to short-term providers and provider turnover. Because some of the providers and nurses who staff the emergency and urgent care departments are short-term and turnover frequently, they are often unfamiliar with the health facility, the system of care in the Indian Health Service (IHS), and resources that are available to cancer patients. Our data showed that these transient providers may not be familiar with the cancer center located down the street from the IHS facility or the support they provide, such as consults for primary care providers to assist in diagnosis through guidance with cancer specific care processes. Therefore, the new or short-term providers spend an extended period of time working-up patients before referring them to a cancer center for care. This may cause the patient to receive unnecessary tests, which are costly to the health facility itself, but more importantly, can cause delays in the patient's diagnosis and treatment.

One barrier is that the physicians come and go, and they don't know that we are there. If people send us the patient, we can really manage those patients so that they do not have the delays. We're seeing huge amount of delays and every time the docs change over, we'll see that they have been trying to work on them [patients with symptoms] for a month or 6 weeks or 8 weeks and then they refer them [to the cancer center]. – *Specialty physician*

Furthermore, our data illustrated that because of the transient nature of short-term providers' tenure, without longitudinal follow-up, they may not realize that prolonged symptoms are an indication of a more worrisome disease. That means patients have to return to the emergency department or urgent care multiple times before the symptoms they experience are escalated for follow-up testing or referral. Even when testing is ordered, the ordering physician may not be there to follow-up with the patients on their results and connect them to the next level of care. Moreover, when short-term care providers do not connect individuals to available resources, such as help with transportation or lodging, patients are less likely to have the support they need to be able to complete treatment.

Finally, several participants discussed the barrier in accessing care in the form of missed opportunities to provide care. This was discussed with respect to individuals that come for care in the emergency department or urgent care and could be offered cancer screening while they wait. They also described a similar initiative that is being implemented in the primary care setting:

In terms of pap smear rates; it's really great having a person who comes to our clinic to do pap smears. There have been many times where a patient is not necessarily scheduled, but I'm like 'you're already checked in, let's go ahead and all you need to do is walk over to get your pap smear.' So that's been really helpful. – *Primary care provider*

Given that patients presenting to care have likely overcome significant challenges, their attendance represents a unique opportunity to offer them other medical services, such as routine screenings, especially given many individuals do not have a primary care provider. This would also be true for family members who accompany patients to medical appointments.

*Awareness of and access to resources and support:*

Respondents discussed two main challenges in terms of patients accessing resources. One challenge was that short-term staff are often unaware of the resources where patients can be referred. Consequently, patients are not aware of what resources are available, if they are eligible for those resources, and if so how to access them.

Even just the part about losing their hair. If they have breast cancer, the prosthesis – things like that. People don't really know where they can get help with that. I usually let them know that they have that support at the cancer center. "Nobody ever told me," [the patient says]. Resources available to them, things like that would really work. – *Health facility patient support staff*

Interviews revealed that an unmet need in terms of resources is access to peer support for individuals and their families who are affected by cancer. This was discussed in terms of support groups as well as one-on-one support, which would be beneficial to improving cancer treatment, as the narrative below demonstrates.

I think what would really help too would be having somebody that has been through the whole thing sit down with them and tell them this is what I experienced, and this is what you can expect. Or even just an emotional counselor. You know [they could ask], "How do you feel today?" Sometimes we try to do that, "How do you feel today?" And a lot of them, they'll be scared. "Oh, I am scared." "What part of it is making you scared?" You kind of just let them talk it out. That's what I see is that it would be good if you could have somebody go in and actually talk to these patients – maybe even more cancer support groups. They can bring grandmas, and elderly cancer support groups, elderly Navajo cancer support groups. That would work good too. That way you can talk to them about how they are feeling, what do they need help with? – *Nurse/interpreter*

### Communication:

#### *Lack of Navajo language translators:*

Respondents indicated that there are only a few certified Navajo translators in cancer terminology who are also trained to have complex conversations about cancer treatment, procedures, and goals of care discussions. Providers described that they often have to depend on individuals that work in other roles in the clinic and pull them in to translate when translation is required. When more complex and difficult conversations need to be arranged, the few individuals that have those skills are sought out; however, they cannot always be there due to their own working schedule or because they are assisting another provider. The result is that individuals who may be comfortable speaking in Navajo, not necessarily explaining complex medical cancer terms, are called on to translate.

Participants mentioned that because complete medical record sharing is not in place across care facilities, this can pose an additional barrier to care for individuals who are Navajo speaking. Patients assume the burden of understanding their clinical information and communicating it in order to coordinate their care across facilities. Our data indicated that in some cases, family members are also filling the role of translating for their relatives, either because they feel this is their responsibility or because a translator has not been offered to them. Taking on the role of translating puts family members in a difficult position, because they may not know the exact medical terminology to facilitate the translation and also because some details of a diagnosis or condition may be hard for a

family member to convey to their mother, grandmother, grandfather, father, etc. due to the nature of the respectful relationships among family members. When translation falls to family members, it adds another layer of stress since families are already trying to coordinate care and access to resources, which is often an overwhelming time commitment and large financial strain.

Respondents explained that misinterpretation continues to take place in terms of the Navajo word chosen to be translated for cancer. This misinterpretation starts patients out with a negative perspective when cancer is described as “the sore that doesn’t heal” or “contagious” instead of the technical Navajo terminology which describes cancer as “a cell that becomes abnormal and begins to grow in an unhealthy way.” Many respondents discussed the importance of accurate and culturally sensitive interpretation. Cancer disproportionately affects elderly individuals due to the nature of the condition itself; however, our participants indicated that many other Navajo individuals, including those who are very comfortable speaking, reading, and writing in English, could benefit from having a translator.

We have a lot of patients out there that speak English very well – read and write English very well, but they understand better in Navajo, so for those patients if providers would just see that they aren’t getting across to these patients and their families, it might be good if they ask, “do you need an interpreter?” Because I feel they really need interpretation – that’s what they need to actually get the information across. – *Nurse/interpreter*

*Patients and providers:*

Participants mentioned one of the challenges for patients is being able to access accurate information about their diagnosis through transparent, communication from clinical staff members about a patient’s prognosis and care, thereby enabling patient driven decision making.

One of the things that is really frustrating is that many times clinicians are reluctant to really be honest with the families as to what the prognosis is, and when that time has come when there isn't anything more that can be done. I think that was true with my son-in-law – they never really said, “this is going to be terminal.” There was never a time when his doctors, ever said, “I am sorry about that – we killed your liver and your kidneys, but you know, you're going to be ok,” it was always that “you know we'll see how this works and we'll try this and let's see how this works.” – *Hospice staff member/family member of cancer patient*

Aside from challenges in language translation that may be present between a patient and his or her provider, our data showed that effort needs to be made to share information in an open manner with patients. They should be asked if they want to know about what is happening with them. If they do want to know, that information should be shared with the patient directly instead of sharing it indirectly with family members, because the latter puts the onus on families to decide how to share it with the individual.

I make it a point to tell let them [patients] know, this is what you are here for, this is what’s wrong with you. I do that with the provider [physician], not just me, myself. The provider tells them, but we do ask them [patients], do you want to know? If they say yes, then we share that

information with them. We give them a choice, which the way it should be anyway. Everyone should know what is being done to them, and what they hope to achieve. – *Health facility patient support staff*

### Coordination of Care:

#### *Role of champion health professionals:*

Our data demonstrated that despite being understaffed, many champion health professionals including primary care providers and ancillary staff go above and beyond to ensure high quality care is provided to patients. This was expressed by the support staff and specialty providers as well as primary care providers themselves who indicated their patients inspired their motivation and dedication in their role. It was discussed that whole departments in the outpatient setting may share one case manager, so in order to fill this gap in coordination, primary care providers play multiple roles including following-up on labs, tests, appointments, and care received at other hospitals or clinics. They facilitate the provision of culturally relevant care by coordinating their patient visits to coincide, when needed, with the few certified translators that are available or by linking their patients to the Office of Native Medicine. Respondents identified key elements of their care that allowed them to provide comprehensive cancer services. Provider stability builds trust and open communication with his or her patients, especially given the turnover that many patients have experienced in the past. Provider longevity in their role also enabled them to be repositories of knowledge about the health care system, its complexities, referral processes, and the resources available in order to ensure that patients are connected to these resources. However, providers also described how not having sufficient ancillary support staff could impact patient diagnosis in the cancer continuum.

It's hard for people to keep track of everything and I wonder if sometimes things fall through the cracks. I know sometimes someone will have an abnormal test and the doctor will set them up for a CT scan, but they miss it and they don't reschedule it. The doctors sometimes are trying to pick up the pieces and make sure the patients don't fall through the cracks, and I know I have a small patient panel and things fall through the cracks, if I were a regular doctor with 800 patients, you can totally see how that could happen. If they just miss that scan, they get their cancer diagnosis delayed. – *Primary care provider*

#### *Patients as care coordinators:*

Our data indicated that by and large, cancer patients themselves bear the brunt of the burden in coordinating their own care. If an individual who has not received formal medical training, is only given partial bits of information due to the language barrier and lack of transparent information available, lapses in the quality care that people can receive is eminent. Solely relying on patients to coordinate their own care cannot guarantee quality of care across the board. Each provider they visit, each health facility they visit, adds an additional layer of complexity to their treatment.

In our healthcare system, you have to really advocate for yourself. And you have to question your doctors, and when you have a complicated medical illness, you have to have a notebook with everything because medical records don't follow you, and I have some patients who have a

family member who's got everything written down and the more you are like that, the better care you are going to get. – *Primary care provider*

Participants discussed coordination of care – from scheduling appointments to arranging specialty care and services, as significant challenges to receiving cancer treatment. Since coordination of care is sporadic, when champion providers and the few available case managers are not able to fill the gaps, the burden falls inappropriately on the patients and their families. One respondent explained how the challenge in cancer treatment for patients starts with making appointments:

Part of the problem is with our hospital is how we do appointments. The way we do appointments is we just send a letter. We're like here's your appointment time and date and it goes to people's P.O. boxes that they don't always check or it's a time of day that is inconvenient for them. Some of our patients have jobs where they can't easily get time off or when they have to work, they have to be there and they can't be flexible about that. If my doctor and dentist just sent me a letter with the time of my appointments, I would be so annoyed! – *Primary care provider*

*Coordination from health facility to cancer center:*

The degree and speed at which records are shared varies from one health facility, clinic, and treatment center to another. This challenge in coordination extends to other services such as pharmacy, where prescriptions from cancer centers often have to be re-written to be filled at the patient's IHS pharmacy. Patients can have a delay in receiving their cancer treatment medications due to difficulty in the coordination and alignment of operating procedures between the cancer treatment center and the pharmacy at the patient's usual care facility. The coordination and continuity of care during treatment – from oncologists to primary care provider – was mentioned by participants during the interviews. They explained that even though individuals are receiving cancer-specific care at a cancer center, they come back to their primary care facility for other health issues that arise as shown by the quote below:

They start doing their cancer care over there, but they do still come back over here when they have other issues that arise, and we still provide care to them here too. You know, like they have pneumonia, they have a cold or they have an adverse reaction to their medication, maybe it's causing thrush in their mouth – just different things that we can treat here, we help them with that. – *Health facility patient support staff*

In this way, when patients seek care, whether with their primary care provider or at the emergency department or urgent care, it is not always clear what treatment regimen they are on for cancer specific care, including any pain medication. The reverse is also a problem since the cancer center may not know if the individual has been prescribed other medications during their urgent care visit. Participants suggested adopting an inter-professional, cross-departmental approach to cancer care coordination as a way to improve this coordination and break down silos within each health facility and across facilities. They identified hiring additional care coordinators, an inter-sectorial tumor board, and shared Electronic Health Record access as several ways to work towards improved coordination.

Larger systemic challenges:

Respondents indicated that the type of funding sources impact the procurement of care on Navajo Nation. This was described through Indian Health Service federal funding and state sponsored Medicaid that is funded federally and yet the type of services provided differ depending on which state Medicaid a person has. Additionally, the insufficient appropriation from Congress every year that funds Indian Health Services was also mentioned as a challenge in providing care and services. This impacted the primary health centers as well as the cancer center because when these earmarked funds (called purchased referred care funds) for specialty care services, in this case cancer treatment, are depleted, the cancer center has to carry the expense for several months until the next fiscal year starts when their services can then be reimbursed. Some cancer centers are not able to or have policies against bearing these expenses for such a duration of time, which translates into breaks in patient care. If the cancer center does carry the expense, it places an enormous amount of strain on them, jeopardizing their ability to stay open and provide care. Providers described underfunding and bureaucracy as challenges with respect to the aging physical structure of the hospital, lack of space to provide sufficient care, procurement complexities leading to lack of supplies and space to deliver care – whether it be colonoscopies or cultures.

### **3. Discussion**

This qualitative study took place among health sector workers, some of them also patients and caregivers, who have roles along the cancer care continuum in one geographic service unit on Navajo Nation. As the second leading cause of mortality on Navajo Nation, cancer is emerging as a significant issue. Our data illustrated some of the barriers patients face as well as some positive opportunities to improve cancer care delivery. Patients and family members are doing the lion's share of coordinating care. Larger system level challenges are impacting cancer care including insufficient staffing, provider turnover, as well as funding shortfalls and unique complexities arising from facilities being dependent on federal funding streams. Patients lack resources like support groups or one-on-one peer support and resources to cover treatment costs such as transportation and lodging. They also have challenges engaging with the health system for appointment scheduling and communicating with providers, including challenges that arise from a lack of Navajo translators. These findings also elucidated several key strengths including champion health professionals that are going above and beyond to connect patients to care and resources. These individuals with their amazing energy and vision are integral to bringing together perspectives and ideas in a collaborative manner to help find opportunities for improvement in synergistic ways along the cancer care continuum.

Our results, similar to studies done in other settings (Smith, Nicol, Devereux, & Cornbleet, 1999; Walsh et al., 2010), demonstrated cancer treatment and associated care involves a high degree of complexity, both due to the nature of the diagnosis itself, but also to the sheer number of health facilities, clinics, treatment centers as well as corresponding staff who are involved. Our respondents explained that patients have a different record at each hospital or clinic they visit, whether for primary care or cancer treatment. Taken as a whole, our data indicated that the healthcare system serving Navajo patients is not coordinated. Ultimately, the burden falls to patients, provider champions, and a few case managers to coordinate across these several different points of care.

Our qualitative data revealed that a lack of certified Navajo language translators means that patients, family members, or other ancillary staff who are not certified in Navajo terminology for cancer are asked to translate for patients. Other studies have indicated that language translators are linked to better care coordination and better quality of care (Masland, 2010). Furthermore, studies have highlighted the importance of access to culturally appropriate care in Native communities (Clifford, McCalman, Bainbridge, & Tsey, 2015; Harjo, Burhansstipanov, & Lindstrom, 2014). Diné College, a Navajo tribal college, released a resource describing official Navajo terminology for cancer, cancer treatment, and related complex medical terminology using culturally appropriate definitions. This resource was disseminated to standardize terminology and discourage the use of phrases with negative connotations that have previously been used in the community and by medical providers. The Navajo language is very descriptive and detailed, which can help individuals have a better understanding of what cancer is and the treatment options available to be able to make well-informed decisions. For this reason, quality, accurate Navajo interpretation, which is vital to the patient's understanding of the cancer treatment process should be offered to all patients and family members, not just those who are perceived to be elderly or who seem like they do not understand what is being shared with them.

Ideally, Navajo language translators should be comfortable having culturally appropriate conversations with patients. This is especially crucial in the Navajo community because using outdated terminology could directly impact a patient's understanding of their diagnosis, prognosis, and engagement in care. In order to overcome this barrier, highly trained Navajo language translators who are experts in cancer specific Navajo terminology and can accurately and appropriately translate medical information regarding the pathophysiology of cancer as well as cancer treatment in a culturally appropriate way are needed. Such translation services would ensure high quality care across the cancer continuum if they were available in all departments and facilities across the spectrum of care including the emergency department, urgent care, as well as the primary care setting and at cancer treatment facilities.

This study illustrated that champion medical professionals emerged as key players in the cancer care continuum. Our data highlights that the provision of high quality cancer care in this community is achieved through the rigorous efforts of long-term, committed providers and clinical support staff who go above and beyond to coordinate patient care. These individuals stand out because they have a long-term commitment to the community. Because of their knowledge of the health care system, its complexities, as well as resources that are available for patients and families, ensure that patients are connected to resources. Our data demonstrated that these champion medical professionals are the pivotal link for timely and coordinated patient care. These champions provide high-quality, coordinated care; on the other hand, new or temporary providers may provide less consistent care due to a lack of knowledge of the resources and referral processes. To our knowledge, this phenomenon has not been documented in the literature, especially as it pertains to Indian Health Service primary care providers. Recognizing that committed, long-term staff make high quality care achievable, more needs to be invested in not just staffing departments, but mindfully staffing them with individuals who will be in their position long-term and are well versed in the services available to their patients. This extends beyond the primary care provider to all medical staff that will be part of the care team

for individuals affected by cancer. Meaningfully addressing cancer care in this community requires commitment to new strategies must be built to draw and retain talented local staff who are planning to have a long-standing presence in the community.

Despite the fundamental role champion medical professionals play in continuity and coordination of care, there are not enough primary care providers to empanel every individual that needs to be seen. Health facilities in the Indian Health Service (IHS) system experience a shortage of providers ("Indian Health Service Recruitment"). Additionally, our data indicate that some individuals may need to be seen before their primary care provider has availability to schedule an appointment. This means that individuals have to seek care through the urgent care or emergency department. Studies examining IHS Emergency Departments as a whole have documented that they are often understaffed, have a shortage of physician providers, and frequently operate over capacity (Bernard, Hasegawa, Sullivan, & Camargo, 2017). Our data demonstrated that these staffing shortages often result in positions being filled with short-term providers. This is consistent with the findings of the Health and Human Services Office of the Inspector General's report that IHS Hospitals' reliance on contracted/short-term providers affects continuity of care for patients and creates vulnerability in the hospital itself (Levinson, 2016). Within the framework of patients acting as their own care coordinators, overreliance on the emergency department and urgent care services coupled with the general shortage of PCPs means that patients' first point of contact for their cancer symptoms is often within the emergency department and urgent care setting. Short-term medical staff and their continual turnover creates significant breaks in continuity of care. One potential solution is putting a system in place, so these providers are aware of resources, have received training on referral processes, and practice a 1-to-1 handoff to the new staff that is coming in, so there can be continuity of care for patients.

To offset the burden many patients and family members bear, functioning as their own care coordinators, health facilities could address this burden by hiring dedicated cancer care coordinators, who are well versed in the health care processes and could engage patients in a culturally sensitive way. These care coordinators would ensure more equitable access to care coordination, as high-quality cancer care would not depend solely on champion providers or patients themselves. Cancer care coordinators would understand all of the cancer related resources that could be available to patients. They would collaborate with staff at all entries to care including emergency department and urgent care and would work across the cancer care continuum with primary care providers, oncologists, surgeons, emergency medicine providers, and traditional practitioners, etc. to keep everyone on the same page and create an atmosphere of strong collaboration where patients are driving their care. These coordinators would be a resource to short-term and new medical staff, thereby ensuring appropriate and timely referral to cancer specialty care and cancer related resources. With this approach, anyone suspected of having cancer could be handed off to a cancer care coordinator who can facilitate and catalyze the next steps in the provision of high quality care. They would function as a critical bridge, as a central focal point linking individuals to all the services available between all departments within the facility and across health care facilities.

With the challenges surrounding access to care especially for those who do not have a primary care provider, having a care coordinator that is closely linked with the emergency department or urgent

care could provide the opportunity to review cases and follow-up with individuals who presented repeatedly with the same symptoms or who might have had an abnormal test, but did not have a follow-up appointment arranged. They could also help to provide continuity of care as providers cycled in and out, for example to remind the providers of the 24-hour consult service the cancer center provides, enabling consults to take place in real time with an oncologist to expedite the process of diagnosis and treatment for those who may have cancer. If a certain number of case managers were hired, the responsibility of care coordination would not fall to patients or physicians.

#### **4. Limitations**

This study has the following limitations. As part of a larger study, this component only included the perspective of health sector workers. Some of these health sector workers were former patients or caregivers for family members. This study does not include the perspective of broader patients and family members who are implicated in the health system overall. The larger study collected data from a wide-range of patients and family members. These findings will be forthcoming. Furthermore, only one Service Unit was included in this component of the study. While we believe these findings will be applicable to other service units, they cannot be generalized to all Indian Health Service Units across Navajo Nation and beyond. Moreover, we had to take additional steps to protect the anonymity of the participants to ensure confidentiality of their responses.

#### **5. Conclusion**

Although there are significant systemic challenges in providing cancer treatment to individuals living on Navajo Nation, there are also important opportunities to improve cancer care that can be addressed at the health facility level. There is a strong cadre of champion medical professionals who take on the cancer care coordination for their patients, going above and beyond, they provide very high-quality care. However, this champion-based model needs to be transformed into a system level change that addresses the challenges in continuity of care, provision of culturally appropriate care, and timely referral, especially in departments that have a higher staffing of short-term providers such as the emergency department and urgent care. To relieve the care coordination burden placed on patients, certified mentored Navajo translators and cancer care coordinators are needed to ensure equitable access to cancer treatment and resources.

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