# University of New Mexico

# **UNM Digital Repository**

**Communication ETDs** 

**Electronic Theses and Dissertations** 

Summer 5-18-2021

# IINA DZIIL BE'AT'IIN (ON THE PATH OF A STRONG LIFE): DINE (NAVAJO) PERCEPTIONS OF SELF-CARE AND SOCIAL SUPPORT WITH DIABETES MANAGEMENT

Chenoa Bah Stilwell-Jensen University of New Mexico

Follow this and additional works at: https://digitalrepository.unm.edu/cj\_etds



Part of the Journalism Studies Commons

#### **Recommended Citation**

Stilwell-Jensen, Chenoa Bah. "IINA DZIIL BE'AT'IIN (ON THE PATH OF A STRONG LIFE): DINE (NAVAJO) PERCEPTIONS OF SELF-CARE AND SOCIAL SUPPORT WITH DIABETES MANAGEMENT." (2021). https://digitalrepository.unm.edu/cj\_etds/134

This Dissertation is brought to you for free and open access by the Electronic Theses and Dissertations at UNM Digital Repository. It has been accepted for inclusion in Communication ETDs by an authorized administrator of UNM Digital Repository. For more information, please contact disc@unm.edu.

Chenoa Bah Stilwell-Jensen
Candidate
Communication and Journalism  Department
Department .
This dissertation is approved, and it is acceptable in quality and form for publication:
Approved by the Dissertation Committee:
Dr. Tamar Ginossar, Co-Chairperson
Dr. Jaelyn DeMaria, Co-Chairperson
Dr. David Weiss
Dr. S. Fawad Ali Shah
Dr. Laura Burton

# IINA DZIIL BE'AT'IIN (ON THE PATH OF A STRONG LIFE): DINE (NAVAJO) PERCEPTIONS OF SELF-CARE AND SOCIAL SUPPORT WITH DIABETES MANAGEMENT

by

### CHENOA BAH STILWELL-JENSEN

B.U.S., University Studies, University of Mexico, 1996 M.S., Health Education, University of New Mexico, 1997

#### **DISSERTATION**

Submitted in Partial Fulfillment of the Requirements for the Degree of **Doctor of Philosophy**Communication

The University of New Mexico Albuquerque, New Mexico

July, 2021

# **DEDICATION**

Dii' naaltsoos bee'naashniishigii ee' shi'ke' doo shi'dine'e baansiskeesgo bi'niina iishlaa' (With respect and honor for my Diné relatives and community kinship, I am writing this dissertation).

#### **ACKNOWLEDGEMENTS**

First and foremost, I would like to acknowledge the land and Indigenous people through the languages of the Tiwa, Tewa, Towa, Keres, Zuni, Apache and Dine communities that honor this sacred mountain known as the Sandias, the river and traditional cornfields. I am grateful to the traditional Indigenous place names of our precious homelands.

Traditionally in Diné way of life we acknowledge our relatives through our clans as a formal and respectful greeting. We introduce ourselves by sharing the collective identity and family kinship in our Diné language: Ya'at'eeh, adone'e ninshliini' eeya Dzil Tl'laani' ninshlii doo' English doo French bashishchiin, Ashiihi' dashichei adoo French-Canadian ee' dashinali. Hello, I introduce my mother's clan lineage as Mountain Cove Clan; my father is of English and French-Canadian ancestry; my maternal grandfather is of the Salt Clan, and my paternal grandfather is of French-Canadian ancestry. I honor our ancestors and relatives who came before us in order for us to exist today. I wish to be of service to our relatives and communities as we go forward on this path of a strong life (iina dziil).

I would like to respectfully and honorably acknowledge our sacred deities, *Nahasdazan Shima, Yadilhil shi't'à'*, *Diyin Diné'é, t'adadiin diyiini, k'ó shi chei, t'ó' asdzaan, doo dzil asdzaan doo shikei Hataalthi daanlinigii*. With deep appreciation and love I thank my family for all of your support, prayers and strengthening encouragement throughout my academic journey. *Ayoo aniinshni shima, shizheii, bil iina ashlinigii*, Darrell, *shi awee*, Shante Daan and all of our relatives and *Hataalthiis, na'hansin doo ahe'hee*. I am deeply grateful to the members of the Navajo Nation Human Research Review Board and Dr. Mark Bauer, for your leadership on behalf of our people and lifeways. Thank you for allowing me to conduct this study to support our Diné narrators and community members for diabetes self-care and support. I wish to also

sincerely thank the Navajo Nation Scholarship Office and the American Indian Graduate Center for the scholarships and fellowships that aided in my completion of my degree.

I am truly thankful for UNM's Department of Communication & Journalism and the support from the faculty, staff and students. I am grateful for the teaching fellowship that allowed me to teach throughout my doctoral program. My passion for teaching was reignited through your support. I am thankful for my cohort and dear friends in the program. I am appreciative of the mentorship by Dr. Lorenda Belone and Dr. John Oetzel. Thank you both for sharing your insights and encouragement to begin my academic journey in health and intercultural communication. I am deeply grateful to my Co-Chairpersons, Dr. Tamar Ginossar and Dr. Jaelyn DeMaria. You both created an empowering support system for me. I value the guidance, mentorship and knowledge you provided for me. As well as the support you give to our communities with health and resiliency through your words, research and community health contributions. I would also like to thank my dissertation committee members Dr. David Weiss, Dr. S. Fawad Ali Shah, and Dr. Laura Burton for your wisdom and guidance. Thank you, Tamar, Jaelyn, Laura, Fawad and David, for mentoring me and our collective work together. I share my deep appreciation for the mentorship and friendship with Dr. John (Jack) Condon. I would also like to thank Dr. Magdalena Avila, Dr. Jan Schuetz, Dr. Judith White, Dr. Ilia Rodriguez, Dr. Mary Jane Collier, Valerie Clements and Tomide Oloruntobi for your incredible support.

# IINA DZIIL BE' AT'IIN (ON THE PATH OF A STRONG LIFE): DINÉ (NAVAJO) PERCEPTIONS OF SELF-CARE AND SOCIAL SUPPORT WITH DIABETES MANAGEMENT

by

#### Chenoa Bah Stilwell-Jensen

B.U.S., University Studies, University of New Mexico, 1995M.S., Health Education, University of New Mexico, 1997Ph.D., Communication, University of New Mexico, 2021

#### **ABSTRACT**

Managing diabetes requires a detailed self-care regimen of physical activity, eating well, testing glucose, healthy weight maintenance, and positive emotional outlook in order to maintain health outcomes. Education, clear communication, and sufficient support are needed to address challenging aspects of daily self-care at the onset of diagnosis and throughout the management of the illness. However, many people diagnosed with diabetes are unable to successfully manage their condition. Native Americans are twice as likely to have diabetes than Whites. Although diabetes-related kidney failure and other negative health effects remain a concern among Native Americans, rates of kidney failure in this population have decreased by more than half.

Therefore, it is important to understand both strengths and barriers in self-care in this population.

The goal of this study was to understand the experiences of Diné (Navajo) community members who have type 2 diabetes mellitus and to explore their perspectives of diabetes, self-care, and support. Methods included qualitative analyses of the diabetes meanings, self-care, and support

narratives of 12 Diné narrators. Conclusions led to a new way of seeing diabetes self-care and new ways of managing this chronic illness for personal well-being, home practices, and clinical management. The narratives provided significant understandings of diabetes self-care that are grounded in the use of the Diné language, lifeways, and philosophies. This study provides a narrative that shifts power to Diné people and their form of self-determination when managing diabetes through dominant Western medical standards. Results from this study led to the creation of a culturally congruent framework called *Nizhonigo ádaa áháshya*: diabetes self-care model, and it bridges Diné centered self-care with Western clinical guidelines. This new, culturally centered framework with diabetes self-care also may contribute to other health communication theories and frameworks.

*Keywords*: Indigenous, Native American, American Indian and Alaskan Native, Diné (Navajo), type 2 diabetes mellitus, diabetes self-care, decolonization, indigenization, holistic

# TABLE OF CONTENTS

LIST OF	FFIGURES	Κi
LIST OF	TABLESx	ii
Chapter 1	1: Introduction	
Ir	ntroduction to the Study	1
В	Background of the Problem	5
P	Purpose of the Study	8
R	Research Questions	0
O	Organization of chapters	11
Chapter 2	2: Literature Review	
Ir	ndigenous Resilience	13
D	Diabetes and Disparities in Indigenous Communities	14
D	Decolonizing Diabetes	16
D	Diabetes Self-Care	19
D	Deconstruction of the Biomedical Model	21
Н	Health Communication and Indigenous Health Narratives	23
N	Varrative Embodiment of Illness and Healing	27
T	The Diné Paradigm and Challenges with Behavioral Change Models	28
T	Theoretical Framework	29
Chapter 3	3: Methods	
R	Research Methods and Design	38
R	Research Questions	39
В	Background of the Study	39

Methodology		40
Participants		43
Coding		43
Summary		46
Chapter 4: Analysis		
Research Que	estion One	48
Research Que	estion Two	58
Research Que	estion Three	82
Chapter 5: Discussion	n	
Discussion		111
Implications .		
Limitations		
Conclusion		
Appendices		
Appendix A. Intervie	ew Guide	
Appendix B. Rational	le for the Interview Guide	140
Appendix C. Navajo	Nation Human Research Review Board Approval Let	ter 148
Appendix D. Norther	n Navajo Agency Council Resolution	149
Dafamanaaa		150

# **List of Figures**

Figure 1. Decolonizing Diabetes	16
Figure 2. Navajo Wellness Model (Nelson, 2018)	35
Figure 3. Visual model: Nizhonigo Ádaa Áháshya:	
Healthy Diabetes Self-Care Model	127

# **List of Tables**

Table 1. RQ1 Themes for Diné narrators description and meanings of diabetes	65
Table 2. RQ2 Themes for Diné narrators explanations for diabetes self-care (ádaa áhaya)	75
Table 3. RQ3 Themes for Diné narrators explanations for social support with	
diabetes self-care	92
Table 4. Nizhonigo adaa ahashya: Diabetes Self-care Model	124
Table 5 Visual model: Nizhonigo Ádaa Áháashya: Diabetes Self-Care Model	124

# IINA DZIIL BE' AT'IIN (ON THE PATH OF A STRONG LIFE): DINÉ (NAVAJO) PERCEPTIONS OF SELF-CARE AND SOCIAL SUPPORT WITH DIABETES MANAGEMENT

### Chapter 1

In support of understanding the perceptions of diabetes self-care in my Diné community, I reflect on how I learned about the narrative of illness and well-being through my family and my Diné cultural identity. My grandparents and extended family stood strong, protecting our ancestral lifeways (way of life, cultural practices), emergence narratives, relationships with the land, and community well-being. My mother and father dedicated their lives to upholding my grandparents' vision and the values of civil rights, racial justice, and health equity. In the community, they persisted in their work through education, cultural and human rights, and social services to empower and collaborate with youth, educators, and community members. At home, my parents partnered with my grandparents for the perpetuation of our Diné language and traditions. These bilingual and bicultural approaches were nurtured by their collective efforts for all of our loved ones between our traditional *hooghaan* (home) and the urban environment.

Our family emphasized the significance of honoring our cultural communication through cultivating the earth, participating in ceremonial lifeways, and caring for each other. My grandparents instilled ádaa áháyá (self-care) through many forms of self-care from learning how to communicate for our well-being, to staying active through walking and running, as well as harvesting and using nanise azee (healing plants) for medicinal purposes. Furthermore, we were taught t'ô' ee iina (water is life) is sacred and should be used sparingly due to its scarcity. The value of water is meant to help the earth and all living elements. Thus, family and cultural understanding of self-care means to be careful with our natural resources and what the earth and water provide for us. This environmental cycle of natural resources is viewed as community

ecological health that brings forth health and well-being but only if we respect it and not misuse it. There is a Diné term for this concept of moderation; it is *to 'bi 'kiini'go*. The meaning of this term teaches us to carefully use water and food. Growing up in this manner formed a foundation for me with self-care in life. I carry these teachings with me—our family communicating the meaning of *nizhinogo ádáá 'halya' shi yaazhi*, take good care of yourself, my child.

Our family also communicated cultural daily practices about ádaa áháyá. Similarly expressed by Werito (2014), our loved ones would say, "Ndi'da' shi yaazhi, shi awee, k'adee ha'ii'a." This meant to wake up, my child, get up now before the sunrise. This served as a motivating factor and precautionary teaching so we would not sleep in late, allowing lazy monster (naayee hwi'yee') to control us. The process for greeting the dawn meant to take care of ourselves by brushing our hair and make a tsi'yeel, a traditional hairstyle that represents being prepared for the day and being alert with intentional mental and emotional awareness. If we did not take care of our hair, we would be asked if we were not feeling well, or our thoughts would be scattered. This process was done with the use of a white wool yarn hair tie that represents the clouds while tying our hair, representing the rain. Taking care of our hair in this manner also meant adaa ahaya, ultimately, protecting our knowledge. With this preparation of self, we would go outside and offer our morning tsodizin (prayers) to greet the day, standing east and offering nadaa ligai (white cornmeal).

Furthermore, the value of ádaa áháyá related to being physically healthy. In this sense, we run towards the sun for protection of our health, to ward off poverty monster (nayee té'é'î) and to prepare for life on our running path. Running prepared me for the kinaalda (coming of age) blessing way ceremony when I became an adolescent. This ceremony teaches us about ádaa áháyá by honoring our traditional lifeways with hozhó (healthy life, communication, thinking

and actions) (Kahn-John, 2015) and about endurance by running each day and about the many attributes of our matriarchal resiliency. My grandmothers, aunts, nieces, and mother provided the family grinding stone (for me to traditionally grind corn) and stirring sticks (representing our weapons against hunger monster (nayee dichin) to use for the alkaad (corn cake baked in the earth). Ádaa áháyá is a core teaching in the kinaalda ceremony which focuses on self-discipline with food and the importance of eating healthy (not consuming salt, sugary beverages, or sweets) and running each day in protection of our health (Todacheene, 2014). To this day, I uphold the significant principles from this ceremony for my lifelong journey of well-being. These teachings are special forms of ádaa áháyá honoring our traditions and daily practices of protecting our health and promoting a positive outlook for the day.

In our Diné language we communicate about ádaa áháyá through the significance of the value of self-determination. We are taught to walk this path of thinking for the collective well-being of self, family, and community. This teaching is honored in the phrases *t'áá awolí bee iintí* (meaning to go forth with perseverance), "hozhoogo shil haz'á (my domestic affairs are in order) (Austin, 2009, p. 55), and *t'aa hwo ajit'eego* (meaning it is up to each person to take action, to have self-reliance, and to have the ability to lead oneself with healthy decisions and healthy behaviors). When walking this path of well-being, we prepare ourselves through cultural expressions that convey resiliency, holdzilii be' (with strength and assertive thinking). This journey is a lifelong process, from birth into old age, on *t'ádadíín ke'atííin* (the corn pollen path). Family and community kinship narratives communicated in the form of storytelling, songs, and prayers provide the foundation for lifeway wisdom, through sa'ah naghai bik'eh hozhoon (long life journey blessing and happiness), k'e (kinship) (Austin, 2009; Todacheene, 2014), hashké (discipline), hózhó, (healthy life, communication, thinking and behavior) (Austin, 2009; Kahn-

John, 2015; Todacheene, 2014; Werito, 2014), and gl'o' dichidi (humor). These narratives emphasize the honoring of sacred elements that created life for ádaa áháyá – nilch/i (air), t'o' (water), k'o' (fire), and nahasdzaan nihima (mother earth)—each are to be revered and celebrated for attaining good health (Kahn-John, 2015). These forms of narrative communication for self-care and self-determination are meant to perpetuate life. I cherish them through my family and community kinship practices for self-care, support, compassion, resilience, and holistic communication; these qualities have pulled me through the toughest times in my life and have allowed me to care for our communities.

One of the most important aspects of ádaa áháyá is being nourished by food. I remember my grandmother often cooked our meals on the earth, on the ground next to the woodstove at the center of our home. She would take the charcoals from the fire and put them on the ground with a small grill. I recall her sitting on the earth preparing tortilla dough in a bowl with a rose flower design. This bowl was treasured for taking care of our family. At evening time, we would all sit on the earth and eat together, with no utensils, out of that beautiful rose flower bowl. We ate very little at times, due to hardships; however, we loved these moments of being together and digesting stories from the day and family teachings with our food. We shared what we had together, and this provided us all with nourishment from family conversations and teachings. A special expression that my grandmother aught us to say after we ate was "Ahe'hee nizhoono iiyaa, nizhoono naashadooleel, k'os nawhiloo dooleel'" (I am thankful for the food I have eaten and that it will nourish me as I walk forward. May rainclouds come). These experiences provided a life world of love, kinship, and well-being through food and family.

As I approach diabetes self-care and support, I look to the health and cultural guidance from my family and community. I reflect upon my relatives who have diabetes and how they

perceive this illness, their lived experiences with managing it and what they need for support. In more recent decades, our family's communication about illnesses or hospitalizations began shifting to the emerging stories of diabetes, hearing the term type 2 diabetes mellitus (T2DM). We heard more about the health concerns of our Diné community members who were being diagnosed, taking new medications, and, more recently, undergoing dialysis and even suffering the amputation of limbs. Diabetes has impacted my family in devastating ways. I have come to understand that having diabetes should not define a person's identity or their life. They have helped me learn that living with diabetes becomes a lifelong learning process. My relatives have taught me the about the struggles of managing diabetes with constant attention to all aspects of monitoring their body with testing tools, medications, meal plans, and physical activity. They also have shared the strengths they have gained from managing diabetes, even in the midst of experiencing the adversities from the illness. Their healing narratives help me to advocate on their behalf and on behalf of our Indigenous communities that endure this chronic disease. I draw on my life experiences to weave together the cultural threads (Tachine, 2015) of these narratives that bring forth the realities of diabetes in a manner that will inspire hope and optimism in others. This chapter includes a background of the problem, purpose of the study, research questions, significance of the study and organization of the dissertation. This next section discusses the background of the problem.

# **Background of the Problem**

In our home food represented sustenance and protection. We felt nurtured by traditional meals with steamed corn stew, mutton and blue corn mush with ash. We also became accustomed to many of the foods found only at the trading posts, "in town" at the modern grocery stores or commodity foods that were distributed in our communities. In the 1970's our

foodways shifted through "nutrition transition" from growing food in our family gardens to living on land that could no longer grow corn, squash, beans and melons from our previous generations of loved ones (Compher, 2006). Commodity foods and foods from town included bleached white flour, canned fruits and vegetables, canned meats (due to having a long shelf life and no refrigeration), sugar sweetened drinks such as fruit juices and soda pop and table salt. We did not realize that the foods we were eating were processed, high in sodium, cholesterol and sugar (or fructose) would eventually harm us causing obesity, diabetes, heart disease and high blood pressure. Many of the modern staples came from the rations through the Treaty of 1868 (Frank, 2020). In 1863, approximately 8,500 (other estimates were as high as 10,000 or more) of our ancestors were forced by the U.S government to march on foot over 450 miles from our sacred mountains and homeland to a site known as *Hweeldé*, Bosque Redondo, in Ft. Sumner, New Mexico (Austin, 2009; Todacheene, 2014). This is known as the genocidal act of the Long Walk where many of our people perished on the journey and at the internment camp. The inhumane colonial settler policies of the United States purposefully justified the destruction of our ways of life, burning of crops, killing our animals and forcefully removing us far away to assimilate our people in order to steal traditional homelands. These colonized laws forcefully removed Diné people (Joe, 1988) and were intentionally meant to destroy our traditional lifeways and the growing of our sacred plants or *nadaa* (corn), *nayizi* (squash), *na'ooli* (beans) and other foods in the daa'ke (community gardens, crops). As a result of these colonized acts, the decline of our health and well-being has been evident in the last 153 years since the treaty was signed and we returned to our homelands. Diabetes never existed prior to U.S. settler colonization (Joe & Young, 1993). A collective vision is to reclaim our health and journey forward to support our community members as they manage and heal through diabetes.

Nationwide, diabetes rates have increased dramatically in the past several decades and particularly among children and minority populations. According to the Centers for Disease Control (2020) the total number of people diagnosed with diabetes in the United States is 34.2 million (10.5% of the U.S. population) with 15% were smokers, 89% overweight and 38% were not active with physical movement and the highest percentage of existing cases among American Indians/Alaskan Natives. Diabetes is the seventh highest leading cause of mortality in the United States (U.S.), with nearly 88 million people are considered pre-diabetic, a condition in which individuals have higher than normal blood-glucose levels but not so high as to be considered diabetic (Centers for Disease Control and Prevention, 2020).

With higher rates and increased social disparities among Indigenous populations, it is imperative that these health concerns be addressed in ongoing efforts to decrease pre-diabetes and diabetes diagnoses and to improve overall health of Indigenous populations. The Centers for Disease Control (2020) stated that the "prevalence of diagnosed diabetes was highest American Indian/Alaskan Natives" (14.7%) (p. 4). According to Trevisi et al. (2020), nearly half of the Navajo Nation population at an estimate 100,000 Diné community members have been diagnosed with type 2 diabetes or have prediabetes. Type 2 diabetes is also cited as being one of the major causes of premature death in Indigenous populations, and there is need for more preventative and management services and resources (Sequist et al., 2011). Sequist et al. (2011) state, "Substantial challenges must be overcome in the process of care—including limited access to care, problems with cross-cultural communication, and widespread social inequities" (p. 1966). There are significant disparities within Indigenous populations, which provide a need for community-grounded initiatives to reduce and prevent diabetes.

#### **Purpose of the Study**

This study addresses critical aspects of social support and self-care for diabetes management in Diné communities through health communication. This study draws attention to Diné and Indigenous narratives that center on Indigenous research methodologies (Denzin et al, 2008; Kovach, 2009; Smith, 2012; Wilson, 2008) and, thus, has the potential to break new ground in health and cultural communication. Decolonization frameworks, Indigenized theories, and culturally relevant health interventions allow Indigenous people to be proactive through the process of reclaiming and identifying science, medicine, health, illness, and healing centered in an Indigenous cultural worldview.

When conducting the literature review, I found multiple variations of my research topic. In terms of narrative paradigm, narrative-based medicine, and narrative interventions, I found many resources from physicians, nurses, health communication and Indigenous scholars. In terms of Indigenous health, increased ethnographic and qualitative studies have emerged in Indigenous communities focused on well-being, illness, recovery, and healing (Barkwell, 2005; Goins et al., 2011; Kahn-John, 2010; Kahn-John & Koithan, 2015; Mendenhall et al., 2010; Woodbury et al., 2019). The literature for self-care also focused on the term "self-management of chronic illnesses" (Corbin & Strauss, 1988; Kretchy et al., 2020; van Smoorenburg et al., 2019). Indigenous-based narrative studies (Edwards & Patchell, 2009; Satterfield et al., 2014) provided deep insights and significant contributions to health promotion through traditional ecological knowledge (TEK) systems (Satterfield et al., 2014). More qualitative studies comprised of healing narratives have emerged globally with an emphasis on Indigenous communities in New Zealand, Canada, and Australia (Bartlett et al., 2007; Kulhawy-Wibe et al., 2018; Landzelius, 2006).

This study was developed with a steadfast approach that was mindful of providing health promotion support for the well-being of Diné people, lifeways, philosophy, and future generations. An axiological construct of this study focused on the Diné worldview known as *hozhó* (Austin, 2009; Khan-John, 2010; Kahn-John & Koithan, 2015; Werito, 2014). *Hozhó* means beauty, sacredness, and blessedness. It is a core value taught through our kinship system known as *k'e* (Austin, 2009) and serves as a central belief in traditional healing.

This study was designed to present the narratives of Diné community members, who I view as community-based experts and narrators, about their lived experiences. The Diné narrators can enlighten and expand community health and medical knowledge of social support and self-care for treating Diné and Indigenous community members affected by diabetes. It is significant to learn how Diné people explain diabetes, cope with it, and mange it. I share their perceptions, wisdom, and experiences.

This dissertation is a qualitative study exploring the use of social support in the management of diabetes in Diné families and communities. I conducted secondary data analysis of interviews with Diné women and men from the study, "Making a Difference: The Role of Family Support in Navajo Diabetics' Self-care." The original study was conducted by Dr. Mark C. Bauer (PI), in 2003 at Dine College in Shiprock, New Mexico and approved by the Navajo Nation Human Research Review Board (NNHRRB). Dr. Bauer facilitated the study at Diné College. Semi-structured interviews were conducted with twelve individuals living with diabetes. I was not involved in the study; however, Dr. Bauer suggested that I might find the study of interest as the object of secondary data analysis. He stated it would be important to have the narratives be supported in this manner.

## **Research Questions**

This study is centered on the foundation of understanding the ways in which Diné people perceive diabetes and how they care for themselves through the complexities of this chronic illness.

This study was designed to answer the following research questions:

RQ1: In what ways do Diné people describe diabetes?

RQ2: How do Diné people describe self-care when managing and coping with diabetes?

RQ3: How do Diné people describe social support for diabetes self-care?

#### Significance of the Study

This qualitative study honors the perspectives of Diné people with how they manage diabetes, an illness that is difficult to manage. The Diné narrators bring forth unique viewpoints through their stories that would not be heard if their experiences were only studied through quantitative research. Their narratives provide critical insights to better understand and provide supportive responsiveness to this significant health issue. In support and honor of the Diné people who shared their diabetes narratives, I looked to the manner in which Indigenous scholars value narratives. Tachine (2015) asserts,

Stories breathe life into research. Listening to or reading a story privileges us to be connected to or belong to that story world. For Native peoples, stories have been a way of life and a legitimate tool for relating with others, sharing knowledge across generations, analyzing life circumstances, and seeking solutions for the future. (p. 27)

The Diné narrators' lived experiences expand community health and medical knowledge about social support and self-care when treating Diné community members affected by diabetes. Health programs need to tailor health and cultural communication for training family,

10

community members, and clinicians in a collective effort to reduce and eliminate diabetes in our local, tribal, national, and global communities. This research study can inform diabetes self-care and support interventions with Diné and Indigenous communities who are living with diabetes.

# **Organization of Chapters**

Chapter 1: In this chapter, I began with an introduction: grounding who I am through my identity and how it applies to the foundation of this study. I shared the concepts of Diné cultural health communication through family lifeways and Diné historical roots of *ádaa áháyá* as they apply to diabetes and the concepts of self-care. I then presented the background of the problem with data on diabetes, the purpose of the study, research questions and the significance of the study.

Chapter 2: Provides a review of the literature on health and diabetes disparities in Indigenous populations, diabetes self-care, the biomedical model, decolonizing diabetes, narrative-based health communication and Indigenous health narratives, narrative embodiment of illness and healing, Diné narratives and qualitative approaches, the Diné paradigm and challenges with behavioral change models, and the theoretical framework.

Chapter 3: Focuses on the research design and methodology. In this chapter I provide an overview of the study, my research design, and data analysis.

Chapter 4: Analysis: Centers on the research findings from research questions one, two, and three. Themes from the findings are provided with exemplars from Diné narrators. Findings from the three research questions are discussed in the analysis, which focuses on the diverse explanations of diabetes, the range of how the Diné narrators describe self-care from barriers and struggles to positive changes with healthy eating, physical activity, and traditional health communication of self-determination, in Diné known as *t'aa hwo ajit'eego*. Findings also

include barriers to social support to positive support from family members, spiritual/faith support, and positive communication from healthcare providers and community members.

Chapter 5: In this last chapter, I share the summary of findings and provide a discussion about a diabetes self-care conceptual framework that is Diné centered, *Nizhonigo ádaa áhaashya:* Diabetes self-care model. The themes drawn from the Diné narrators provided the core concepts of the Indigenized diabetes self-care model that weaves together the personal and cultural ways the Diné narrators manage diabetes as well as the clinical standards for management of this illness. I relay a discussion of how this framework can contribute to health communication interventions for patients, health care professionals, family members who support loved ones with diabetes, and community health programs. I conclude with implications and limitations.

#### **CHAPTER 2: LITERATURE REVIEW**

In this chapter I will review literature related to understanding diabetes and health communication in Indigenous communities. I will discuss Indigenous resilience, disparities and diabetes in Indigenous populations, diabetes self-care, Indigenous resilience, decolonization of diabetes, deconstruction of the biomedical model, health communication and Indigenous health narratives, Diné (Navajo) paradigm and challenges with behavior change models, and the theoretical framework.

# **Indigenous Resilience**

The resilience of Indigenous people rests within their identity, cultural teachings, health narratives, history, and their sovereignty. Indigenous people have been visionaries for their traditional lifeways, and the stories that are passed along, have protected each generation of children, adults, and elders for countless centuries. These stories and teachings, from emergence in the Diné worldview of the First World to the present time, have strengthened each generation of families and communities to endure the challenges before them. However, the endurance has come at a great cost. To survive, Indigenous people have made profound sacrifices due to impeding forces of colonization, genocide, and termination policies. The effects of these sacrifices are reflected in historical and contemporary times. Being forced to sacrifice sacred ancestral homelands, family gardens that grow medicinal and nourishing plants and a holistic way of life. Brody (1999) attributes many factors to the multiple reasons for the "ethnic cleansing" and the ultimate tragic loss of indigenous women, men, and children. The colonizers used "... steel, horses, germs, guns, courts, churches, schools and parliaments – in whatever combination or sequence that worked best for each particular invasion" (p. 43). The sovereign laws enacted empowerment and a reversal of policies from that of termination and genocide to a more holistic value system of protecting the health and well-being of Indigenous peoples. Indigenous communities, researchers, scholars, tribal leaders, and legal advocates have historically and are presently reclaiming land, identity, traditional languages, concepts of wellness, medicinal plants/foods, healing ceremonies, and cultural values that were forcefully removed from their ancestral homes and lifeways (Hodge et. al., 2009; Jernigan & Lorig, 2010; LaDuke, 2005; Porter, 2004).

# **Disparities and Diabetes in Indigenous Communities**

There are currently over 575 federally and additional state recognized American Indian and Alaska Native tribes, or Native Nations, in the United States living in urban communities and 334 reservations (National Congress of American Indians, 2020) with a total estimated population of approximately 5.2 million people who identify as American Indian/Alaska Native (NCAI, 2020; Sequist, T., Cullen, T., & Acton, K., 2011). Health disparities have impacted Indigenous families living in rural reservations as well as living in urban areas. Jones (2010) asserts that the mere presence of health disparities is a moral wrong and needs to be eliminated. She refers to the *Declaration of Human Rights* affirming that health disparities are essentially a social injustice to humanity in the United States. Since the time of colonization in the United States, tribal nations have been subjected to inhumane and discriminatory acts through political, cultural, social, and economic oppression (Greymorning, 2004; Jones, 2006; Porter, 2004). Genocide and termination policies of the United States government attempted to eliminate Native people from their indigenous homelands, denigrated their language and cultural beliefs, and devastated them with new diseases leaving those generations that have survived with impoverished living conditions today (Deloria, 1999).

One of the most concerning of all health disparities affecting Indigenous communities is diabetes. Type 2 diabetes affects Indigenous peoples at disproportionately high levels.

Historically, Type 2 diabetes was not evident in Indigenous communities until the mid twentieth century (Joslin, 1940; Narayan, 1996). In a report by the National Congress of American Indians (NCAI, 2015), diabetes is described as an endemic that is rooted in collective loss or also known as historical trauma, or collective trauma, from Unites States policies that enforced genocide, forced removal from ancestral lands and disrupted cultural ways of life, ultimately causing the high rates of poor health and mental health, including PTSD, anxiety, depression, diabetes, cardiovascular disease, and pain responses in Indigenous communities (p. 4). Furthermore, the NCAI (2015) report noted the epigenetic study in the documentary *Are Unnatural Causes Making us Sick? by* Dr. Don Warne states that the intergenerational suffering from diet, famine, and stress has caused the onslaught of diabetes between several generations (i.e.- child, parent and grandparent). Warne states:

When we look at different measures of stress like cortisol or epinephrine, which is adrenaline, all of those chemicals can increase blood sugar; so, not only are people faced with diabetes and high blood sugar, they're faced with stressful living environments...There is a direct biochemical connection between the trauma that people face living in the culture of poverty and blood sugar control. (p.5)

Nationwide, diabetes rates have increased dramatically in the past several decades and particularly among children and minority populations. Trevisi et al. (2019) state that cardiovascular heart disease and type 2 diabetes are the 3<sup>rd</sup> and 4<sup>th</sup> leading causes of death on the Navajo Nation. Among Indigenous communities, type 2 diabetes is the fourth leading cause of mortality (O'Connell et al, 2010). With higher rates and increased social disparities among

Indigenous populations, it is imperative that these health concerns be addressed in ongoing efforts to decrease pre-diabetes and diabetes diagnoses and to improve overall health of Indigenous populations. There are huge disparities within indigenous populations, which provides a need for community-grounded initiatives to reduce and prevent diabetes.

There are numerous ways that communities, organizations, and health professionals have contributed to raising awareness about, preventing, and managing type 2 diabetes. Many national agencies, state departments, and organizations, in addition to local and tribal health organizations and partnerships, have developed health education and nutrition materials in an effort to alleviate diabetes in Native American populations. One such organization is the national Centers for Disease Control and Prevention (CDC), which developed a series of culturally appropriate and educationally insightful materials for diverse populations, and specifically with Indigenous community members. Specifically, the Community Outreach and Patient Empowerment (COPE) Program has focused their efforts in the Southwest with Diné people and communities for local engagement for capacity building, health promotion, disease prevention, community collaboration, innovative partnerships, and elevating access to nutritious foods (Trevisi et al., 2020; Trevisi et al., 2019). This study provides new insights from Diné women and men about living with diabetes; it is through their voices that we learn how to better support their needs, ultimately providing them with better quality of life.

# **Decolonizing Diabetes**

Diabetes in Indigenous communities was non-existent until the early to mid-1900's. It is viewed as a foreign disease as it did not exist prior to colonization (Bartlett, Iwasaki, Gottlieb, Hall & Mannell, 2007; Joe & Young, 1993; McLaughlin, 2010; Pilon et al., 2019; Warne & Lajimodiere, 2015). In her dissertation titled *So that the people may live* – Hecel lena oyate nipi

kte, Satterfield (2001) describes women as reservoirs of knowledge about health protection and diabetes prevention. Satterfield identified diabetes as a new and chaotic phenomenon, as conveyed in the following statements:

Type 2 diabetes is spiraling upward around the world, ensnaring adults and youth from societies in the throes of industrialization. Over time, uncontrolled diabetes leaves in its wake people facing renal failure, blindness, or heart disease, and communities with little hope for preventing this "new," chaotic phenomenon. Westernized lifestyles (e.g., physical inactivity, processed foods), in concert with human genomes yet being mapped, are recognized explanations for the escalating prevalence. The web of causation, however, is woven by complex interactions with environmental, sociological, and historical roots. (2001, p. 1)

Diabetes management and prevention are essential in addressing the global epidemic for diverse populations diagnosed with the disease. Several studies have analyzed the perceptions and beliefs of diverse Indigenous people about diabetes from many Native Nations such as Cherokee, Dakota, Lakota, and many First Nations Aboriginals in Canada (Barton, Anderson, & Thommasen, 2005; Cavanaugh, Taylor, Keim, Clutter, & Geraghty, 2008; Dignan et al., 1996; Hood, Kelly, Martinez, Shuman, & Secker-Walker, 1997; Womack, 1993). The Navajo Nation and national Special Diabetes Project for Indians (SDPI) has created innovative and significant strides with Diné and Indigenous communities through its prevention, wellness and management focus. Beginning in 1997, SDPI has provided training, funding and infrastructure development for Indigenous communities that were normally underserved or had little no access to wellness centers and fitness trails. Additionally, CDC (2013) has provided funding to a series of projects resulting in cookbooks and storytelling from Indigenous communities focused on traditional

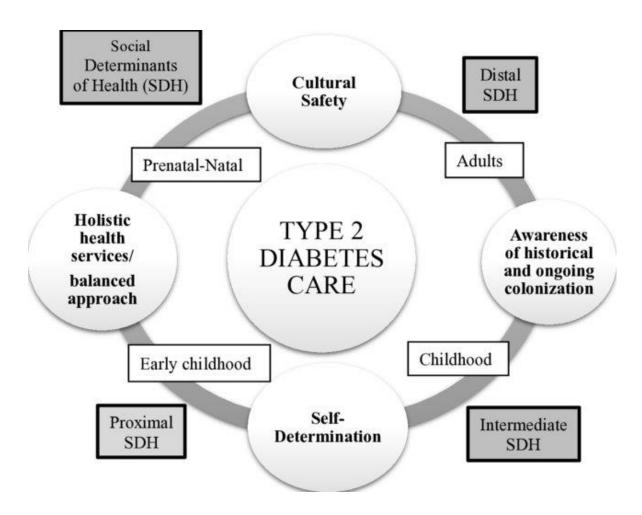
foods prompting a reunion with ancestral medicine plants that nurture children, adults and elders with sustenance for the heart, mind, body and spirit. In Part IV (CDC, 2015) Valerie Segrest with the Muckleshoot Nation and Muckleshoot Traditional Foods and Medicines Program. states,

The land is our identity and holds for us all the answers we need to be a healthy, vibrant, and thriving community. In our oral traditions, our creation story, we are taught that the land that provides the foods and medicines we need are a part of who we are. Without the elk, salmon, huckleberries, shellfish and cedar trees we are nobody. ... This is our medicine; remembering who we are and the lands that we come from (p. 6)/

Specific diabetes studies targeting Indigenous communities include research using the health belief model (HBM; Carter et al., 1997) used HBM in an intervention for Indigenous diabetes health education materials. The HBM and transtheoretical model (TMM) empower Navajo patients by providing them the opportunity to communicate with family and by involving them in dual decision making rather than requiring individualized responses to the healthcare provider (physician, pharmacist, certified diabetes educator, nutritionist, etc.). Perhaps combining an individualized theory such as the HBM or TMM with a group health communication theoretical approach. A key study from Pilon et al. (2019) focused on the impact of colonization with developing type 2 diabetes in Aboriginal people in North Shore Lake of Lake Huron. 22 community members living with diabetes were interviewed. The key themes that emerged from their narratives included: changing ways of eating, developing diabetes and choosing your medicine. Pilon et al (2019) stated that the findings and interpretation of the narratives created a proposed model for decolonizing diabetes as a conceptual framework. The core elements focus on social determinates of health, cultural safety and postcolonial holism (Please see Figure 1).

Figure 1.

Proposed model for a decolonized approach to type 2 diabetes care for Indigenous Peoples Pilon et al. (2019)



#### **Diabetes self-care**

Self-management, also known as self-care, of chronic diseases can often be challenging. Skills, education and support are needed to provide a person living with chronic illness a way of coping and management strategies (Corbin & Strauss, 1988; Kretchy, Koduh, Ohene-Agyei, Boima, & Appiah, 2020; van Smoorenburg, Hertroijs, & Dekkers, et al., 2019). Corbin and Strauss (1988) assert the core concepts of self-management, including the following: 1) medical

management such as taking medication and adhering to dietary advice; 2) behavioral management – adopting new behaviors with chronic disease and 3) emotional management – e.g. dealing with feelings of frustration, fright, and despair. Due to a few medical visits per year, self-management is key with controlling diabetes. Shrivistava, et al., (2013) state, "Diabetes education is important, but it must be transferred to action or self-care activities to fully benefit the patient. Self-care activities refer to behaviors such as following a diet plan, avoiding high fat foods, increased exercise, self-glucose monitoring, and foot care." The general clinical self-care guidelines for managing Type II diabetes include: 1) eating healthy; 2) engaging in physical movement; 3) check blood sugar (glucose self-monitoring); 4) taking prescribed medications; 5) problem solving; 6) coping with emotional feelings; 7) reducing and monitoring risk factors such as foot care and eye care; and 8) social support. Modern approaches to self-care state that these guidelines provide disease management for the prevention of severe complications from diabetes. According to van Smoorenburg, et al. (2019) stated key findings from their study on healthy outcomes from diabetes self-management, including:

Most important "right moments" to help with self- management, 1) Upon first diagnosis when glycemic control deteriorates; 2) When problems occur, self-management needs increase, when physical limitations such as pain and fatigue, feeling loss of control and disappointment with previous self-management strategies have failed; 3) Open to professional support for making sustainable behavioral changes to maintain glycemic control; 4) Provide support for daily life issues such asfood and drinks, exercising, regular schedule, medication, being in control and knowledge; and 5) Focus outside medical context, support the individual as a person not a patient (p. 605).

#### The Deconstruction of the Biomedical Model

Perceptions of health and illness are unique in diverse cultures throughout the world. The roots of the contemporary medical model emerged from multiple ancient philosophies from Africa and the Middle East to the era of Greek medicine, which still dominate in the modern social construction of health and illness (Turner, 2000). One of the primary concepts that governs medicine is Hippocrates' medical code of ethics known as the Hippocratic oath recited by medical school graduates (Mattson & Hall, 2011). Historical tensions have existed throughout time focusing on opposition to the dominant scientific medical system with clashes from alternative forms of healing (Turner, 2011). The dominant term used in contemporary times is the biomedical model. The focus of the medical model is on purely biological factors and physical processes such as pathology, biochemistry, and the physiology of disease through diagnosis, treatment, and prognosis (Laing, 1971; 1999). It is viewed as the standard for healthcare in Western nations for diagnosing and treating illnesses. Thus, there is no explanation for disease beyond illness.

Anderson (1995) states that the traditional medical model is unacceptable when addressing the complexities of diseases, in particularly diabetes. Anderson further states that a patient empowerment model is needed for treating diabetes in a comprehensive manner. Metaphors of war and battle are often described in cancer (Clark & Everest, 2006) and now are entering other disease communication such as diabetes. The medical model sees an individual who is ill as the problem, or metaphorically as a machine, that needs to be fixed or changed. These experiences often lead patients feeling helpless, shamed, judged, or alienated in a power dynamic within the medical model's authoritative and paternalistic system. This is in contrast to a Diné concept of health that is focused on the healing nature of ancestral ceremonial practices

that honor medicinal plants, communication through songs, blessings (prayers) and a matriarchal foundation for honoring kinship (k'e).

The contemporary biomedical approach to illness is to address risks through clinical approaches. According to Fischoff, Bostrum, and Quadrel (1993), the medical model and risk communication add to the complexities of chronic illness through the different definitions that can lead to controversy and confusion. Fischoff, et al. (1993) state that the common definition of risk communication centers on a safety plan through potential threat of environmental hazards, medical outbreak, or other harmful situations. The definition is contextual and differs in its application. The risk communication model comprises risk assessment, risk communication, risk management, and consensus of a strategic plan to address risk (Lipkus, 2007; Lipkus & Hollands, 1999; Misselbrook & Armstrong, 2002). Typically, the model is used for risk communication for emergencies, cancer, heart disease, HIV/AIDS, diabetes, and many other health issues. This model is not culturally centered for diverse cultures and communities (Battiste, 2008; Dutta, 2007, LaDuke, 2005). Recently, health communication scholars and clinicians have debated about the term and the model using only "risk" and are re-considering new approaches for disease management (Misselbrook & Armstrong, 2002). In addition, there is not a standardized approach for the model, and it often uses an array of visuals such as graphs, pie charts, tables with statistics, or risk ladders (Lipkus, 2007). The visual aids to show the risks are also vague and often confusing as evident with the use of stick figures and diagrams that do not translate well to patient understanding of the risks—perhaps adding more harm to injury (Lipkus & Hollands, 1999). Although many critiques have been made about this model, it is still being used.

Whereas, in indigenous communities the explanations for illness connect to holistic explanations. The inclusion of ancestral holistic approaches includes physical, emotional, mental, and spiritual health, differing from the Westernized biomedical model. A deconstruction of the biomedical model through an Indigenized approach would bring a more culturally-centered way to use dialogue and narrative storytelling as a reconstruction of what has been forced away from — traditions, our narratives, and our ancient healing practices.

## **Health Communication and Indigenous Health Narratives**

Narrative has been used often in diverse health communication initiatives and studies. It comprises many ways in which healthcare professionals and patients can relate for positive health outcomes. As Gray (2009) states, "Narrative has become increasingly recognized in health contexts as a form of communication that brings patients (rather than their pathologies) into the focus of illness experiences" (p. 3). Narratives are also highly valued for their positive impact in health communication research (Gray, 2009). Some theoretical approaches that focus on narrative in health communication have utilized narrative transportation theory and narrative interventions with cancer communication (Green, 2006). Narrative transportation theory includes cognitive, emotional, and imagery processes for narrative-based interventions (Green, 2006). Furthermore, Sharf and Vendervord (2003) explain the significance of narrative in health communication,

Health communication scholars have approached illness narratives as psychosocial maps, revealing the storyteller's emotional and cognitive journeys. These narratives challenge the voice of medicine as the primary means of understanding health and disease. Narrative-based health promotion utilizes first-hand accounts, or personal stories, from individuals and healthcare providers to convey persuasive health

promotion messages. Patients become "experts" in the experiential aspects of living with their condition (Winkelman & Chun Wei, 2003) (p.15).

Providers can affirm their patients through respectful communication, affirmation of personal and cultural identity and development of positive long-term relationships. According to Coulehan (2003), physicians who use narrative-based medicine often have three core personal qualities: 1) empathy—the ability to understand accurately the patient's feelings and experience, and to communicate that understanding; 2) genuineness—the ability to be yourself in a relationship, without hiding behind a role or façade; and 3) unconditional positive regard—the ability to accept and validate patients just as they are (p. 94). These physicians have the opportunity to integrate narrative approaches and digital storytelling to acknowledge, understand, and be more mindful of their patient's illness narratives and life stories. Healthcare providers can draw on the cultural, historical, and linguistic strengths of their patients in a way that can positively transform their relationship and potentially reduce health disparities.

It is important to research the collectivistic values of Indigenous communities versus the individualistic perspectives held in Western society. In order for mutual understanding and communication to occur, it is vital that individuals and cultures take time to understand the diverse viewpoints, perceptions, and values of one another's lifeways. If not, health disparities will continue to rise. Continual research has evolved in Indigenous communities about illness and healing narratives. Indigenous stories about health experiences create a form of empowerment that allows individuals who may often be marginalized in society to create narratives (i.e., health, illness, or other dimensions of their outlook on physical, social, emotional, and/or spiritual well-being) of their life stories (Baltruschat, 2004; Poudrier & Mac-Lean, 2008; Tom-Orme, 1993; Tucker, 2006). On a more global scale, health communication

research has utilized narrative approaches with health promotion and disease prevention issues such as HIV/AIDS prevention and intervention projects (Brinson & Brown, 1997).

In terms of Aboriginal health in Canada, Photovoice has been used as an important intervention for women who have breast cancer (Poudrier & Mac-Lean, 2009). Poudrier and Thomas Mac-Lean (2009) applied critical discourse theory, post-colonial theory, and feminist theory in framing their use for narrative through Photovoice. Their methodology for using Photovoice included qualitative, participatory, and visual research that involved participants taking photos that prompted dialogue on their feelings, experiences, and needs as breast cancer patients (Poudrier & Mac-Lean, 2009, p. 306). To further extend the importance of qualitative research methodologies and Indigenous narrative, an Indigenous woman shares her personal narrative on the challenges of having diabetes and the need for social support. Arpan (2002) states:

Another exemplar of a narrative that engages the reader/listener with the emotional aspects of testing blood sugar levels for managing diabetes is shared by Mora (2008), a Pauite/Diné woman in a book she authored entitled *Why I Had Meltdowns*:

I am a Pauite/Diné woman and consider myself a brave, warrior woman. Just like most Native Americans, I am a survivor.

I have survived the death of loved ones, the devastation of alcoholism, the injustice of boarding school, and countless unkind words said by strangers. I have felt my heart break. I have lived through freezing winters without heat. I have experienced ongoing starvation.

of these things. I am tough as nails and a survivor. So why did a tiny

I am not unaccustomed to spiritual, emotional and physical pain. I am not afraid

I think having diabetes is like the "final insult." My thought pattern was this: After surviving all the injustices, I get diabetes and have to suffer like my mother. Testing my blood sugar is proof that I have diabetes. I think these thoughts were some of the reasons testing my blood sugar was nearly impossible.

But the deep down reason I had "blood sugar testing meltdowns" had to do with the huge bag of emotional and spiritual anguish Native Americans carry around with us. It had to do with the reality of what it is like to be Native in the United States. Testing blood sugar is like another false promise, like a treaty to be signed.

One of the main persons who helped me overcome my blood sugar testing meltdown was my Diné clan aunt. My clan aunt has suffered greatly in her life: a newborn child was taken from her and her son almost died in a car accident. She is wise, tough and fearless, just like most Native women. She believes in traditional Native ways, prayer and ceremonies.

About three months after I found I had diabetes, my aunt came to visit. I got up to make her coffee, and I noticed a glucometer and test strips set out on the kitchen table. I didn't know my aunt had diabetes. It was early in the morning. The sun was just coming up. She was not in the house. I went to the window and saw her facing the east, praying. She then turned to the south, the west and the north, and prayed. (pp.41-44)

These narratives convey teachings about wellness, strength, and positive regard for one's identity and one's beliefs. The teachings from the narratives can trigger new emotions and provide an affirmation that they are not alone in dealing with the challenges of diabetes. Individuals may feel a sense of hope from the narratives that they hear or read thereby helping them to enact motivation to change. Essentially, when the narratives are shared from one Indigenous person to another, this process may in itself be decolonizing and Indigenizing the health messages in a natural, cultural manner (Barkwell, 2005; Barton, 2004; Poudrier & Mac-Lean, 2009).

### Narrative Embodiment of Illness and Healing

The use of narrative is of particular importance in Indigenous communities where healthcare professionals may not often understand the historical, cultural, linguistic, or personal experiences of their American Indian patients. In order to truly understand each patient, healthcare professionals need to initiate enhanced listening skills. Gray (2009) states, "It has been said that listening to patient narratives is the 'point of medicine.'" Gray also states that, more recently, many recommendations and model programs have been implemented in provider training in medical schools and in healthcare settings for enhanced communication and interviewing skills. In the article, "Bodies Don't Just Tell Stories, They Tell Histories: Embodiment of Historical Trauma among American Indians and Alaska Natives," Walters et al. (2011) states,

The concept of embodiment is consistent with AIAN spatial and relational worldviews that recognize the interdependency between humans and nature, the physical and spiritual worlds, the ancestors and the future generations (Walters et al., 2011). According to AIAN worldviews, environment, mind, body, and emotional health are inextricably

linked to human behavior, practices, wholeness, and hence, wellness (Walters et al., 2011) (p.6).

### The Diné Paradigm and Challenges with Behavior Change Models

Making decisions and communicating beliefs about behavior change is often challenging for any individual in mainstream society. It is especially true for Indigenous people who live in a collectivistic culture to take on the burden of sharing personal beliefs without consulting their family or community elders. The assumptions of providing individualized actionable steps and maintenance of behavior change through the HBM and TMM models are contradicted by the beliefs of Dinè culture, which focus on collectivistic approaches with family and community. Tom-Orme (1993) explains Diné collectivistic lifeways and the paradigm of balance using holistic philosophy of a person's and cultural belief system in four elements: (a) physical, (b) emotional, (c) spiritual and (d) kinship network. This balance is also considered as interrelatedness, which is a fundamental belief for collectivistic cultures. Guisinger and Blatt (1994) posit that relatedness must be part of health approaches as compared to the dominant use of interventions focusing on individuality. Health programs must balance relatedness with autonomy. Furthermore, LaFromboise, Trimble, and Mohatt (1990) have expanded the concept of promoting Native American culture within health interventions to support holistic well-being and the family unit when providing treatment services. These key concepts of integrating collective family and holistic approaches could be potential constructs integrated into HBM and TTM for diabetes behavior change in Navajo communities.

An additional limitation of the HBM in working with Indigenous communities includes the cultural incongruity of talking about perceived susceptibility and severity. Navajo individuals and families may not want to discuss risks due to the cultural beliefs that voicing these matters

may actually manifest them into reality. Moreover, using more strengths-based terminology vs. perceived words that may be deficit-based, such as two of the HBM constructs known as perceived barriers and perceived threats, contradicts Diné values and lifeways about communicating health and well-being. Interpreting barriers and threats into the Dine language disrupts the cultural concept of hozhó, known as harmony and balance (Tom-Orme, 1993). In Navajo and AI/AN cultures, these concepts eventually can be discussed, but not through unknown healthcare professionals using Western treatment methods due to a lack of trust in modern medicine techniques (LaFromboise, Trimble, & Mohatt, 1990). The discussion of problems, threats, risks, and barriers may be discussed through the support system of holistic protection from respected Diné and Indigenous elders. Behavior change theories such as HBM and TMM emphasize the individual for self-management without much emphasis on the variables of cultural, historical, environmental (land-based beliefs for AI/AN), social, and economic factors. Traditional Navajo and AI cultural beliefs are interrelated with how they perceive health, illness, and healing through honoring the land, water, and each other as human beings (Tom-Orme, 1993). The cultural variables of traditional health beliefs and activities could be added constructs to both HBM and TMM in the management and prevention of diabetes in Indigenous communities (Ravussin, Valencia, Esparza, Bennett, & Schulz, 1994).

#### **Theoretical Framework**

In this study, I examined several health models including the health belief model (HBM; Rosenstock, 1974) and the transtheoretical model (Prochaska & DiClemente, 1982; Prochaska, DiClemente, & Norcross, 1992) also known as TTM, and the Stages of Change Model. The application of these behavior change theories can contribute to supporting the lived experiences of Indigenous people with diabetes. Both models address health behaviors on an individual level

focusing on individual perceptions, beliefs, challenges, readiness, and motivation to change. As I explored the HBM and the TTM, I became interested in knowing more about perspectives from Diné families. I decided to use qualitative research methods to explore how Diné families balance a relative's diabetes experience with the clinical and societal dimensions of the disease.

Health belief model. The health belief model (HBM) emerged as an explanatory model that describes the reasons why a problem exists (Glanz, Rimer, & Lewis, 1997, 2002; Janz & Becker, 1984; Rosenstock, 1974). The key elements of the HBM focus on the constructs of perceived susceptibility, perceived severity, perceived barriers, and perceived benefits. This model readily applies to issues concerning health behavior change through the awareness of risk factors and personal beliefs about health and about chronic diseases and illnesses. It guides the search for factors that contribute to a problem (e.g., a lack of knowledge, self-efficacy, social support, or resources) and the potential for behavior change. The HBM is one of the first models that focused on health behavior (Rosenstock, 1974). It was developed in the 1950s by a group of U.S. Public Health Service social psychologists who wanted to explain why so few people were participating in programs to prevent and detect disease (Mattson & Hall, 2011). The HBM is a widely-used model for addressing problem behaviors that evoke health concerns (e.g., risky sexual behavior and the possibility of contracting HIV or other sexually transmitted diseases).

The HBM is frequently used in health education, public health, health communication, and nursing. In clinical settings, the HBM is especially important for issues focusing on patient compliance and preventive healthcare practices. According to Glanz, Rimer, and Viswanath (2008), the model postulates that health-seeking behavior is influenced by a person's perception of a threat posed by a health problem and the value associated with actions aimed at reducing the threat. Furthermore, HBM addresses the relationship between a person's beliefs and behaviors. It

provides a way to understand and predict how individuals will behave in relation to their health and how they will comply with healthcare therapies.

Major concepts and definitions of the health belief model. According to Rosenstock (1990), the health belief model proposes that a person's health-related behavior depends on the person's perceptions. The six major concepts in the HBM are the following: (a) perceived susceptibility, (b) perceived severity, (c) perceived benefits, (d) perceived barriers/costs, (e) motivation, and (f) self-efficacy. The constructs range from whether a person's perceptions of an illness are true to whether a person is motivated to take action once the illness is accepted as a risk that needs to be addressed. Additionally, the concepts examine the worth of treatment as benefiting their diagnosis or preventing the occurrence of disease. The concept of costs is also explored to understand the individual's perceptions of potential complications, time, and access. Two variables of the HBM are motivation and self-efficacy. These constructs appeal to an individual's beliefs for becoming proactive with protecting one's health or for treating the disease and acting upon the belief that they will maintain their health. Glanz, Rimer, and Viswanath (2008) emphasize that additional variables need to be considered when addressing modifying factors about an individual's behavior change using the HBM. The variables include: age, gender, ethnicity, personality, socio-economic conditions, and knowledge. As an example, a Diné person's beliefs about follow-up for diabetes treatment may support high motivation to take action. However, the cue to action may be hindered by a lack of transportation to travel 50 miles to the nearest clinic due to socio-economic circumstances and transportation barriers. This modifying factor of transportation will interfere with the individual's behavior to follow through with their diabetes treatment, thus, perhaps, causing a lack of motivation to continue their treatment plan -- unless the clinic adapts to the patient's needs by providing home visits or free

shuttle service.

Transtheoretical model (stages of change model). The transtheoretical model (TTM) is a behavior change model that focuses on the stages of change that evolve over time. The process of change is difficult for individuals to attempt with any given behavior (Prochaska, 1979; Prochaska & Velicir, 1997). The model emerged from a comparative analysis of the leading theories of psychotherapy and behavioral change. Prochaska (1984) conducted an analysis of more than 300 fragmented theories of psychotherapy and identified 10 processes of change among these theories. It was determined that behavioral change unfolds through a series of stages (Prochaska & DiClemente, 1982). This model initially was used in studies on smoking and other substance use, and is now also used for a broad range of mental health behaviors and, more recently, type 2 diabetes management (Gomez & Saldana, 2008).

Stages of change constructs. According to Prochaska and DiClimente (1982), behavioral change involves a progression through five stages. The first stage is precontemplation. People in this stage are typically not ready for change and are not motivated to discuss their behavior. People are usually in this stage for six months, refusing to consider a plan, and are not prepared to take any action. In the second stage, contemplation, people have intentions to change within a six-month timeframe. They are informed, aware of the benefits of changing but also aware of the risks of not changing. They may be known as chronic contemplators or procrastinators, unsure about the next phase of their decision to change (Glanz, Rimer, & Viswanath, 2008). The third stage is preparation, in which people intend to take action through a short-term goal, typically the following month. These individuals have developed their own plan of action and are ready for change. The fourth stage is action. In this stage, individuals have made specific adaptations in their behavior and integrated those changes into their lifestyle. In the fifth stage, maintenance,

people work to prevent relapse, but they do not apply change processes as frequently as people in the action stage. They are less likely to relapse and increasingly more confident they can continue their changes (DiClemente & Norcross, 1992).

Processes of change. Behavior change is challenging and complex. Processes of change guide people through the challenges of behavior change (Glanz, Rimer, & Viswanath, 2008). Gomez and Saldana (2008) posit that the process of change serves as a guiding framework for health interventions. Experiential and behavioral modification processes include several action-oriented approaches to how individuals proceed through each stage. Glanz, Rimer, and Viswanath (2008) elaborate on the core constructs of 10 experiential processes of change: (1) consciousness raising, (2) dramatic relief, (3) self-reevaluation, (4) environmental evaluation, (5) self-liberation, (6) social liberation, (7) counter conditioning, (8) stimulus control, (9) contingency management, and (10) helping relationships. Examples of these processes will be described for individuals who have type 2 diabetes.

Strengths of the health belief model and the transtheoretical model. The strengths of both models provide validating and affirming approaches for people to share their feelings about perceptions, beliefs, ambivalence, resistance, fears, hopes, and potential changes in behavior. The HBM and the TTM are action-oriented models that focus on the purposeful journey through an illness or an unhealthy behavior. The journey begins with the acknowledgement of a health concern or the possible denial of the harms, risks, awareness of protective factors, and eventual actionable steps through self-efficacy to make positive behavior changes. Both models have several strengths; they (a) address empowerment for the individual through the phases of behavior change, (b) are goal oriented, and (c) can be used with other theories for health interventions. The TTM provides the theoretical framework for motivational interviewing (MI),

which is being used in interventions for substance use disorders, addiction treatment, and obesity prevention/treatment (Shinitzky & Kub, 2001). Additionally, several diabetes interventions have used the HBM and the TTM together in their study designs to frame their approach to behavior change (Powers, Carstensen, Colon, Rickheim, & Bergenstal, 2006; Reaney, Eichorst, & Gorman, 2012). Constructs from these two models can be adapted and applied to people who are living with diabetes for potential interventions that include an Indigenized approach that centers on cultural health with the clinical aspects of diabetes management. The models' constructs may be used with Diné culturally relevant health models if they are culturally modified to reflect a Diné person's readiness for change, health knowledge, and practices.

Ecosocial theory A variety of frameworks encourage health advocates to think critically and systematically about integral connections between our social and biological existence. From a social epidemiological perspective, Kreiger (2001) states that ecosocial theory reveals the deep underlying causes of illness and poor health through the lenses of economic and political determinants of health, and distribution of diseases in the society. Embodiment is a central construct of ecosocial theory. Embodiment is the term Kreiger (2001) uses to describe how humans can physiologically and biologically absorb the social world, in which we exist from conception to the end of one's life. Once we learn more about the embodiment of an individual and their disease, we can understand their life history, which may include social inequality. Essentially, this theory studies the structural barriers for health. "Who and what drives current and changing patterns of social inequalities in health?" is a critical guiding question asked by Kreiger (2009). This question is posed to lead us, as a society, to be concerned about accountability for our actions and to not be complicit in allowing those who are the most marginalized to continue on a pathway of chronic illness from birth to the end of life. Add new

Kreiger citation here Individuals and communities who are oppressed deserve to have equal chances in life to thrive and to live in communities that break down the barriers that deny their right to healthy lives.

As an extension of the aspect of accountability, ecosocial theory focuses on economic and political institutions and on the decisions that create, impose, and perpetuate economic and social privileges and inequality (Kreiger, 2001, 2005). I view ecosocial theory and embodiment as ways for us to use our Diné traditional lifeways to explain the challenges of diabetes and to create solutions for managing it. Ecosocial theory of disease distribution (ESTDD) differs from other theories in that it examines disease causation rather than only looking into biological concepts in the explanation of social health modeling. Krieger's (2001) ecosocial theory addresses six multi-level pathways linking expressions of racial discrimination and biological embodiment across the life course to the following indicators: (1) economic and social deprivation, (2) toxic substances and hazardous conditions, (3) socially inflicted trauma, (4) targeted marketing of commodities, (5) inadequate healthcare, and (6) resistance to racial oppression. Each of these indicators provides a strong framework for addressing the health inequities of diabetes in Indigenous communities. Food insecurity, lack of access to healthy foods, poverty, sedentary lifestyle, oppression, and lack of access to transportation and healthcare all potentially lead to type 2 diabetes.

Ecosocial theory views core issues of health through poverty, biological expressions and diverse types of discrimination, such as race, ethnic group, gender, sexuality, social class, incapacity or age (Kreiger, 2001). Furthermore, the theory focuses on the social conditions surrounding an individual and/or community, which include poverty, schooling, nutritional insecurity, exclusion, social discrimination, quality of housing, lack of hygiene, and lack of or

limited employment opportunities. These are factors in health inequality, morbidity, and mortality. Ecosocial theory seeks to understand the origins of the differences in health between social groups, seeking an understanding of social conditions and deeper roots of diseases. Ecosocial theory also leads researchers to the differences in the conditions of observed health (i.e., cancer, diabetes, depression, addiction to substances). Finally, the theory creates a pathway to possible interventions to reduce inequities in health. I am interested in how health communication can draw from the discipline of social epidemiology to create an ecosocial narrative approach in healthcare settings and in community health.

#### **Conclusion**

This literature review has provided a diverse range of scholarly publications, Indigenous resilience and epistemologies, decolonization of diabetes, health behavior and communication theories, health communication models, Indigenous narratives, and other literature. The literature guided the research process in an empowering manner for coping with and managing diabetes. Health communication about diabetes in Diné communities must take a holistic approach to wellness and illness. Diné people and Indigenous communities are "indigenizing" current mainstream medical models and diabetes prevention programs. Vine Deloria's vision of indigenizing education was well-stated by Wildcat (Deloria & Wildcat, 2001) in *Power and Place*. He wrote:

Deloria's proposal that we explore an indigenous (in this case American Indian) metaphysics must be among the first projects American Indian educators undertake if we are to not only decolonize, but also actively "indigenize" and truly make Native educational institutions our own. American Indians have a long history of rejecting abstract theologies and metaphysical systems in place of experiential

systems properly called indigenous—indigenous in the sense that people historically and culturally connected to places can and do draw power located to those places. Stated simply, indigenous means "to be of a place." (p. 31)

Through the application of Indigenized education to the concepts of health communication,
Indigenous people can become active creators of their health narratives and not passive
recipients of the medical model. In this study, the Indigenous scholarly contributions will engage
Native American communities at a participatory approach level for transformative health. Denzin
& Lincoln (2011) state that the use of theory serves as cultural revitalization and an agent of
change within the "parameters of language, culture, identity and healing practices" (p. 22).

Health communication research needs to serve as protective health factors for tribal youth, families, and communities. This research study for Diné communities focuses on centering traditional health practices with modern clinical diabetes self-care regimen as distinctive and unique with practice-based evidence, fused with evidence-based approaches. Indigenous people who are impacted by current Western wellness approaches may find a sense of empowerment and self-efficacy if different communication practices are used. Indigenous language and communication practices may ensure that health promotion and disease prevention aspects are integrated into their lives. Thus, the departments of health and education within tribal nations have the opportunity to create health leadership in innovative ways. Ultimately, collective health communication research and practices can serve an important role in the community to improve quality of life and prevent diabetes in children, adults, and elders.

#### **CHAPTER 3: METHODS**

The purpose of this phenomenological study was to explore and understand how Diné narrators perceive and manage type 2 diabetes. The central concepts were to learn how Diné narrators describe their meanings of lived experiences with diabetes self-care and support. This chapter includes the research method and design, research questions, background of the study, population, data analysis framework and coding. This section concludes with a summary.

# **Research Method and Design**

My research focused on qualitative analysis of Diné narrators' narratives. A qualitative approach was initiated using thematic analysis from secondary data collected through Diné College (Riessman, 2008). The Diné narrators provided their perceptions and meanings of self-care and support through their narratives centered on diabetes. Brill de Ramirez (2007) described the interweaving of Indigenous oral and literary worlds that centers the research focus with emergent tribally informed scholarship. Denzin and Lincoln (1994) define qualitative research as: (a) an exploratory and descriptive focus, (b) an emergent design, (c) data collection in the natural setting, (d) an emphasis on "human-as-instrument," (e) qualitative methods of data collection, and (f) early and on-going inductive analysis. An inquiry process of understanding concerned with a social or human problem, qualitative research describes the researcher as creating "holistic pictures" through in-depth analysis and detailed perspectives of participants while the study is conducted in a natural setting (Creswell, 1994, p. 94). According to Reissman (2008), there are several approaches to data analysis to capture the story and the human condition. In this study, I used thematic analysis to analyze the transcribed the interviews.

### **Research Questions**

The following research questions were used to explore the Diné narrators' perceptions of diabetes and how they describe the management of diabetes through self-care and social support.

RQ1: In what ways do Diné people describe diabetes?

RQ2: How do Diné people describe self-care when managing and coping with diabetes?

RQ3: How do Diné people describe social support for diabetes self-care?

# **Background to the Study**

As a community health educator, I worked with several health programs and organizations that sought research approval from the Navajo Nation Human Research Review Board (NNHRRB). During this time, I became familiar with the NNHRRB staff, chairperson, and board members. One of board members at the time, Dr. Marc Bauer, faculty at Diné College (tribal college at the Shiprock, NM, campus) provided support by sharing about a previous qualitative study that had been conducted in the Diné communities, as a professor in public health and a researcher with community projects. Dr. Bauer asked me if I would be interested in analyzing a body of existing data for my dissertation project. He told me about a specific project that needed data analysis, known as #NNR-01-81 "Making a Difference: The Role of Family Support in Navajo Diabetics' Self-care" (Grant number: S06GM 08163-23). This study was conducted in 2003 and approved by the Navajo Nation Human Research Review Board (NNHRRB, Study #NNR-01-81). I agreed, and we created an MOA (Memorandum of Agreement) to complete the data analysis. To conduct the original (2003) study, the Diné College project team asked Diné College students to serve as the interviewers to support their academic experiences with research experience. The students provided flyers to the community using purposeful sampling. Twelve community members with diabetes voluntarily participated

in the study. The follow-up interviews (one to two years later) were unique to each narrator to permit further elaboration on specific themes and the "explanatory models" identified in the first sets of interviews. In addition to the main Diné community members who volunteered for the interviews, a support person also was interviewed. This study analyzed the first year set of interviews. Each interview was recorded and transcribed. The interview guide and the rationale for the interview guide are provided in the appendices (Please see Appendix A and B). This study was approved by both the Navajo Nation Human Research Review Board (NNHRRB) and the Northern Navajo Agency (Please see Appendix C. and Appendix. D.) for conducting secondary data analysis from the original research study conducted in 2003. The research team from the original study included the following personnel: (1) Dr. Mark C. Bauer, Principal Investigator (P.I.); (2) Carolyn Epple, PhD, was the Research Director for the project; (3Frank Morgan, Diné language and culture consultant who conducted the interview that was in Navajo and participated in all the development and analysis sessions; (4) Principal interviewers, Julia Roanhorse and Shirleen Phillips, both Diné staff; (5) Members of the earlier planning included Robert Alsburg and Roxanne Peterman and (6) Amanda McNeill, who left the project to become Dean at Shiprock, and is currently our Director of Institutional Grants Office.

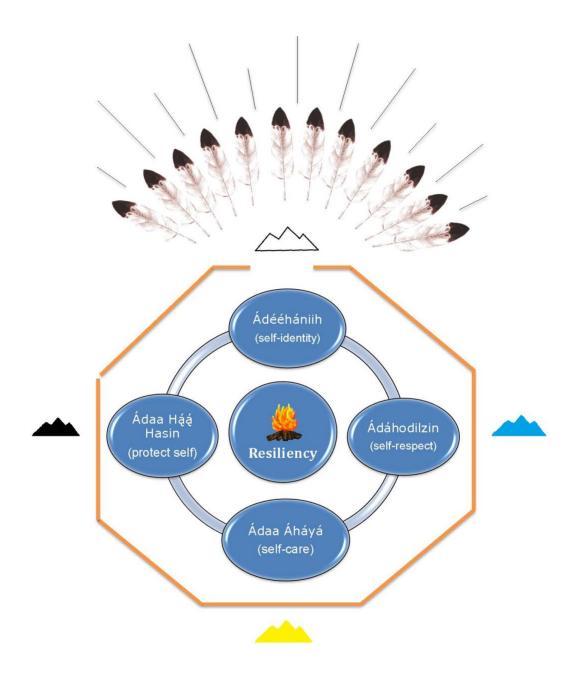
## Methodology

One of the paradigmatic frameworks I used that illustrates this perspective in my learning is known as the Navajo wellness model (Nelson, 2018) which includes elements of the Diné Philosophy of Learning (DPL)/DPE (Diné Philosophy of Education) (Benally, 1994; Clark, 2009). The philosophy has been part of our teachings and lifeways for centuries. Now it is being used as a model, a theoretical model perhaps, in educational and health settings (Kahn-John, 2015). It is based in four cardinal directions beginning from the east, to the south, to the west,

and then finally to the north. There are several interpretations, but a commonly used one translates the east as *Nitsahakees* (Thinking); south *Nahata* (Planning); west *Iina* (Life) and north *Sihasin* (Evaluation/Reflection) (Aronilith, 1992; Clark, 2009; Werito, 2014). This Diné theoretical construct is an important way to integrate traditional philosophy with contemporary models in health communication. DPL/DPE complements the way in which I understand the viewpoints of academic discourse and traditional epistemologies on addressing personal health and well-being. This model has been applied to student services, tribal college settings for academic degree programs, healthcare systems on the Navajo Nation, and social service programs with the Navajo Nation Office of Self-Reliance. The model illustrates the collective knowledge for well-being and the wisdom from a Diné worldview. This grounds the study with Indigenized learning and education for the holistic nourishment of research.

Figure 2

Navajo Wellness Model (Nelson, 2018)



The Navajo Wellness Model (Nelson, 2018) is based in the Navajo Area Indian Health Service (I.H.S.) model and curriculum known as *Sha'bek'ehgo As'ah Oodaal: A journey with wellness and healthy lifestyle guided by the journey of the sun*. The curriculum was created by the Navajo Area Health Promotion and Disease Prevention Program, Indian Health Service, for promoting Diné-centered health literacy, cultural awareness and health education for Diné communities. The words communicate Diné terms for self-care and well-being through a

bilingual approach in Diné and English with detailed constructs of Diné lifeway thinking and communication for self-care (ádaa áháya). The Diné expressions provide cultural guidance and empowerment for the daily practice of taking care of self. The entrance, or first place to begin is exemplified in the first statement to the east (ha'a'aah) with the white mountain (representing white shell, yoolgai) image for the east sacred mountain, Sisnaajiní with the main concept of Ádééhániih (concern for the self). The teaching with this eastern direction is: Hayoolkaal bi' na'ada: practicing wellness in the dawn light. The next part of the model directs us to the south (shadi'ah) with the blue mountain (representing turquoise stone, dootliizh) image representing the south sacred mountain known as *Tsoodzil*, honoring the wellness concept of *Adáhodilzin*, respect for self. The third direction centralizes on the west (e'e'aah) sacred mountain (representing abalone shell, diichili), Dook'o'oosliid, focusing on the value of Ádaa Áháya (selfcare). The fourth phase of the wellness model is represented in the direction of the north (nahook'os) with the black sacred mountain (representing obsidian, baashzhini) known as Dibé Ntsaa. This fourth direction of the wellness model centers on the value of Ádaa Hááh Hasin (protect self). The visual model communicates the principles of cultural lifeways, personal wellness, connection with the sacred mountains, relationship with the elements of the fire in the center and the core values of strength and self-determination.

## **Participants**

The original (2003) sampling process included the recruitment of Diné people with diabetes through purposeful sampling of Diné families who previously participated in another project with a Diné College project team (Lindlof & Taylor, 2002). A total of 12 participants volunteered for the study.

### **Coding**

Thematic analysis is a process for collecting themes through learning from a narrator's stories. Braun & Clark (2006) state that themes are important as they relate to the research question. I analyzed the transcriptions of the narrators' responses from the semi-structured interviews. I was given the transcriptions by Dr. Bauer (P.I.) through a flash drive. Firstly, I printed each of the 12 transcribed interviews. Each transcribed interview ranged in pages from one interview comprising of 11 pages of transcription to 32 pages of another interview. Secondly, I then used thematic textual analysis (Braun & Clark, 2006) in order to synthesize the data (transcribed narrator interview responses). I created a code frame and identified the codes from the 12 interviews. Coding was used to facilitate ease of analysis by concept (e.g., perception of diabetes, explanatory models, diabetes self-care, types of support, communication, etc.) and by narrator. Thirdly, data were analyzed for trends, noting perceptions and practices specific to people with diabetes. And, fourthly, I used the (health belief model and stages of change model) and the Diné framework known as the Navajo wellness model (Nelson, 2018) to guide me as I conducted the coding process. I read the transcriptions multiple times to immerse myself in the data. Throughout the readings I took notes on major points and concepts. The next step, I began to write the major themes that supported each of the three research questions. I was then able to reflect on the themes that were emerging and began a journal noting the patterns and unique statements. The journal served as a core source for my reflections, coding and notes for potential categories. I then examined them with Dr. Tamar Ginossar. She provided guiding points for me as I completed the coding for each of the three research questions.

As stated by Rallis and Rossman (2003), I, as the researcher, occupy a position of researcher as learner. As a Diné woman, being raised in a community known as *Tseyaato* (area where the water flows from the rocks) on the Navajo Nation, I must be aware of my

assumptions, biases, and perceptions when reviewing the narratives from the Diné narrators. Ganga and Scott (2006) would state that I am a "cultural insider" with emic insight into the community through social proximity, but I also need to understand that this research relationship is complex. As an insider, I have approached the study with cultural humility and through the Diné philosophical framework of k'e (kinship). I have been cognizant of my assumptions of the shared cultural, linguistic, ethnic, and traditional beliefs of the participants as well (Ganga & Scott, 2006). I have been careful to not assume that I know of their way of life or lived experiences even though we are from our respective Diné communities. For example, a Diné community member who lives near the San Juan river may have more access to water and able grow a garden for healthy foods versus a Diné community member who is from an area with no river nearby and may not have access to having their own garden due to lack of access to water. Their lived experiences may be similar culturally and also very different in terms of distinctive community environments. I have used cultural humility and k'e (kinship) as a way to approach the narrators' narratives respectfully and carefully with honoring the stories through Indigenized research ethics.

In accordance with a qualitative approach, I positioned the research through Creswell's (2003) explanation of seeking to understand constructivist perspectives (i.e., the multiple meanings of individual experiences, meanings socially and historically constructed, with an intent of developing a theory or pattern) or advocacy/participatory perspectives (e.g., political, issue-oriented, collaborative, or change-oriented) or both. Hymes (1974) affirms, "speaking is itself a form of cultural behaviour, and language, like any other part of culture, partly shapes the whole; and its expression of the rest of culture is partial, selective" (p. 127). I wanted to ensure that I read the narratives using these understandings of narrators sharing multiple meanings and

perspectives. Each transcribed interview gave powerful perspectives that conveys meaningful expressions and lived experiences that are significant to understandings diabetes self-care and support.

I have worked diligently as a researcher/learner to embrace the following principles of good practice: (a) comfort with vagueness, (b) capacity to make reasoned decisions to communicate the logic behind those decisions, (c) deep interpersonal or emotional sensitivity, (d) ethical issues of potential consequences to individuals and groups, (e) political and cultural sensitivity, (f) determination, and (g) awareness of when to bring closure (Rallis & Rossman, 2003).

### **Summary**

This chapter was organized to address the methods process for the three research questions through the Diné narrators' narratives. The chapter comprised of six core areas: (1) research method and design; (2) research questions; (3) background of the study; (4) population; (5) data analysis framework; and (6) coding. The next section includes chapter 5 which will provide the discussion, summary and findings, implication and limitations.

### **CHAPTER 4: ANALYSIS**

The purpose of this qualitative study was to examine the lived experiences of type 2 diabetes self-care and support among Diné people. The research questions and the subsequent themes provided the findings in this analysis section. Understanding the range of perceptions from the narrators' narratives provide key insights for how they define diabetes, to self-care and social support with managing diabetes. 13 main themes emerged for the three research questions. Research question one examined the ways in which Diné people describe diabetes. The five main themes included: (1) barriers and struggles with the explanation of diabetes, (2) explanation of diabetes through lifestyle and foods, (3) medical explanation of diabetes, (4) hereditary explanation of diabetes and (5) traditional cultural lifeway explanation of diabetes (Please Table 1). Four themes emerged from research question two included: (1) barriers with managing selfcare, (2) positive use of food for self-care, (3) healthy physical activity for self-care, and (4) traditional explanations of self-care (Please see Table 2.). And, lastly, four themes emerged from the third research question: (1) barriers with social support, (2) positive family support, (3) supportive patient/provider communication, and (4) positive community support. (Please see Table 3.)

I share my analysis in accordance with the stages of change theory, also known as the transtheoretical model (Prochaska & DiClemente, 1982; Prochaska et al., 1992), and facets from the Navajo wellness model (Nelson, 2018) from the Navajo Area, Indian Health Service. The pillars of the stages of change theory include: (1) precontemplation, (2) contemplation, (3) preparation, (4) action, (5) maintenance, and (6) termination. The visual component of the Navajo wellness model (Nelson, 2018) also helped to uncover meanings in certain responses from participants. The core concepts from this model include: (1) Ádééhániih (self-identity), (2)

Ádáhodilzin (self-respect), (3) Ádaa áháyá (self-care), and (4) Ádaa háá hasin (protect self). These models are used as a framework for my analysis of the narrators' lived experiences with diabetes.

# **Research Question 1**

In this section, I analyze the responses to RQ1: *In what ways do Diné people describe diabetes?* Research Question 1 (RQ1) focused on understanding what diabetes means to Diné narrators. Each person conveyed their lived experience by communicating how they define type 2 diabetes. Five themes emerged from the narrators' responses: (1) the barriers and struggles with the explanation of diabetes, (2) explanation of diabetes through lifestyle and foods, (3) medical explanation of diabetes, (4) hereditary explanation of diabetes and (5) traditional cultural lifeway explanation of diabetes. The responses reflect personal, cultural, social, and community understanding of diabetes. Narrators' experiences varied depending on their own exposure to type 2 diabetes education, community health information, and/or connection with a family member who has diabetes (Please see Table 1).

The following examples provide details from the narratives as expressed by narrators.

**Table 1**RQ1 Themes from Diné Narrators' Description and Meanings of Diabetes

Theme 1	Theme 2	Theme 3	Theme 4	Theme 5
Barriers and	Explanation of	Medical	Hereditary	Traditional
struggles with	diabetes through	explanation of	explanation	cultural lifeway
explanation of	(a) lifestyle and	diabetes	of diabetes	explanation of
diabetes	(b) foods			diabetes
Not knowing how to describe diabetes	Sweet and greasy foods cause diabetes	Failure of the human body	Family history of kidney failure	Diabetes did not exist long ago

Adjusting to the diagnosis with initial assumptions of effects from diabetes	All parts of the body will be affected, extreme complications vs healthy outcomes	Sugar is harmful to the body	Family history and being overweight causes diabetes	Unclear of the origin
Limited information on diabetes	Become weak from the sweets	Insulin issues with the pancreas and kidneys	Not curable	
Severity of diabetes complications vs sharing about the management of it		Prevention of diabetes by keeping physically active and healthy eating  Diabetes causes other illnesses – illnesses of the eyes, heart, nervous system		

# RQ1 Theme 1: Barriers and Struggles with Explanation of Diabetes

This section provides insight into the narrators' understanding of type 2 diabetes.

Narrators who were in their first stages of their diagnosis described what diabetes meant to them.

The responses reflect a lack of explanation after diagnosis. A narrator stated, "I really don't know anything about it yet. I initially heard about it, and I still couldn't understand what it means. ... I don't know, I haven't found what it's about it yet." Another narrator similarly stated, "[Diabetes is] a disease, isn't it?" With further lack of clarity, they expressed, "[laughter] Well, it's a disease, um, I'm not really-know anything about it. Just found out I had this disease, so."

Similarly, a third individual provided a forthright response, "I don't really know diabetes."

These statements should not be mistaken for the narrators' lack of ability to understand their diagnosis. Rather, their answers could reflect the way in which they were informed about having diabetes. These responses could also indicate that they felt discomfort discussing it or were feeling overwhelmed by talking about it. A person may first appear to be in a state of denial, as exemplified by a narrator who stated, "They just tell me I have diabetes. I don't know if it's true or not but...." This type of answer indicates the challenges with acceptance of an illness.

In relation to the ádaa áháyá (Nelson, 2018) model, the narrators are not expressing self-care thinking. Furthermore, the narrators are at the stage of precontemplation with the stages of change model (Prochaska & DiClemente, 1982; Prochaska et al., 1992). They have not fully understood or accepted their diagnosis. Their responses indicate they are not at a place of thinking about diabetes as being part of their lives. The diagnosis might be overwhelming for them to embrace, and they might not be prepared to address it at an emotional, mental, physical, or cultural level.

In terms of managing diabetes, these answers demonstrate how the narrators may relate to their diagnosis. A narrator conveyed, "I don't know. They just told me that I had high blood pressure and high cholesterol. This is what they told me and to keep checking it." Furthermore, they noted that they were told, "You can do a lot of exercise" as a way to understand how to cope with self-care for diabetes. Additionally, the narrator expressed the risks associated with their perspective on what happens when living with diabetes, "... you get your leg cut off. You can get sores. Some people use, like shots." These explanations for managing or coping with diabetes during the beginning stages of being diagnosed reveal the different barriers to understanding the assumptions and complications of the illness. The assumptions can affect a

person's self-care and management of diabetes until they find more security, safety, and empowering coping strategies when they learn more about the meaning of diabetes. The narrators are at a stage of precontemplation (Prochaska & DiClemente, 1982; Prochaska et al., 1992) and are not able to express thinking or communication about *ádaa áháyá* (Nelson, 2018), for diabetes self-care.

# RQ1 Theme 2, Part (a): Explanation of Diabetes Through Lifestyle

This section provides explanations focused on lifestyle through the narrators' perspectives on food choices and about sharing physical health issues. A narrator said,

Sometimes, when they [family members] get carried away with sweets... That sugar, you know, it's not good for you. You know, tell them it can get your health problems later, when you get older. Or any time, you know. So, I try to keep them off of it. Sometimes you know. They can have it sometimes. A snack or something.

Another narrator said, "Diabetes, I think diabetes is, you get weaker. Um, I know they were telling me that you sweat a lot. And it's really hard for people that were diabetics. They get sick worse." Another narrator said, "Eating sweet food and greasy food. You will catch it if you eat those kinds of foods and if you don't take proper care of yourself with these foods. That's what the teachers say."

A narrator expressed how sugar is a part of his lifestyle and stated that it relates to the cause of diabetes: "Ahh!! I mean, it's... It's like too much sugar. It's the only thing I would answer right now... In my blood system... I go crazy on pop." The narrator conveyed their understanding of diabetes through problems that arise from not making healthy changes at the onset of diabetes. These responses provide the complexities of understanding diabetes and how sugar or other physical issues affects the body. These explanations indicate the Diné narrators are

at the stages of pre-contemplation and contemplation when expressing their understanding of diabetes (Prochaska & DiClemente, 1982; Prochaska et al., 1992). In terms of *ádaa áháyá* (Nelson, 2018), the narrators are not able to think about diabetes self-care yet. Their initial explanations are focused on low blood sugar and how they are not able to voice the detailed medical information.

### RQ1 Theme 2, Part (b): Explanation Through Foods with Diabetes

This section focuses on traditional Diné explanations for describing diabetes in the narrators' lives. A narrator said,

If you don't eat the proper foods, if you eat sweet and greasy foods, if you eat food with a lot of fat, your kidney (*achá'áshk'azhi*) will begin to have problems. Your kidney will have problems and your blood will have to be boiled [dialysis]. All this will happen, and if you have a sore on either your feet or your hand it will have to be sawed/cut away. Also, your thinking will also be affected; you will not be able to think properly. Your eyes too; your eyes will be blinded and or your ears will become deaf. That is what they say, that's how it will affect you. If you are a woman your (*hwiishch'id*) uterus/womb will be affected. That's why you are to eat properly, and you will live long - is what they say.

These responses address the anatomical failures with diabetes. The narrators described the physical explanations for how diabetes affects the body. A narrator said,

Well, I think diabetes is something that has to do with the chemicals that your body should get rid of all the sugar in your body. And where your...that part of the body, umm, the human anatomy which fails to get rid of your sugar. So that's where you become a

diabetic, where you have to control it by dieting and exercise. Walking and running and doing daily values.

Another narrator similarly expressed,

I know it's something to do with sugar, in your blood. Sometimes its producing too much, sometimes it's not producing enough. And along with that, it affects a lot of parts of your body. Your, eyesight, your heart, your blood flow, your kidneys ... That's about most of the things I know about diabetes.

Similarly, a narrator spoke about the body's processing of sugar. She said,

Yeah, I have doing a little bit of reading on it. It's just that the body, what is it, when the body starts to, in the... when the body no longer has control over the amount of sugar that's being put into your...how do you say, passed on to your, and it just builds up in the body.

These answers reveal that the narrators' perspectives may be based on what they have heard from their family or in the community. Their responses offer a range of explanations for the meanings of diabetes. Several narrators spoke about sugar and greasy foods while others spoke about severe effects from diabetes, including kidney failure, amputation, blindness, becoming deaf, and female reproductive organs being harmed. The meanings of diabetes to these narrators are important to value as a way to understand how narrators communicate their lived experiences. Understanding these explanations provides a connection to the narrators' insights and how to support them with self-care and diabetes management. These explanations align with the stage of contemplation (Prochaska & DiClemente, 1982; Prochaska et al., 1992). The narrators provide important understandings with the midst of ádaa áháyá (Nelson, 2018), for diabetes self-care.

The narrators' responses relay diverse ways of thinking about the meanings of diabetes.

This is a significant phase of health behavior to begin the process of thinking to build understanding and acceptance of diabetes. Once this occurs, certain steps for managing diabetes may proceed by making healthy self-care decisions.

## RQ1 Theme 3: Medical Explanations of Diabetes

These responses focus on the medical explanations of diabetes. The narrators were able to share medical reasons for the causes of diabetes in relation to the health information on the function of their organs. A narrator said,

Yeah, they show me pictures of a pancreas then in the blood vein that goes out from it. They said if the insulin is not working right, the sugar doesn't actually go into your muscle like it's supposed to. It goes through your blood vein and the blood goes all over your body. So, we have to get like our feet check[ed] and everything. Physical check. They show me pictures of pancreas and then the kidneys. Sometimes they said it can start affecting your kidneys. So, they show me pictures of how the body system works. For me it was my pancreas, so they taught me more about the pancreas.

The narrator was able to express the connections between blood flow, circulation within the body, the body's processing of sugar, and the function of the pancreas. This answer conveys their initial knowledge of diabetes and how visual aids of the organs were helpful to them for health education. Similarly, another narrator answered with an explanation for how lifestyle can cause or prevent diabetes. The narrator said,

Okay, diabetes... from the understanding I got was that it's ah! It's ah!...

I guess it's a disease that is caused by eating too much fatty foods as well as anything with high sugar, and it's when your body can no longer process that sugar properly, and

therefore it just builds up in your blood and ah! Diabetes can be prevented by exercise and watching what you eat and [ah!] how you live your daily lifestyle. If you live a lifestyle that involves just eating fast foods and not getting any exercise, eating fried foods and a lot of high sugar foods, then you're more likely to get diabetes. Diabetes also can cause other diseases. The illness of the eyes, the heart, the nervous system, and so forth and that's why it's more important that you get regular checkups - dental, eyes, and foot care -things like that, and also that you watch what you eat and eat a well balance[d] diet and get plenty of exercise. That's what I understand what diabetes is.

The explanations convey an awareness of the complexities that arise when describing meanings of diabetes. Both narrators' responses reflect the stages of contemplation and preparation (Prochaska & DiClemente, 1982; Prochaska et al., 1992). In relation to the Navajo wellness model (Nelson, 2018), their explanations focus on each concept. The narrators were becoming aware of diabetes and the steps towards *ádaa aháyá* (self-care) and *ádaa háá hasin* (protect self). The meaning of diabetes for these narrators contributed to health and cultural communication for management of self-care in Diné communities.

### RQ1 Theme 4: Hereditary Explanations of Diabetes

The responses for hereditary explanations for having type 2 diabetes provide an understanding of the narrators' knowledge of the existence of diabetes in their families and the perception of it as unavoidable and incurable. A narrator explained the relationship between family history of diabetes and having sugar in the body. The narrator said,

Diabetes is when you have a lot of sugar in your system. You can get it - its hereditary. You know it could be like from kidney failure. You know, for it's on my real dad's side

of the family. It's a history, so that's how I got diabetes, and mainly you got a lot of sugar in your system.

A narrator also expressed,

Yeah, I wonder about it. I know that it is hereditary, in most cases it is hereditary. Then another thing is that if you're overweight for a long period of time and you are not active, it produces extra sugar that your body can't digest.

Another narrator said, "Well, they said I had gotten [diabetes] from my mother. This is what they [I.H.S.] told me. And that's when they kept checking the A1C." These answers relay the narrators' understanding of diabetes in their lives. In terms of viewing diabetes as a certain disease that one will acquire someday, narrators shared their perspectives. A narrator said,

Diabetes, from what I understand, it is, it's a disease that you can't avoid, and you just can't put it aside. It's there and it follows you around wherever you go. You cannot outstep it; it's kind of like it's impossible. And that's the way I feel about it.

One narrator expressed that diabetes is incurable. The narrator said,

Having diabetes is .... in a way, I think you can't, is not curable. It stays with you the rest of your life, and I don't think there is no cure for that, even though they try to find a way, in such a way like medication or other means of finding. It will still be in you. In a way, it is still in your system. And in the long run, it's not going to get cured, I think. In terms of what they call diabetes...this is how I think about that.

The narrators provided explanations for the seriousness of diabetes with their narratives. They are able to communicate *ádaa aháyá* (Nelson, 2018) for diabetes self-care through their feelings and statements. They each expressed the reality of the illness, however, with more education and awareness, the narrators will learn that diabetes management and the self-care

steps to live healthy and activity. They each communicated their perspectives of diabetes in a reflective manner that relates to the contemplation stage of change (Prochaska & DiClemente, 1982; Prochaska et al., 1992)

### RQ1 Theme 5: Traditional Cultural Lifeway Explanations of Diabetes

Some narrators viewed diabetes from a traditional lifestyle explanation. A narrator said,

What they call diabetes is...we don't know where it originated. Long time ago, what we used to eat, we were raised, we ate different. What they call exercise, we used to herd sheep and ride horses. This is how we were raised. Where it [diabetes] originated I don't know.

This narrator's answer focused on the challenges of facing diabetes in modern times and the cultural conflict about the cause and meanings of diabetes. The narrator highlighted traditional Diné lifeways and health practices that did not include the illness of diabetes. Rather, she explained that traditional foods and healthy activities promoted wellness and a defense against diabetes. Her modern understanding conveys the struggles with addressing what diabetes means to her since there are no traditional cultural explanations for it. She centered on how daily practices such as caring for the livestock and eating traditional foods were a natural way of life and not viewed in the contemporary manner of "exercise." In accordance with the Navajo wellness model (Nelson, 2018), the narrator's explanation alignment with ádaa aháyá in her life and is at the stage of contemplation and preparation (Prochaska & DiClemente, 1982; Prochaska et al., 1992).

# Summary of RQ1

RQ1 explored the meanings of diabetes to the Diné narrators. Their narratives communicated the range in which they described diabetes through their lived experiences. They

spoke about the issues that arose when explaining diabetes, mostly from being unaware of the ways to manage and cope with it. They also conveyed that they were very knowledgeable of medical information. The meanings of diabetes from Diné community members' perspectives provide vital insight into how they communicate about lifestyle, food, and traditional health explanations. Their narratives provide vital information about their home life, culture, and social and community awareness about diabetes. Overall, the narrators expressed variations with ádaa aháyá (Nelson, 2018) and the beginning stages of change through precontemplation and contemplation (Prochaska & DiClemente, 1982; Prochaska et al., 1992) for their perceptions about what diabetes means to them.

The next section provides the analysis for Research Question 2 (RQ2), which focused on how Diné narrators describe self-care when managing and coping with diabetes.

### **Research Question 2**

In this section, I provide answers to RQ2: *How do Diné people describe self-care when managing and coping with diabetes?* The narrators described diverse ways in which they cope with diabetes through self-care. Living with a chronic illness such as diabetes is multifaceted and often presents complexities that require drastic changes to one's lifestyle. This section illuminates the lived experiences of the narrators and their self-care journeys. Four themes emerged: (1) barriers with managing self-care, (2) positive use of food for self-care, (3) healthy physical activity for self-care, and (4) traditional explanations of self-care. (Please see Table 2.) Again, I provide my analysis of these themes through the stages of change theory, also known as the transtheoretical model (Prochaska & DiClemente, 1982; Prochaska et al., 1992) and the Navajo wellness model (Nelson, 2018).

 Table 2

 RQ2 Themes for Diné Narrators' Explanations for Diabetes Self-care (Ádaa Áháyá)

Theme 1 Barriers with managing self-care	Theme 2 Positive use of food for self-care	Theme 3 Healthy physical activity for self-care	Theme 4 Traditional explanations of self-care
Communicating struggles with taking medications	Action oriented communication - Healthy eating changes, reducing sugary foods, portion control, weight loss	Communicating active connection with the land through planting crops and caring for sheep	T'áá hwo' ajit'eego' (self-reliance, feeling capable, taking responsibility)
Communicating barriers - Stressors with adapting to new foods, changes with cooking healthier	Communicating readiness - Gradual steady changes with healthier cooking, less grease, less fat	Being active with children, animals, and use of treadmill	Ancient lifeway teachings - Respecting the land, rising early, honoring the sunrise for wellness
Negative, stigmatizing communication from family on diabetes diagnosis	Empowerment communication - Awareness, using nutrition education for sugar reduction, increasing healthy behaviors	Walking up to 2-4 miles, adapting to healthy movement practice	Resiliency through traditional practices
Communicating challenges with changes - Difficulty with reducing and eliminating sugary drinks/pop	Access to traditional foods, healthier cooking, and balanced meals with increased vegetables	Inter-generational strength and connection for walking with grandfather	Ceremonial strength, praying at dawn, and using traditional medicinal plants for healing
Communicating fear of diabetes and the adverse effects from complications	Communicating need and value for having traditional food to feel healthy and feel better		

## RQ2 Theme 1: Barriers with Managing Self-care

The self-care journey from the time of diagnosis to acceptance of living with diabetes poses many challenges for managing the condition. The Diné term for self-care is ádaa aháyá, which means to have positive thinking, thoughtful and resourceful actions, and healthy behaviors. It can often be difficult to attempt self-care using these values when an individual feels overwhelmed by illness. The Diné narrators described the barriers and struggles with managing diabetes while conveying feelings of being threatened or intimidated by the onset of the chronic illness. Self-care serves as a protective factor in modern and traditional Diné lifeways. When an individual does not use self-care, the risk of loss of sight, renal failure, or loss of a limb could increase. The following excerpts from the narratives illustrate these challenges.

A narrator communicated her struggles with self-care. The narrator stated,

When I don't take my medication...I feel not right...and then when I take my

medication... [makes faces]... it just puts me to sleep, so I sleep. Sometimes I don't like

to sleep...sometimes, I don't take my medication (that's my reason). And then some

other time...when I don't eat much, I stuff myself with medication...my surrounding is

unbalanced. So, either way it affects...it affects my...it affects me, so I just have to

function daily. This morning I look my medication ...everyday...either way it still affects

me. The way I feel about it... I know a lot of people feel like that...People that live

around here...they don't have time to sit at home...They spin wool and herd sheep doing
their daily routine...They don't have time to sit at a meter three or four times a day

messing with it...

The narrator communicated the stressors associated with adhering to her prescribed medications. She is at the stage of contemplation and has not fully engaged with preparation yet (Prochaska & DiClemente, 1982; Prochaska et al., 1992). The narrator is feeling real emotions that are often felt when diagnosed with diabetes. There are side effects from new medications that take time to acclimate to a person. The narrator expressed frustration with the self-care practices for diabetes management. Thus, she is feeling how difficult it is to bring balance to her daily life through the medication regimen. The narrator may not fully adhere to the medication as being supportive for her well-being until she feels acceptance of diabetes in her life. This may take time and with encouragement from her family and healthcare providers she may find balance in the future with the self-care regimen. The narrator may also take care of herself through ádaa aháyá but in a different way with other forms of self-care such as what she shared about daily tasks (Nelson, 2018). Self-care can represent many forms to people who perceive it in their own respective approaches.

The next example is from a narrator who conveyed her challenges with healthy food for diabetes self-care. The narrator said,

Why does everything have to be, uh. Why does everything...why can I cook what I cook for ourself that any kind, why can I eat the same thing like these guys? Why do I have to change my menu just because that I have diabetes? That's what I don't like, and I have to do it something. I have to think about myself. But sometimes I get frustrated with it, so I just eat what we cook for ourselves. Him and I, as far as me keeping up with my diet and eat vegetable and all this and that sometimes I don't - I don't do that. To be honest with you, I just cook what we cook as a family, and that's how we eat. That's how I do it. I don't want to lie about it. It's just like that.

The narrator is not fully ready for ádaa aháyá (Nelson, 2018) with diabetes self-care and is at a stage of precontemplation. As well as not being ready for contemplation about adjusting to

healthier foods (Prochaska & DiClemente, 1982; Prochaska et al., 1992). Diabetes self-care promotes changes for more nutritious foods that provide blood sugar balance. However, the narrator may not have access to healthy foods in her community, considering that the Navajo Nation has a limited number of grocery stores and less access to fresh fruits and vegetables. Self-care through food changes is a barrier for this participant who may not have tried healthier options due to not having access to them or the foods may be more expensive. This narrator also felt pressure to continue conforming to the family's familiar meals rather than the family adapting their meals to accommodate the narrator with her diabetes self-care plan.

Another narrator focused on the stigma and shame of having diabetes. This type of communication hinders an individual's self-care journey and does not honor their path by expressing negative comments. The narrator said,

[People would say,] "You're going to go blind." Or maybe, "If you don't stop eating that, they're going to cut off your legs," or things like that. But they use to say in a joking way. But I think now, they are aware that it can happen, because my one grandma... the one grandma before... about three years ago, the one that died. She actually had her leg amputated from her knee down. And then she couldn't handle that, and I think that also was a factor to why she just went ahead and gave up. And then eventually just died. But um! I think from then on they realized that this is not a joking matter. So, they take it... They know it's [a] serious illness, of what the causes can be, but there [are] still a few who really don't say anything because they're ashamed of it.

The narrator relayed feelings of doubt about her family's self-care approach. However, the narrator also expressed statements that denote she is at a stage of preparation and action since she is recognizing diabetes as a serious illness that needs to be cared for diligently (Prochaska &

DiClemente, 1982; Prochaska et al., 1992). She shared the story of her grandmother's experience through the essence of *ádaa aháyá* (self-care) and *ádaa hááh hasin* (self-respect) for her needs living with diabetes versus her relatives who feel shame towards it (Nelson, 2018). The issues of family support pose more challenges to the narrator when she is needing increased support for positive communication.

The narrators also shared their challenges with reducing or eliminating sugar. Increased levels of sugar serve as risk factors for people with diabetes. It was critical for this next narrator to communicate the struggles with adapting to new changes and, ultimately, alleviating sugary drinks for healthy self-care actions. The narrator stated,

You know diabetes is really hard. You can hardly drink. You can drink diet soda and some other stuff. It's good to have low sugar stuff and that's sugar free. Before I was, before I was going to be diabetic and everything, I used to drink like pop and pop all the time.

This narrator openly shared their experiences with the struggle to adapt to not having sugary "pop." Their healthy changes show they are protecting self (àdaa háá hasin) and ádaa aháyá (Nelson, 2018). They are at a stage of action and acknowledge the importance of making these changes, no matter how hard they may be, for managing diabetes (Prochaska & DiClemente, 1982; Prochaska et al., 1992). This change to shift from sugary drinks to water is especially remarkable when a person may be addicted to sugar.

Challenges with diabetes self-care may also originate from a place of fear. Self-care encompasses coping with the feelings often experienced when people begin to understand the seriousness of the illness. This narrator became aware of the severity of her diabetes condition and how to address it at home with her child. The narrator stated,

Be careful, and because I don't know... All they were telling me that you have to be careful, you might faint. And there's nobody there for you. The only thing that they say that is there for you is your little girl. In this household, everybody goes to work. They have a different schedule, and you know. I already told my daughter, if I ever faint or anything, just go call the neighbor or go call 911. I'm scared inside. It's something, I feel something is going to really happen. There's nobody there to watch my daughter.... When you have diabetes, you have it. You can't treat it. You have to take medicine or you have to take shots.

This narrator's feelings convey the realities of confronting a chronic illness such as diabetes. She was able to raise awareness from her feelings of fear and being scared to taking precautions at home with her child. This example shows the participant is at the stages of contemplation and preparation in the stages of change theory (Prochaska & DiCliemente, 1982; Prochaska et al., 1992). She is adjusting and adapting to the challenges of living with diabetes by providing a ádaa háá hasin and ádaa áháyá plan in case something serious were to happen to her (Nelson, 2018).

In summary of RQ2, the narrators experienced diverse barriers with diabetes self-care. Their narratives communicate their struggles with *ádaa aháyá* (Nelson, 2018), including struggles taking medications, removing sugar from the diet, and negative stigmatizing feelings from family members. Their stage of change in relation to their lived experiences conveys the difficulty of adapting to diabetes self-care changes (Prochaska & DiClimente, 1982; Prochaska et al., 1992). The journey with behavioral changes initially ranges from precontemplation to contemplation to preparation. In the first two stages of precontemplation and contemplation, behavioral changes often take 6-9 months. This timeframe shows how challenging it is to adopt

new behaviors, let alone how challenging it is to accept a chronic illness such as diabetes. In addition, denial may also occur for several months or even for several years. Accepting diabetes and acknowledging new self-care steps take time and ought not to be judged. Rather, people should be viewed with empathy and support. For these narrators, eating new foods, although healthier, caused distress since the participants were unfamiliar with the new tastes and not accustomed to them. The next level of stages of change (Prochaska & DiClimente, 1982; Prochaska et al., 1992) for the narrators' readiness with diabetes self-care is exemplified in the preparation and action stages of adapting to healthy food changes.

### RQ2 Theme 2: Positive Use of Food for Self-care

Managing diabetes with food is a critical aspect for controlling the disease and reducing risk factors. The main changes required under the theme of positive use of food for self-care include weight loss, portion control, education about healthy eating, and reducing or eliminating sugar. In this section, the narrators' self-care experiences with healthy food adaptations are shared. Each of these examples further elaborates on the themes for food as a protective factor for diabetes self-care.

One narrator spoke about healthy food changes. These changes positively contributed to his weight loss. He described how his companion supported him to actively use portion control for his meals. He stated,

Well, my weight has decreased quite a lot. Before they use to tell me I was overweight and [needed] to lose a lot of weight. This is what they use to tell me back then, and I did not listen or obey them, and it was just like that for a long time. But then I started to think about it and, besides, she [my companion] tells me also. I got use to eliminating sweets

and high cholesterol food, so now I don't think about those things. I don't feel like eating a large portion these days.

The narrator's healthy food experiences indicate a strong example for the action stage in the stages of change model (Prochaska & DiClimente, 1982; Prochaska et al., 1992). His healthy behaviors reveal how he was being mindful with his relationship with food and the amount he chose to eat. He respected food and himself. He was able to express *ádáhodilzin* (self-respect) and *ádaa aháyá* through these changes for diabetes self-care (Nelson, 2018).

The second example for healthy food changes is provided by a narrator who shared that healthy eating and healthy cooking were helpful self-care practices. The narrator said,

It took a gradual time to get everybody used to eating good and right. Everybody helped out, and they didn't really complain because they thought, well, this is for us too, because Mom has diabetes, and any of us. Because earlier, like I said, I explained to them why grandma and grandpa have diabetes. So, my husband tries, he cooks. And he only cooks, he tries to cook with less fat, less grease. And he's learned how to do that. You know, he's a good cook. The kids like his cooking.

This narrator communicated that her family had a history with diabetes and that promoting self-care through a unified effort to protect her family from the risks of diabetes was important. She reflectively communicated that these changes took time through gradual steps, honoring the process for change. Together, she and her family are in the action stage in the stages of change model (Prochaska & DiClimente, 1982; Prochaska et al., 1992). They are working on healthy cooking at home. These practices relate to *ádaa aháyá* and *ádaa háá hasin* (protect self) with the Navajo wellness model (Nelson, 2018). She cares for and honors her family's well-being, ensuring they all move forward together with healthy food actionable steps.

Another narrator communicated about her healthy food changes through mindful practices such as reading food labels and having balanced, nutritional meals. She became educated on the unhealthy effects from sugar intake and the impact this has on blood sugar levels. She expressed the following,

Ah! Well, how to eat a balance meal but to have a little portion of it. How you measure it. You know like ah! Some stuff that ah! food that wasn't ah! I thought was good for me was certain things that would make ah! my sugar would go up. Like I always thought that milk was healthy for me. So, I would you know, since I'm a diabetic I would probably drink two or three glasses of milk. Thinking it was good for me. Well, it turns out that it's got fat in there. That can make your body produce more sugar. See, that's where I was getting it wrong and then ah! I knew... like sweets would you know. But the different... even the watermelons, the cantaloupes and stuff I guess it has natural sugar in them. Which I wasn't aware of you know, and here I thought well, there good for me you know. And I'll eat that you know. Or orange juice but that contains different grams of sugar. So now I've learned how to ah! I never use to look at bottles of things that I've drank to kind of look at the grams of sugar. Now I do. I was never really... put myself aware of that and now I'm aware of those things.

This narrator's experiences show her awareness of the multi-faceted dimensions of healthy food choices Becoming aware through nutritional guidelines and reading of food labels takes time and is often complex. However, she was able to discern how a variety of foods contain sugar, even healthy fruits, and she learned how to balance her food choices and adjust the grams of sugar she consumed each day. This level of responsiveness to self-care with food illustrates she is at the action and maintenance levels of the stages of change theory (Prochaska

& DiClimente, 1982; Prochaska et al., 1992). Through these stages she is able to form healthy habits and a natural routine each day with a continual flow of nutritious self-care choices. These actions exemplify the ádaa áyáhá and ádaa háá hasin realms of the Navajo wellness model (Nelson, 2018). As a person managing her diabetes, she is empowering herself through these educational approaches and is taking control of her healthy food practices.

A narrator shared about cultivated foods in her community. She expressed the knowledge of where the food was grown locally as well as healthy food changes for diabetes management. She expressed,

Lately they've been bringing me vegetables from the garden, so I guess that's healthy. Tomatoes, squash and I eat raw squash and put it in my salad. About, well, right now it's harvest time. So probably once a week.... I used to love steak with fat. I cut it off. I cut the fat off and I just eat not too much of the meat you know? And ah! Right now, my sisters and them have given... been giving me, like fresh tomatoes. We tend to be eating supper like with slices of tomatoes and bell peppers, cucumbers. So basically, my diet has been pretty good. I think just by eating the fresh vegetables and I don't put butter in my veggies any more like I use to. I mean, I use to and ah! Kind of eased up on the season. I don't put season in there anymore and I cut out most of my bread because it's carbohydrates. And that can turn into sugars, so I've been educated about that. So, I've learned a lot.

This narrator's awareness and diligence for her diabetes self-care is evident through how she is using local resources and healthy nutritional foods for her changes. She is able to access to fresh grown foods, practice her new behaviors of eating leaner meats and eating fewer carbohydrates. The connection to healthy foods for her self-care provides a relationship to the land and

supportive nourishment. Typically, community members may not have access to locally grown foods. However, having this access promotes protective health factors and supports diabetes management. Fresh vegetables from the community garden and knowledge of carbohydrates provide a link to the Navajo wellness model (Nelson, 2008): traditional foods provide resilience and ádaa háá hasin (protect self), ádééhániih (self-identity), ádahodilzin (self-respect) and ádaa áháyá (self-care). This level of healthy eating supports the action and maintenance stages in the stages of change theory (Prochaska & DiClimente, 1982; Prochaska et al., 1992).

Another narrator conveyed *ádaa áháyá* through traditional healthy food changes. The narrator said,

When I eat blue corn mush I feel healthier. Sometimes I make it for myself in the morning. Or in the afternoon. That's all I eat. Blue mush. I like to eat that, and mutton stew once in a great while. That's how I like to eat it.

The narrator mentioned the healthy practice of making *t'oosh'ch'iin* (blue corn mush). This food is a cultural custom that is meaningful and is honored for its sacred traditional value of bringing forth nourishment as well as protection. The recipe is made with finely ground roasted *nadaa dootl'izh* (blue corn), *gad* (juniper or cedar ash), and boiling hot water. The *adeest'iin* (traditional stirring sticks used for making *alkaad* and *t'oosh'chx'iin*) are viewed as resiliency tools to ward off hunger monster, sickness monster, and poverty monster. The stirring sticks are a shield when used with preparing foods such as the *t'oosh'ch'iin*; essentially, the monsters fear this home and will not enter it. In traditional teachings, the *adeest'iin* are placed on the north side of a *hooghaan* (home), or in modern times in a kitchen on the wall, as a symbolic representation as a guardian for health and well-being. In contemporary times, a whisk may be used for the preparation of the *t'oosh'ch'iin* while the symbolism is still respected, and the nutrients are still

provided with the protection for a healthy life. The language of strong health and well-being is communicated (either silently or aloud) when preparing the *t'oosh'ch'iin*. This positive thinking and conveying of the words in a holistic manner provide cultural strengths, love, mental strength, and good energy for the people who consume it.

The self-care experiences of these narrators focused on healthy food changes for diabetes management. Their stories included access to traditional plant foods (such as cultivated fruits and vegetables) that serve as protective factors. Narrators also described their new healthy practices with modern foods (trimming fat from red meat, having less bread and less sugar) that often led to weight loss and more positive energy. The narrators spoke about how they were taking a healthy stand for their well-being through nutrition education and how they were empowered to take action with the healthy choices for ádaa áháyá (self-care). An important aspect of the narrators' experiences focuses on weight loss and portion control. To' bi'kii'nigo is a respectful approach to food and represents the core values in the Navajo wellness model (Nelson, 2018): ádééhániih, ádáhodilzin, ádaa áháyá, and ádaa háá hasin. This traditional indigenized concept focuses on self-control, in this case with food, and can have positive contributions for diabetes communication about self-care. The next theme focuses on physical activity and movement for ádaa áhaya.

# RQ2 Theme 3: Healthy Physical Activity for Self-care

Coping with diabetes and managing it through physical activity is a vital aspect of ádaa áhaya. The theme of physical activity emerged from the narrators as they communicated their self-care experiences. Physical movement and being active provide essential protective factors and healthy behaviors for people with diabetes. Activities such as walking, gardening, yard

work, and playing team sports increases the heart rate, decreases blood pressure, and brings forth positive thinking. The following narratives illustrate these activities.

A narrator shared her experiences with being active with the land and animals. The narrator expressed, "During the summers we have the sheep here. So, we all pitch in to do our part in... We do a lot of yard cleaning and planting things like that. We're getting a lot more active." Similarly, another participant spoke about her experiences with her family, primarily, her children. The narrator said,

Always doing something, always outdoors with them. And running after them or whatever. Even on weekends, I'm doing this and doing that. Um! Even outdoors things, summers are really good for me because they have 4-H animals. My sons are in 4-H so, we do a lot of stuff with walking the animals and working with them and being outside and it's the winter months that kind of get me. But we do have a tread mill... Which I hope to start using (laughs) and as far as ah! my emotions and personal life that one gotten a lot better.

This narrator's experiences exemplify the four constructs of the Navajo wellness model through ádaa háá hasin (protect self), ádééhániih (self-identity), ádáhodilzin (self-respect) and ádaa áháyá (self-care) (Nelson, 2018) through collectively identifying with the land and with family through planting traditional foods, herding the sheep, and cleaning the area. These types of activities form a way of life for ádaa áháyá. This relationship with nature honors cultural lifeways for healthy movement. The narrator's stage of change is action and maintenance for self-care.

The next set of stories connect to walking for diabetes self-care. The narrators communicated a desire to be active whether alone or with family support. The first narrator expressed,

Well, I'm taking [care] of myself right now and doing a lot of walking. Still take a hike here and there upon the mesas.... Mostly walking in the evenings, probably about two miles. Until I really...it's mostly downhill and on the way up it's up hill. So, it's walking in the evening.... I usually take my walks for 15 minutes a day or thirty minutes. Then I started doing a little bit of exercise like sit-ups, or push-ups. Well not so much because

I'm not that strong yet. I haven't got my strength back so usually it just walking.

She stated that she also walks with her grandfather,

We always walk like, walk about, it takes about at least 45 minutes a walk. I exercise...I exercise a lot. I take about, at least 45 minutes to walk [with] Grandpa every morning. I weighed like a hundred and seventy. I think I weigh a hundred and forty [from walking each day and healthy eating practices].

The next narrator said,

Right now, I'm walking like 4 miles a day. So, it's helping. I was, I started to get kinda like a little, um, what do you call it? ... Yeah, she's (wife) the one who tells me to go walking. Cause I'm trying to get myself back to where I can run. That's kinda my goal is, what I'm striving for that... Go about 2 miles, that way, half an hour, another 2 miles back, another half an hour.

These narrators described their healthy self-care changes by initiating a more active lifestyle. Coping in this manner through traditional or modern forms of physical activity provides a stronger outcome for diabetes management. These narrators described the collective support of

their new wellness practices including walking, moving, and being active. They communicated similar feelings about having more energy and experiencing more positive thinking. Additionally, they commonly stated that they lost weight and felt better. In these stories, the stages of change they are demonstrating are healing action and maintenance (Prochaska & DiClimente, 1982; Prochaska et al., 1992) to activate ádaa áháyá (Nelson, 2018) each day. Furthermore, the narrators communicated their reasons for and connections to being physically active. They conveyed how helpful it was to be active with others. A participant honored her walks with her grandfather. These walks supported inter-generational strength for diabetes selfcare, which was mutually beneficial for both the young person and the elder. Another participant communicated their perspective of physical activity through being with animals. The concept of ádaa áháyá in Diné teachings supports the healthy active movement between self (human) and Nahasdzaan Nihima (Mother Earth) such as walking on the land, in the mountains, and with animals. Collectively, the narrators brought forth the Navajo wellness model (2018) holistically through àdaa háá hasin (protect self), ádééhániih (self-identity), ádahodilzin (self-respect) and ádaa áháyá (self-care). The next section provides the exemplars for the Diné narrators who communicated about traditional explanations of adaa ahaya.

## RQ2 Theme 4: Traditional Explanations of Self-care

The final RQ2 theme that emerged from the narrators' stories focuses on the concept of *T'áá hwo' ajit'eego'* (meaning self-reliance and responsibility and feeling capable in Diné).

Becoming aware and being self-reliant for self-care (*ádaa áháyá*) support a person living with diabetes. Managing diabetes at clinical, social, physical, emotional, and cultural levels can be overwhelming when attempting to control it. Coping with diabetes at these multiple levels can be stressful and exhausting for an individual who may not have the information, self-efficacy, or

skills to process the self-care steps. However, through comprehensive diabetes self-management, education, and practice, a person can become self-reliant. Self-reliance (individuals' ability to care for themselves at home and in the community) is a vital step for health care teams to support. The value of self-reliance is critical to the daily practices of self-care such as checking blood glucose levels, emotional well-being, monitoring food labels, cooking, eating, physical activity, and taking prescribed medication.

The traditional Diné term for self-reliance is *t'áá hwo' ajit'eego'*. This is a culturally honored term and a value that upholds a holistic mindset to think positively, have self-reliance, by stating, "I am capable," "I have the ability to take action," and "I am ready to be responsible." This cultural term is about empowering the self physically, emotionally, mentally, and spiritually. *T'áá hwo' ajit'eego'* is taught by elders and families to children. It is a concept that encompasses cultural strength and that teaches responsibility and resilience. Elders say the term to convey healthy discipline for instilling healthy lifeways often using the value with the action of running before the sunrise. Ultimately, this term is used as a Diné health concept for promoting wellness by keeping away sickness monster and embracing resilience for protection of self. In a collectivistic culture, this value supports personal leadership for an individual to honor self-care so that one may be well in order to help others in the community. The following stories by narrators exemplify this traditional form of self-care.

The first example of traditional self-care connects this narrator's lived experience with cultural lifeways. The narrator communicated a way of life with connections to the land, to hunting, and to eating locally grown foods. The narrator expressed,

Back then, back in those times, we used to herd sheep. We used to eat good food. Our mothers and fathers use to hunt. Like prairie dogs and rabbits. They would kill for us.

This we used to have. Back then it was hard to come by. Even though we herd sheep we would butcher once in a great while. Our sheep would be more important, it was like that back then...this is what our parents taught us. Later on they would feed us with better meat but then back then, when our dad would bring gray rabbits it was fixed real good like chicken-cooked like chicken and we had corn with it. Corn that are planted at home. We use to boil-roast and dry them. Then we would grind them for mush. This we used to eat with sheep...sheep milk or goat milk. Corn was made into mush like blue corn mush. This is what we used to eat as far as I can remember. As time went by we were introduced to food stamps. And we went wild on that. Different foods were introduced to us. I think this is where it started [DM] this is what I think, that's the way I believe it and I know that's what happened. People used to eat in ways they were back then, but now its ruining them-their ways of eating. They also ate more than their fill...this is what I've noticed. We used to ride horses...in the very early mornings we were told to get up and herd sheep during the coolness of the day and herd the sheep to the water hole. So, when the day turned hot we would herd the sheep towards home. After we herd the sheep home in the heat of the afternoon around 5:00 pm, then we would eat tortillas or frybread with water. This is what I remember.

This narrator shared her narrative about life experiences that honored self-reliance prior to the emergence of diabetes. The term *t'áá hwo' ajit'eego'* relates to the personal daily action of sustainability at home and in the community. The concept of self-reliance was evident in her life through her use of local resources and not being dependent on modern conveniences such as grocery stores. The participant recounted having "good food" and described the varieties of natural foods that were grown, cultivated, and hunted. Her narrative exemplifies how a natural

way of living allowed her and her family to be independent and self-sufficient and to not be reliant on modern amenities for self-care and nourishment or for living in healthy ways. She discussed the paradox of communities having access to food stamps, which propelled the onset of going "wild" with unhealthy foods at the grocery store leading to DM (diabetes mellitus).

The narrator spoke about the major shift from the Diné lifeway concepts of *to' biikinigo* (having just enough, portion control) to having an abundance of modern foods that are "ruining" their health and well-being. The narrator illuminates a landscape of holistic wellness by describing traditional actions. This level of action and maintenance supports her new healthy behaviors with the stages of change model (Prochaska & DiClimente, 1982; Prochaska et al., 1992). She perceives herself being out of control with modern foods in contrast to living a healthy life through the ancestral practices of cultivating the garden for her nourishment. Her narrative illustrates how being active on the land, herding sheep, riding horses, planting foods, and being nourished from this way of life promotes self-reliance, being responsible for *ádaa áháyá* (Nelson, 2018), and feeling capable to live with and from the land. In essence, the value of *t'áá hwo' ajit'eego'* is exemplified in the participant's mindset, actions, behavior, and communication as she states that this way of living prevents diabetes and provides all of the necessary elements that a person needs to thrive and be healthy.

This second example is from a narrator who explained what the term *t'áá hwo'* ajit'eego' (self-reliance, being capable, ready to take action) represents to them for diabetes self-care. The narrator conveys the traditional concept of *t'áá hwo' ajit'eego'* through the teachings of her grandfather and *hataalthiis* (Diné traditional medicine practitioners). The narrator said,

Well, they always told me that we have our own prayers... And that we could always talk to a medicine man when we, have a problem, you know. But more likely for us it's our, our prayers. They said if you say your prayer, you feel much, and that's what I do... Well my grandpa was saying it's got to be you yourself. To do this and that. *T'áá hwo ajit'eego'* you know. If I think diabetes is not good, then it's just going to get me sick.

But if I think that I can do it you know I can lose weight, eat right, and be healthy for my kids. Because my kids they still need a mom. That teaching that my grandpa gave me it does help.

The narrator's explanation illustrates how the lifeway teaching of *t'áá hwo'ajit'eego'* provides diabetes self-care and wellness through positive thinking and prayers. The teaching provides an acceptance of diabetes. This level of acceptance is difficult to attain with any illness, let alone diabetes. Acceptance is part of the stages of change theory (Prochaska & DiClimente, 1982; Prochaska et al., 1992), which prompts action and maintenance for *ádaa áháyá* and the Navajo wellness model (Nelson, 2018). The narrator communicates a powerful value of self-reliance and taking responsibility for her well-being while managing diabetes. Her narrative about *t'áá hwo' ajit'eego'* and application of the value for diabetes exemplifies how it's possible to learn from traditional teachings and integrate them into one's life using cultural lifeways and ceremonial practices. This example demonstrates the ways in which traditional health communication informs wellness and self-reliance for managing chronic illness.

The third example is provided by a narrator who honored the value of *t'áá hwo'* ajit'eego' from her father's teachings for managing illness and her diabetes self-care. The narrator stated,

I think my dad said it best... When he told me he says, he had a heart problem for a long time from uranium he told me he says your body can have a disease even your mind can have a disease and it can kill you eventually. He told me he says if you let it, it will take

you sooner. If you stand up to it, says to fight it but don't put yourself so much into it that you lose yourself. So just do your daily living and make sure you do what the doctors tell you or what the medicine man tells you. If you fight it too much you lose faster, you'll have not gain or accomplish anything.

The narrator's explanation of self-reliance and self-care honors her father's healing journey. She relayed how her father taught her about *t'aa hwo' ajit'eego'* as a way to manage his illness. In this sense, her father conveyed *t'aa hwo' ajit'eego'* as a core belief in one's own ability to restore and partner with self and others (in this case with *hataalthiis* [Diné traditional medicine practitioners] and physicians) for managing chronic illness. This task is difficult to achieve alone. Thus, the participant relayed how her father's experiences and caring communication provided her with a narrative for *ádaa áháyá* (self-care) and, in a way, permission to be in working partnership with traditional and modern health care lifeways. This balanced way of approaching illness and co-existing with it, rather than combatting it, provides a sense of peacemaking with illness when managing it and brings self-care to its optimal level. This narrator's narrative demonstrates the maintenance stage in the stages of change theory (Prochaska & DiClimente, 1982; Prochaska et al., 1992) and reflects a comprehensive holistic balance of the Navajo wellness model with *ádééhániih*, *ádáhodolzin*, *ádaa háá hasin* and *ádaa áháyá* (Nelson, 2018).

Another narrator communicated about the concept of *t'áá hwo' ajit'eego'* as a philosophy for well-being for herself and her grandchild. The narrator stated,

I believe in that theory because I believe that if you can't you know if you're not strong within yourself your body is not strong. If you're not, if you don't think you're capable of accomplishing anything and then you lost the battle. Don't even start but if you're willing

to sacrifice a little bit and you're willing to work extra you know and make something of yourself then you will obtain your goal you know in this lifetime... I am taking it a day at a time I learn to...I'm a little more receptive to the idea that I'm a diabetic. I tell my grandson; he and I are really close for some reason. I tell him baby I says you have a strong chance of becoming a diabetic that's why I says I want you to not eat so much candy, pop, or a lot of things that will turn to sugar in your body. Watch what you eat and exercise. This morning he was exercising, he exercises every morning now. He exercises by running around the trailer.

The narrator shared her reasons for living a healthy lifestyle, accepting diabetes, and taking ádaa áháyá (Navajo wellness model) action through t'áá hwo' ajit'eego' teachings (Nelson, 2018). Her stage of self-care is connected with preparation and action (Prochaska & DiClimente, 1982; Prochaska et al., 1992). She acknowledges that diabetes is now part of her life, and she is willing think it about it more as well understand the importance of preparing herself for healthy lifestyle changes. The narrator exemplifies how this value of t'áá hwo' ajit'eego' forms protective factors for emotional, mental, cultural, and physical well-being. Essentially, the participant demonstrates that this cultural teaching about self-reliance prompts mental resiliency, aiding in the focus for ensuring the body also becomes strong for diabetes self-care. Furthermore, she understands her role as a teacher and protector for her grandson. Her loving guidance for her grandson is revealed in her teachings on helping him be active and staying away from sugar.

The final two examples of the traditional form of diabetes self-care are provided by two narrators who shared their daily practices of self-care: one through a father's traditional teachings and the other through medicinal plants and ceremony. The first narrator said,

Okay, my dad was a beauty way ceremony medicine man but he didn't start his practice until I guess they have to be inducted or whatever until I was about a teenager. But my dad always stressed the very thing that I always believe in. As far as my religion, religious teachings: you get up early, take care of business and live the best you can every day. Accomplish whatever you can every day. If it is not good don't repeat it. And if it is good then do it. My dad used to make us run in the morning that's what I did yeah. Ever since I could remember we got up we ran until by the time I was a junior in high school. I was running three miles out and three miles back before I took my shower got ready for school. Then after school about 5 or 6 o'clock depending on the weather I would run out again. That always help me to do what I needed to do. Then he taught us to use the corn pollen in the morning when you say your prayer. In the religion that I grew up in the certain thing is you get up and say your morning prayer, good night prayer and your family prayer. That's the way I pretty much lived and I think that we have instill that in our kids, too. Then do the best that you can on a daily basis.

#### The second narrator stated,

I go to a lot of peyote meetings and I believe in that too. Cause my dad taught me lots with herbals and peyote's herbal to me. And they are medicine. I believed that too... It helps me keep my life going... And when I go to peyote meeting. I just sit there and pray and say, "Help me" and it seems like it does help. That's the way it's helping me. Yeah. Keeping my mind...keeping my life going and state of mind. Helping my kids with their support...supporting them.

The first narrator shared about her father's traditional forms of *ádaa áhaya* and healthy living. The practices of physical movement through running, use of *t'adadiin* (corn pollen) with

prayer and being with family formulated her well-being. Her father's teachings and guidance provide her with strength and now able to convey those values to her children. The experiences she shared creates a supportive environment for her to stand with in life. These teachings brings forth hope and resiliency during her journey with diabetes self-care. Her narrative relates to positive perception of self through ádééhániih, ádahodilzin, ádáá hááh hasin and ádaa áháyá (Nelson, 2018). These forms of ádaa áháyá can provide a person with stability in the maintenance stage with diabetes self-care (Prochaska & DiClimente, 1982; Prochaska et al., 1992)

The second narrator expressed his form of ádaa áháyá as taking personal initiative by attending peyote meetings, also known as Azee Bee Nahgha (meaning Native American Church, NAC) ceremony. He was able to share his traditional form of self-care by using azee (peyote, a sacred medicinal healing plant) as sacred forms of ádééhániih (self-identity), ádaa háá hasin (protecting self), ádahodilzin (self-respect) and ádaa áháyá through his ceremonial lifeways. The narrator conveyed how the use of azee (peyote) and the ceremonial process supported his emotional, mental, physical, and cultural well-being. He shared a holistic approach through his explanation of how self-care can further be seen in healing forms through traditional medicinal plants that are provided by Nahasdzaan Nihima (Mother Earth). The cultural humility of asking for help from life-giving forces of healing plants, the land, water, and fire conveys a resilient form of traditional self-care that can be used in modern times. His respect for the ceremonies upholds the values of t'áá hwo' ajit'eego' and healthy ways of living as he continues on his life journey. Both of the narrators' forms of cultural and ceremonial practices provides holistic selfcare which can provide people with stability in the maintenance stage with diabetes self-care (Prochaska & DiClimente, 1982; Prochaska et al., 1992).

## Summary of RQ2

This section presented the four themes from the exemplars for Research Question 2 (RQ2), which explored how narrators described self-care when managing and coping with diabetes. The themes were: (1) barriers with managing self-care; (2) positive use of food for self-care; (3) healthy physical activity for self-care; and (4) traditional explanations of self-care. These themes provided explanations for the diverse ranges of how Diné narrators communicated self-care for diabetes management. The narratives offered deep insight into the modern and traditional forms of self-care through support in a culturally-centered manner. This adds to diabetes research for supporting Diné people with their home-based self-care and clinical care. Using bilingual information with Diné terms such as ádééhániih (self-identity), ádaa háá hasin (protecting self), ádahodilzin (self-respect) and ádaa áháyá (self-care) (Nelson, 2018), t'áá hwo ajiit'eego and education in Diné and English will facilitate empowerment for diabetes self-care.

The next section illustrates Diné narrators' explanations of social support as they manage diabetes self-care.

# **Research Question 3**

In this section, I analyze the responses to RQ3: *How do Diné people describe social support for diabetes self-care?* The Diné narrators described social support as key in diabetes self-care. Their responses included discussions about the stressors of not having social support as they struggled to manage diabetes. Narratives also included the full range of positive support within the home, the clinic, and in the community. The themes that emerged were: (1) barriers with social support, (2) positive family support, (3) supportive patient/provider communication, and (4) positive community support. (Please see Table 3.) As with my analyses of the responses

to RQ1 and RQ2, I used the stages of change theory (Prochaska & DiClemente, 1982; Prochaska et al., 1992) and the Navajo wellness model (Nelson, 2018).

 Table 3

 RQ3 Themes for Diné Narrators' Explanations for Social Support with Diabetes Self-care

Theme 1 Barriers with social support	Theme 2 Positive family support	Theme 3 Supportive patient/provider communication	Theme 4 Positive community support
Lack of support with reducing sugar at home	Positive communication from children and family, encouragement to continue self-care practices	Trust	Community diabetes classes
Pressures within the home with exposure to sugar	Mother's motivating, educational, and affirming words; father and sister's kind reminders for self-care	Communicating empowerment	Community programs promoting diabetes education
Reluctance from family to make healthy cooking and eating changes	Diné and English communication for self-care - Caring and understanding words from mother	Cultural and patient centered communication	Worksite support for healthy foods
Avoidance and communicating shame, embarrassment from family to accept diabetes in the family	Educational and caring support from mother who also has diabetes, eat well, take medication, foot care, eye care	Medical knowledge	Community access for physical activity
Access issues, limited transportation to go to the clinic for support	Support from husband to gain strength, cope through passion and interests – uses art and beadwork to feel empowered, do away with hopelessness		

Theme 1 Barriers with social support	Theme 2 Positive family support	Theme 3 Supportive patient/provider communication	Theme 4 Positive community support
+	Support from brother who has diabetes, affirm self-care and take it seriously, husband learning more about how to be supportive and self-care practices		

# RQ3 Theme 1: Barriers with Social Support

This section illustrates the first theme focused on the barriers with social support when attempting to manage diabetes. The Diné narrators provided their responses when they confronted negative experiences with relatives. Their narratives focused on relatives who did not support their diabetes self-care (ádaa áháyá), their regimen of healthy foods, or a positive mindset. These barriers can devastate people who have diabetes and who are working hard to manage it. Lack of social support can create feelings of being abandoned when they need the circle of support from loved ones and friends. The following exemplars illustrate these challenges.

The following responses convey challenges with healthy practices to reduce sugar at home. The Diné narrators' relatives did not support them. This is illustrated by their continual use of sugar-sweetened drinks at home. One narrator said,

He [son]drinks a lot of pop. Sometimes I have to hide soda pop from him- I put it in the trunk. If we put a 12-pack pop in here [fridge] it would be gone in half of the day. Once he drank-he don't drink one pop a day, two pop-he has to have two pops a day. That's

what I'm really cautious about him. That's what they teach- I teach him and get different kinds of juice-That's what I buy when he's here. So, I can't really say as far as eating with him. I just take care of each other...it's kind of hard, him and I.

Similarly, another narrator faced in-home pressures with exposure to sugary drinks and concerns about his brother who may also have diabetes. The narrator stated,

Just my folks. And one of, my other brother, he got pretty big too, in weight. I want to poke his finger, you know. I mentioned to him about it, but he ignores it, you know. "Oh, there's nothing wrong with me, you know." When I'm on my way home, I'm gonna stop by and give it a try. Yeah. But he ignores. He's been drinking soda like crazy. Its gonna hurt him. My sister's telling me about it. He went grocery shopping one day and he bought about what, six or seven cases of soda. He says he was thirsty, and she tells him about it.

Additionally, a narrator expressed the challenges they faced with family members who were in denial of the healthy foods needed for supporting her with diabetes management. The narrator said,

My mom was in denial so when she goes and buys stuff. She'll buy things like donuts and things like that uh! Spam, bologna, hot dogs and like I said on Fridays or Saturday mornings they want fried potatoes and things like that and sometimes I don't cook it.

They get upset with me and they get tired of me bugging them about this and about that and it could probably be a litter better but... They are supportive. But sometimes it can get very difficult because they're just tired of hearing it and um! I would... Those are the times of, I would say about maybe thirty, forty percent of the time there's no support.

These examples illustrate the major barriers that the Diné narrators experienced with a lack of support from their families. Families can serve as strong protective factors in diabetes self-care when they are making the important changes along with the loved one with diabetes. However, these three examples convey a reluctance to support the loved ones with their diabetes regimen of reducing or eliminating sugar and other unhealthy foods from their meals. The family members are at the precontemplation stage (Prochaska & DiClimente, 1982; Prochaska et al., 1992) with little indication of positive behavior change to support the relatives who have diabetes. The absence of support does not align with ádaa áháyá in the Navajo wellness model (Nelson, 2018).

The narrators, on the other hand, are at a stage of contemplation and preparation (Prochaska & DiClimente, 1982; Prochaska et al., 1992) with their healthy behavior changes of decreasing or removing sugary drinks, such as soda, from their diet. They are taking personal steps towards ádaa háá hasin (protecting self) and ádaa áháyá (self-care) with these positive changes (Nelson, 2018). It is challenging to make these often drastic changes with foods that a family normally uses for their nourishment and perhaps even for comfort. It is important not to judge the lack of changes since these food practices may have been present for years or even generations. Change is a slow process and time is needed to make healthy adjustments for positive self-care outcomes. Lack of support from the family can cause an individual to feel isolated and helpless within their own home. Ultimately, this lack of support can cause disruption to the self-care of diabetes management.

The next example is from a narrator who expressed the unease of her family's avoidance of and negative communication about diabetes existing in the family. The narrator said,

They knew it was out there. But I think they thought that they weren't going to get it.

That it's something that happened to someone else and so there wasn't really given much thought to it. Until all of a sudden it seemed like everybody was being diagnosed with diabetes. And just hearing this and that and then it was embarrassment that no one really want to say anything that they have it. And they were ashamed of it, at the same time.

And I think, I even went through that for a while. But uh! Now they are aware of it. I think they need to be going to more classes to hear more about it. Um! It has been proposed in our family that maybe we put on an awareness type meeting to make people aware that because of what it can cause and how it can be controlled and how it can be prevented if the young kids don't have it now. And at times they ways we can be cooking and eating instead of how we were doing all along. But we just haven't been able to get to that meeting because sometimes a lot of people just, come up with excuses. That they can't be there if they know if they know what that meeting is about.

This example illustrates the barrier relatives may have with diabetes—an important issue that needs to be addressed at home and within the family. This conflict conveys issues with accepting diabetes as a chronic illness for an individual as well as the possibility of it becoming an entire family disease. The narrator's desire and request to address diabetes in a unified family manner was not being heard or honored by her relatives. She appealed to her family to begin taking classes to become more informed about diabetes self-care, upholding the pillars of k'e with her concern and educational support. In terms of the stages of change theory (Prochaska & DiClemente, 1982; Prochaska et al., 1992), the readiness of the family is low (with a gradual level of awareness), yet the participant's readiness is higher. The family is at a stage of precontemplation through their avoidance and not honoring  $\acute{a}daa~\acute{a}h\acute{a}y\acute{a}$  (Nelson, 2018) for their

loved one. The narrator is at the stages of preparation and action, ready to discuss diabetes self-care within the home and with the family. The family's resistance to supporting the participant emotionally, mentally, and socially imparts tension which can interfere with diabetes management.

The final examples show challenges the narrators had with support for accessing transportation that was needed for their diabetes self-care. The first narrator stated that she would be able to attend the diabetes classes at the clinic if she had transportation. The narrator said,

No, I don't go there. They meet real early. So, they usually start very early in the morning at 8:00 am. Some certain day I don't go there cause my husband has other things to do. Running down there for class like that. You know, so I'd rather...he'd rather do. I'd rather let him do what he wants instead of me...taking me to other places, just for class...teaching cooking and stuff like that. This is what I'm assuming. If it was over here at the chapter house, I can walk over there, really early too, you know, but it's kinda far over there [clinic] that's why I don't go over there.

The next narrator similarly stated,

I keep my doctor's appointment like for here, like down here at Montezuma Creek clinic. My appointments down there I keep up with. But at Shiprock, it's kind of hard sometimes. No gas, or something like, something happens to the car or something like that. It's kind of hard for me to go out there. It's like that. Like I said before it would be neat to have a SafeRide. If I go on the SafeRide I would keep my appointments up there. It's like that. But over here, I keep my appointments up with my appointments at Montezuma Creek clinic.

The narrators' barriers with accessing diabetes classes and medical appointments effected their self-care management. The first narrator's companion used their vehicle more than she did. Thus, she did not have access to transportation and could not participate in the diabetes management classes at the clinic. The stages of change theory (Prochaska & DiClemente, 1982; Prochaska et al., 1992) that applies to the narrator is contemplation and preparation. She also is providing ádaa áháyá for herself (Nelson, 2018) by being aware of the classes and creating a schedule for her diabetes educational needs. Her reflections revealed her readiness to attend the classes, but given the distance to the clinic, the classes were not accessible without transportation. The time of the classes was also a factor. The narrator needed additional options for late afternoon or early evening classes that would fit in with her companion's work schedule and the availability of the vehicle. Perhaps having the diabetes classes offered at the chapter house (a local community government facility), which was nearby and within walking distance, would have helped. The narrator did not mention other options for transportation to the clinic such as Medicaid transport or Navajo Nation bus services.

Similarly, the second narrator shared the need for SafeRide to be available to her and others to make their medical appointments at the main hospital in Shiprock, New Mexico. However, there were gaps in services and many rural areas did not have access to free transportation services. Transportation access increases the potential for consistent attendance at medical appointments and increases attendance at diabetes classes, promoting healthier outcomes for the participants. Consistent engagement with healthcare supports people with diabetes and lessens the strain on the healthcare system by preventing crisis care for the person who has diabetes.

The next section relays how building positive family support can increase diabetes selfcare (ádaa áháyá).

# RQ3 Theme 2: Positive Family Support

The second theme that emerged from the Diné narrators focuses on positive communication from family members and how this support helped them with diabetes self-care management. The responses included: awareness and self-care promotion from relatives who have diabetes, encouragement from a mother in Diné and English, parents' prayers and teachings, an aunt's faith and a sister's support at home, a husband's support for creative outlets, and motivation from children. Family members provided supportive Diné values of k'e (kinship) and  $t'\acute{a}\acute{a}$  hwo' ajit'eego' (self-reliance, self-determination) to create a system of care for diabetes self-management. The following section provides the narratives for positive family support.

A narrator who received encouragement from her mother who also had diabetes provides the first example of social support. The narrator's mother shared her form of k'e through loving concern and preparing the daughter for her self-care journey. The mother experienced severe complications from living with diabetes and shared nurturing words to protect her daughter (the narrator). The narrator said,

The first thing my mom said was, "Take care of yourself. You don't want to end up like me. If I had taken care of myself I would, I would have still had my legs." And then my sister told me, she goes, "It's scary but I think the thing we need to do is help each other and take care of yourself." They, they stressed a lot about taking care of yourself. So, you know. They probably mean exercise, eat right, take your medicine, go to your doctor daily, check your feet and you know, just being observant about your health. And if

something's not healing right, you know, get it checked. You know, your eyes, get monthly examination, or yearly examination.

This form of ádaa áháyá and k'e communication provides reassurance and hope (Nelson, 2018). During a time when the narrator might have needed these positive actions and words of support, the mother and sister shared their words of support stating, "We need to do this to help other[s] and take care of yourself." This reflects a collectivist approach. Rather than individuating her and stating, "You need to take care of yourself," both the mother and daughter expressed "we" can care for one another. This communicates empowerment and permission to have the daughter take a stand for her well-being.

Sometimes the communication of hope and reassurance may be what an individual is seeking when confronting a chronic illness. This narrator was alerted to the seriousness of diabetes, and she was supported by her family that she would not have to move forward alone. The narrator's awareness increased as a result educational information; the mother and daughter provided through the comprehensive ádaa áháyá approaches. The information shared with the narrator allowed her to feel the Diné values of t'áá hwo' ajit'eego' (self-reliance, self-efficacy), and she became physically active, ate healthier, took her medications, had her eyes checked, and maintained her continual clinical exams. This form of family support with deep insight on self-care demonstrates how support from home can improve diabetes control and management. Positive, educational family support encouraged the participant to actively engage in her self-care, which might have decreased potential levels of diabetes distress. In this case, the narrator is at the preparation and action stages of change. She had been given life affirming information that also restored ádééhániih (self-identity), ádáhodilzin (self-respect), 3) and ádaa háá hasin (protect self) and ádaa áháýá (self-care), on her path of diabetes management (Nelson, 2018).

The next example is from a narrator who shared about her mother's support through encouraging communication bilingually in Diné and English. The narrator said,

She uses a lot of um! Comforting words um! Both Navajo and English. Like she tells me things on how it would... How I should feel about myself. And just what kind of person is someone who has to respect and things like that. She just uses a lot of encouraging words. She never really says, "I told you so" or say, "You should have done it this way or that way." She's real positive about things and she knows because, she has gone through about the same things that I have. I think I'm living the same life she's lived. And so, she understands. And so, she does a lot of encouraging. Not a lot of "I told you so."

The narrator's experience with the supportive *k'e* communication from her mother conveys positive statements reinforcing her self-care steps in managing diabetes. Her mother's experience with diabetes provided strength to the participant with the knowledge that they would go forward together and not alone. The narrator emphasized the bilingual support in *Diné* and English of *ádaa áháyá* communication that provided a new sense of encouragement and optimism (Nelson, 2018). Hearing the language of support in Diné strengthened the narrator's feelings of *ádaa áháyá* to take self-action that may not have happened if the messages were only in English. Having supportive bilingual communication increased the opportunity for the concept of *t'áá hwo' ajit'eego'* to develop within her.

Another narrator shared about the support from her brother who also had diabetes. The narrator said,

My brother, because he understands what I go through you know. Mentally and physically and ah! Just about being a diabetic, how to take care of myself. And not to take myself for granted. He talks to me about these things you know. That I deserve to

live longer and ah! By eating healthy and try to balance my diabetes. As others they really don't understand it. They don't really know how serious this can be. And ah! My husband is aware of it, but I don't think he knows the seriousness of it and ah! I was wishing I had brought him in that time of that nutritionist had talked with me. But I was thinking it's more for me but I guess I should have brought my husband in with me. It was very good that you should... I would recommend you bring your spouse with you.

Supportive communication in Diné and in English are needed to reassure a relative or individual experiencing diabetes distress. A person facing chronic illness may feel like giving up due to the severe lifestyle changes and pressures to manage every aspect of their well-being on a daily basis. This narrator stated that her husband did not understand her illness since he has not

been present with the nutritionist. Supportive communication promotes positive self-care action for diabetes management.

The next examples are from two narrators who similarly experienced supportive communication from their families for managing diabetes. The first narrator stated,

And it took a while. I took you know a few months . . . 6 months. I finally realized that I can do this and you know the way I thought, that it's just . . . it's just that it puts me way down there. Just put me way down but once I got my strength back to where I can think that I can live with this and go on with it. And with the doctors what they said to me and you know, it's not going to stop you from what to do or anything, like that you know.

And then for my parents . . . with their prayers, their teachings and their lecturing and all that stuff that . . . you know they told me you can go on with this. And then just like what my brothers said, you know, [don't? typist note] let this thing stop you. From there it kind of turned me around. And I said, "Well, if he wants me to do that, you know, I can do it."

And my mom's coping with it for several years now and you know if she can do it, I can do it.

The narrator experienced collective support from his physician, parents, and brother. The supportive progression took time, until he internalized it in his outlook. He heard encouragement, empathy, prayers, and loving communication from his support system. His level of self-efficacy ( $t'\dot{a}\dot{a}\ hwo'\ ajit'eego'$ ) increased, knowing that he could emulate his mother's self-care journey since she was able to manage diabetes well for many years. He was able to actualize the diverse forms of k'e as he reflected on the impact of his whole support system. His family's supportive communication and role modeling of healthy behaviors made a major impact upon him. These important aspects of family and clinical support reinforce the stability and balance of *ada ayaha* 

(Nelson, 2018) in an individual's management of diabetes, promoting healthy outcomes for the action and maintenance stages in the stages of change model (Prochaska & DiClemente, 1982; Prochaska et al., 1992). Similarly, another narrator said the support from her children motivated her to manage diabetes. The narrator stated,

Their interests, their caring, their concern. Um, it's kind of like my cheering squad (laughter). It's like "Come on Mom, you can do it!" you know. Just like my son said, "Mom, you need to take it because we want you here." That kind of positive encouragement. And um, just having them be aware of what I'm going through, and um, being positive for me. Saying positive things and just helping me out. Or even when I'm cooking, "Mom, can I help. You know, how do you make this? How can I make whatever?" And I say, "Oh," and I'll show them. And then just being there. Helping and encouraging me.

This narrator shared similar responses to the previous male narrator, speaking highly of family support. The caring communication from their loved ones provided a home filled with support and helped them to feel safe and nurtured. Their stages of change (Prochaska & DiClemente, 1982; Prochaska et al., 1992) centers on the gradual process of making healthy adaptations in their lives as they manage diabetes. They spoke about the balance it takes to shift to a new way of eating, cooking, and positively coping with diabetes. This exemplifies adaa ahaya and When a person is impacted by a chronic illness, the entire family faces the disease together. These narrators revealed how their families addressed the issues of diabetes together, in a loving manner. The family's supportive communication aided the narrators in their self-care journeys that can lead them to positive management of diabetes. Knowing they were not alone with these

major changes, they felt they could sustain their healthy practices to live a long life for each other.

Another narrator spoke about the support from her family. The narrator said, My aunt, she is more like the religious type, she would come and pray for us. Me and my kids. We would sit around in a circle and she'll pray for us. Then my sister, she knew I couldn't do everything. She knew that I was worried about myself and my kids. So, she spent time with us here. Just helping me around the house you know. Because she knew that I lost all my strength because of losing calcium, potassium, and all that. She came around and stayed here with us. She left her job just to be over here helping me. Then my cousin, he is the one that is a guy. He takes me shopping, too. For food and tells me that he has friends that are diabetic.

The narrator's support from her family conveys caring actions and the communication of k'e from her relatives. She shared the important steps her family took to care for her when she was initially diagnosed with diabetes. The empathic communicative actions of support emerged from her aunt's faith to her sister leaving her job to care for her and her children. The narrator's aunt initiated prayer circles for her, providing support through their beliefs and faith values. These actionable steps in the stages of change theory (Prochaska & DiClimente, 1982; Prochaska et al., 1992) allowed the narrator to feel whole as she healed and recovered in her diabetes self-care management journey. The narrator was able to feel encouraged by each relative's support, giving her the energy for renewed  $\acute{a}daa~\acute{a}h\acute{a}y\acute{a}$  (self-care) (Nelson, 2018).

The final example of social support is conveyed by a narrator who spoke about her husband's encouragement as she managed diabetes. The narrator stated,

There's...my husband is always saying you need to get a grip on it. You need to...how does he usually put it. Find something else to do. Do something that makes you happy and that's what I do. I put in music or I put in...I usually watch TV. But I sew a lot and I do a lot of arts and crafts. That's what I usually do and I put my mind at ease. All that I guess hopelessness and all that just kind of dwindles away.

The narrator focused on the healthy emotional, mental, and cultural support provided by her husband's communication of k'e, centering her focus on self-care activities. She expressed how his affirmation for her self-determination and self-efficacy aided her by providing positive thinking about diabetes management. He encouraged the value of t'áá hwo' ajit'eego' for her to choose and decide what helps her to be happy and restorative. The narrator's use of music, tv, and creative tasks, such as sewing and beadwork, helped her establish positive self-communication, reduce stress, and increase resilience. She stated that these activities help her to not feel hopeless.

The traditional Diné approaches to a healthy *iina* (life) are through staying active, fostering emotional/mental strength through positive thinking, making items by hand, and encouraging *t'áá hwo ajit'eego*. These activities are exemplified with affirmative support for personal growth—ranging from connecting with the land through an early dawn offering of white cornmeal, running at the emergence of the day, weaving rugs, building a *hooghaan* (home), being active with animals (i.e., herding livestock and riding horses), cultivating food plants, singing songs, and helping others in the community (i.e., bringing firewood, hauling water, making a meal for a loved one or visitor). Diné teachings state that being active in life (*iina*) and being creative with cultural practices protects the mind, heart, and body from illness or feelings of sadness or despondency. These traditional forms of *ádaa áháyá* movements also

translate into modern day activities for bringing forth peacefulness and lessening stress, such as the participant's practices of sewing, beading, and listening to music. The narrator's supportive self-care steps supported her diabetes management in the stages of action and maintenance through creative activities. Her identity was reinforced with mindful practices that enabled her to have a connection with ádééhániih (self-identity), adáhodilzin (self-respect), ádaa háá hasin (protect self) and ádaa áháyá for her diabetes self-care journey (Nelson, 2018).

The next section focuses on support through patient/provider communication for diabetes self-care.

#### RQ3 Theme 3: Supportive Patient/Provider Communication

The third theme that emerged from the narrators' perspectives of social support focuses on supportive patient/provider communication for diabetes self-care. Diabetes self-management and positive connection with a healthcare provider are vital for ensuring healthy outcomes for individuals with diabetes. In addition to major lifestyle changes, continual education and medical care are needed to support a person who is managing diabetes.

This section contains narrators' diabetes self-care narratives and the empowerment they gained from patient/provider communication. The complexities of managing diabetes can often feel overwhelming. However, clinical communication from healthcare professionals aided in the self-care journeys for these Diné narrators. Self-care information and social support with messages of hope, kindness, compassion, and empathy can support individuals in ways that promote feeling capable and prepared to manage diabetes effectively. This is especially important when individuals may feel hopeless, scared, intimidated, and exhausted by the daily rigors of diabetes self-care. Behavior change is difficult for anyone whether they have diabetes or not. Behavior change can happen gradually when a person feels empowered through health

communication and education. The following narratives illustrate the experiences of the Diné narrators.

The first narrator described how she managed her A1C levels and wellness goals. The narrator stated,

Well, I hopefully I've been doing pretty good so far. With keeping my A1C right around five or six. The last several... The last couple of years and ah! ... Dr. Mose is my physician. My doctor has been really happy with that. I was glad I was able to do that. So, I hope to continue that some progress of staying right around five and six and not go any higher and I hope to get a lot better on the things that I eat and ah! I really would like to get back down to maybe 130 lbs. And that's my goal.

This narrator fully engaged in her diabetes self-care through the support of her physician and through her personal actions at home. Her experiences convey a trusting working partnership with her physician and a core belief in herself (through the concept of *t'áá hwo' ajit'eego'*) to have the ability to manage diabetes. She was able to comprehend the importance of controlling her A1C levels. The narrator's stages of action and maintenance in the stages of change theory (Prochaska & DiClemente, 1982; Prochaska et al., 1992) exemplify her desire to fully participate in diabetes self-care steps. Although the *ádaa áháyá* (self-care) (Nelson, 2018) steps may be challenging and may feel alienating, she was able to address them with the knowledge and security that her physician was collaborating with her and that she was not alone.

The next narrator shared an experience similar to the first narrator's story about diabetes self-care through the support of their physicians and self-reliance. The narrator stated, Well, it's not my, it's not what my family said. But it's me, myself, you know what I thought about it. And what the doctors told me. You know like if you're in control of it,

it's something that you can live, you know. You can still live a long life if you can, if you know how to control your diabetes. So, it's more likely what the doctor said to me instead of my family... Well, they knew that my sugar level was way up high and then they gave me insulin to control it with and they knew that I was doing everything I could to change that around. And so, later on they knew that I didn't need the insulin no more...

This narrator's experiences convey a genuine, trusting connection with their healthcare team for diabetes self-care. Often, families may not know or understand the intricacies of clinical care for chronic illnesses. The narrator's physicians communicated sincerity with messages of hope and quality clinical care for living a long life as a result of appropriate ádaa áháyá (Nelson, 2018) for diabetes management. This strong working partnership between a patient and provider can manifest into healthier outcomes for individuals and, in this case, the narrator adhered to diabetes self-care knowledge for controlling their diabetes.

The next examples are from two narrators who relayed the support they received for diabetes self-care through community education classes. The first narrator said,

Montezuma [clinic] they gave me all that information like they knew that I can get off of insulin. And try to get on pills. But later on, they knew I was doing good with their teaching and even like nutrition. I went to classes several classes for that. They showed me how to cook and all. Then later on... just a couple of months in October I was off of insulin. I didn't need no pills.

Similarly, the next narrator stated,

But I did attend a nutrition class because I knew that it would be helpful. Then they would come over here and you know. Make home visits with me. They just tell me that I'm not so bad with diabetes yet but to prevent it I have to do this. Like um exercise,

drink a lot of water instead of sodas. We talked for a long time. Then they tell me that you still have to think positive don't think that you can't do it. They said that I am still young I can prevent from getting real bad. So, they come around and they visit. Yeah, they show me pictures of a pancreas then in the blood vein that goes out from it. They said if um the insulin is not working right the sugar doesn't actually go into your muscle like its suppose to. It goes through your blood vein and the blood goes all over your body. So, we have to get like your feet check and everything. Physical check. Yeah, they show me pictures of pancreas and then the kidneys. Sometimes they said it can start affecting your kidneys. So, they show me pictures of how the body system works. For me it was my pancreas, so they taught me more about the pancreas.

Both of the narrators expressed their engagement with diabetes classes at local clinics and home visits from healthcare providers for self-care information. They were both informed about the importance of healthy eating and healthy weight in order to control their diabetes blood glucose levels. Effective nutrition education and access to diabetes information in the communities can lead to patient empowerment and *t'áá hwo' ajit'eego'* for *ádaa áháyá* (Nelson, 2018) diabetes management. In these two cases, the narrators felt nurtured by the educational processes and were able to use the clinical knowledge for managing their diabetes.

The final example is from a narrator who shared her experience with a trusting and respectful relationship with a Physician Assistant (PA). The narrator said,

I think it's the same-I think it's up to the individual. That individual is thinking, I want to have a healthy life and feel good about it-therefore the individual listens and follows directions of one's teachings. That's how you, yourself have to change our life to how the teachings will be. You have to take that, what's been taught you from the hospital...it's

for your own good. Just like what the PA tells me. Take your medication. Don't forget to take your medications-take it daily. Because in the long run another 10 years...20 years...you're going to be like that lady across us. That might be how-you'll have a hard time. This is why I can't stress it enough. So, keep up with your medication...no matter what...if you get behind...if you remember in the noon of the day. But, take it...this is what he tells me. The physician assistant is the only one who cares enough to tell me these things... I value it, the experience that I had when the PA was my provider. The PA used to tell me over and over again. The reason why I'm stressing in tell you is because you will not get to the point of having kidney failure and other complications related to DM. Keep taking your medication and keep taking good care of yourself. This is how he used to give me advices... Well I like to have a Navajo doctor. I'd rather speak Navajo to a doctor. The PA is the only Navajo doctor that works there. I had come accustomed to his conversation in Navajo. So that went smoothly- only thing was that he was a man. If it was a woman doctor-a Navajo woman doctor, it would be good...

This narrative illustrates a caring example of a trusting relationship between the narrator and her PA, clinically and culturally. This relationship of patient-centered care through a balance between medical and cultural *ádaa áháyá* communication is vital to diabetes self-management in Diné communities (Nelson, 2018). The narrator's trust in her self-care regimen through the PA's emphasis on taking prescribed diabetes medication helped the narrator live a healthy life with fewer risks for complications such as renal failure. This level of change connects to both stages of action and maintenance (Prochaska & DiClemente, 1982; Prochaska et al., 1992).

Furthermore, the narrator conveys a cultural connection with the PA who spoke with her in the

Diné language. Patient-centered care provides cultural safety and builds trust, enabling better health outcomes. The next section focuses on the final theme, positive community support.

### RQ3 Theme 4: Positive Community Support

The final theme that emerged from the Diné narrators focuses on positive community support concerning diabetes awareness and self-care management. The responses included: community diabetes classes; educational information about diabetes prevention and awareness from a substance abuse class; free access to a gym, track, and swimming pool at the local high school; awareness about diabetes from a roommate; and access to healthy foods at work. The narrators' management of diabetes was positively supported through local resources, educators, employers, and friends. The community resources provided diverse forms of ádaa áháyá and enhanced their self-determination through the value of t'áá hwo' ajit'eego' (self-reliance, self-efficacy). These community support systems can more greatly expand a person's diabetes self-care management process when they may not have access to these resources at home. The following section explores this theme further through the narrators' experiences.

In the first set of examples, narrators describe community support they received through diabetes classes and local educational information. The first narrator said, "Tomorrow I'm going to that clinic diabetic education at *Dzilnaodilhe* [a Navajo Nation community clinic]. They can tell me how to cook my food. You know that's where I am going tomorrow." She was able to communicate her motivation and plan for taking action with self-care through the healthy cooking class. Another narrator mentions support for accessing local diabetes self-case resources. The narrator said,

Like this lady she comes from Shiprock and tells me you can go like an event at the Indian center you can come over. Will teach you more about diabetes and this and that.

And their telling me like it's like you having like beginning of diabetes. They're going to tell me more you know what's really good for you, but you get tired, you get thirsty a lot and there's some other stuff on there... they give you like booklet and all that stuff to read.

The next narrator stated, "Diabetic Class from there... What they call the Work Force Services. Ah! Where I get my food stamps." The narrator communicated a supportive alignment between the food stamp access and diabetes education. He is able to learn more about self-care through two forms of supportive resources for his well-being. The fourth narrator similarly expressed,

Same as for alcohol. Same things they tell you. You go to those substance abuse class. Yeah, they say you can catch it (diabetes) right, fast, like both of your parents have it. That's what they say... Stay down on the soda and the stuff like that. Drink more water, you know.

The four narrators conveyed the support they received from diverse forms of diabetes management in the community. They each articulated that the support came from places that were near to them, and that they felt supported by having access to diabetes information, including healthy cooking preparation, nutrition education, substance abuse classes, and through a streamlined service where they received food stamps. The levels of supportive local education allowed the narrators to feel reassured that diabetes was understood as an important issue in the community. This social support communicates acceptance of the seriousness of diabetes and encourages self-care in a non-judgmental and open manner. These means of community support reduced the feelings of stigma and anxiety created by other people knowing that the narrators had diabetes. The supportive environment promotes ádaa áháyá (Nelson, 2018) for the narrators. The narrators are at the levels of preparation and action in the stages of change theory (Prochaska

& DiClemente, 1982; Prochaska et al., 1992). Ultimately, people can cope with diabetes in a more positive manner and have healthier outcomes when they hear clinical self-management messages in the community.

The next example is from a narrator who spoke about the access to healthy foods at her worksite. The narrator said,

And I usually grab a fruit with that or else a bagel if we have some or toast and maybe a boiled egg and eat it on the way to work. Once I get to work, I'm busy throughout the day and maybe about 2 days out of the week I eat at the school cafeteria. And they have a salad bar, which I usually try to eat the salad. But every now and then I'll eat the regular meals which is not very much.

The narrator communicated about her healthy eating practices and how her worksite supports access at the school cafeteria. The narrator's employer provided her with nutritious foods. This type of support is needed in more communities, especially in rural areas where there are high rates of food insecurity. The school's salad bar supported the narrator with her diabetes self-care.

The final example is provided by a narrator who shared about the community support for physical activity through access at a local high school gym and track field. The narrator stated,

Oh, we do a lot of things. Um, my husband, um, was practicing for a triathlon. Well, before that, we've all been active. We take walks, when we lived up at the old out corn [?] up at the hill we had a whole area where we, all of us would walk in the evenings. And then when we moved down here, we got into biking. So, the two younger ones, they bike with their dad a lot. And sometimes I do, but I don't really like biking. I like to run or jog, which we do often when we go to the track. Well, we've got an advantage because we live right near a high school. And then we've got a football field and a weight room.

So, all of us usually walk the field, the softball, or the track, or else we go to the weight room. So that keeps us busy... Oh, among our other activities, too, we're all into basketball, so all of us play basketball too. League, basketball leagues, 3 on 3, so we're a pretty active family [laughter].

This narrator communicated about her interest and enthusiasm for having access to the high school's physical fitness resources. This community support allowed her and her family to be active together prompting ádaa áháyá (Nelson. 2018). Access to the weight room, track, and gym provided all of them with wellness resources. She was able to manage her diabetes and enjoy healthy, safe, activities along with her family, providing each of them with protective factors against diabetes. The narrator's levels of stages of change (Prochaska & DiClemente, 1982; Prochaska et al., 1992) center on action and maintenance. This type of support for the narrator and her family was critical since it was local and free. Typically, fitness centers cost a great deal and are often not located in rural areas. The next section provides a summary of the themes for Diné narrators' explanations for social support with diabetes self-care.

#### Summary of RQ3

RQ3 focused on social support for diabetes self-care as described by the Diné narrators. The main themes that emerged included: (1) barriers with social support, (2) positive family support, (3) supportive patient/provider communication, and (4) positive community support. The narrators' explanations serve as a guide for health and cultural communication efforts to better understand how family support, positive health, provider support, and supportive community education can influence Diné people for their diabetes self-care. The themes provide inclusive ways in which traditional Diné lifeways and modern community resources create supportive pathways for managing diabetes. Using bilingual support language for Diné

community members in the clinic, in the community, and at home can encourage positive self-care. The use of Diné terms can further diabetes education information with the value of *t'áá hwo' ajit'eego'* (self-reliance) for promoting supportive *ádaa áháyá* practices.

In addition to the important aspects of diabetes management and self-care, the narrators' words also provide core cultural explanations of how their families created a strong support system, especially with relatives who have diabetes. The encouragement and trust of Diné family members who live with diabetes conveyed empowerment for their own self-care. This form of support correlates with k'e and ádaa áháyá (self-care) communication for managing diabetes through the k'e values of ayoo'oni' (love) and aka'ayeed (assistance). Using the strengths of social support, the narrators spoke about how they felt encouraged and motivated by the caring words from their loved ones, by the culturally-centered care from healthcare providers, and by the accessible diabetes education in the community. Positive support and reassuring communication led the narrators to actualize the Navajo wellness model's (Nelson, 2018) restorative concepts of ádééhániih (self-identity), ádáhodilzin (self-respect), ádaa áháyá (selfcare), and ádaa háá hasin (protect self) for diabetes management. The diverse forms of support connected the narrators to the stages of change (Prochaska & DiClemente, 1982; Prochaska et al., 1992) through action and maintenance. Without support, the participants experienced less efficacy and more distress by the overwhelming steps for self-care, often connecting them to the contemplation and preparation stages of change. Additionally, the narrators also conveyed challenges when there was a lack of support, which could negatively impact their diabetes selfcare. Learning to adapt to the changes that need to happen in order for individuals to feel engaged in their self-care are vital to the long-term management of diabetes.

### **Summary**

The collective analysis from the three research questions provided key understandings through the Diné narrators' narratives lived experiences with type 2 diabetes self-care. The 13total themes that emerged from their narratives gave insights to distinctive cultural understandings about how the narrators describe diabetes, self-care and social support as they manage the illness. Crucial insights emerged from the narrators' narratives leading us to better understanding their perceptions of barriers with describing diabetes as well we barriers with selfcare and with lacking social support as a barrier to diabetes management. Learning about these barriers leads to assessing how communication strategies can support these areas that present struggles for Diné people who live with diabetes. The themes about positive communication with self-care and social support pave the way for personal, family, patient/provider and community contrinutions for diabetes management. In particularly, the important narratives from the Diné narrators helps to inform people with diabetes, family members, healthcare professionals and community programs about diabetes self-care and support. It is imperative that these narratives live on so that the realities, barriers, healthy self-care examples and positive supportive communication can serve as an educational source for diabetes self-care. Additionally, the emergence of cultural narratives from the Diné narrators' communication of ádaa áháyá (selfcare), t'áá hwo' ajit'eego' (self-reliance), traditional foods, kinship support from family, spiritual support through ceremonies and community resources lead to enhancing health communication interventions. The analysis using the Navajo wellness model (Nelson, 2018) and the stages of change theory (Prochaska & DiClemente, 1982; Prochaska et al., 1992) provided a bridging of a Diné-centered self-care model with a modern behavior change model for the narrators'

narratives. These models of analysis formed a culturally relevant process to the narrators' lived experiences with diabetes through the use of traditional Diné language and modern model for adapting to changes with diabetes self-care.

The next section focuses on the final chapter of this dissertation. Chapter 5 focuses on the discussion along with the summary and findings from this chapter's analysis. In addition, the discussion of a conceptual framework for diabetes self-care will be highlighted as a core outcome from this study. Lastly, implication for application and limitations will conclude the chapter.

#### **CHAPTER 5: DISCUSSION**

The purpose of this study was to explore the meaning of managing type 2 diabetes through self-care and social support as experienced by Diné narrators. The study included thematic textual analysis of the narratives communicated by Diné narrators through secondary data analysis. This final chapter provides a summary and discussion of the findings, communicated through the development of a Diné centered diabetes self-care communication model. Key findings from the narrators' themes are presented, including: asserting Diné-centered well-being for diabetes self-care; barriers with diabetes self-care; Diné peacemaking with diabetes; and walking, running, and physical activity as empowerment for diabetes self-care. As a result of these key findings, I developed the *Nizhonigo Ádaa áháashyá*: Diabetes self-care model. This model and an explanation of the importance of the narrative shift are also presented in this chapter. Furthermore, the results from the Diné narrators' lived experiences and their perceptions guided the core elements of the diabetes self-care model. This emerging model contributes to Indigenized health communication through a Diné centered process for present day clinical diabetes self-care models. This conceptual framework contributes to the literature, health communication theories, diabetes treatment, management and education. This chapter also offers implications and discusses limitations.

#### **Summary and Discussion of Findings**

Analysis of the findings led to the creation of a conceptual health communication framework for diabetes self-care and support in Diné communities. The three research questions explored in this study were: (1) In what ways do Diné people describe diabetes? (2) How do Diné people describe self-care when managing and coping with diabetes? (3) How do Diné people describe social support for diabetes self-care? Through data analysis, I found common threads interwoven

in the narratives from each of the three research questions. The threads, or core concepts, that emerged from the themes were: (1) barriers; (2) positive self-care identity; (3) relational support for self-care; and (4) walking the path of self-care. The creation of these core concepts emanated from the themes of the Diné narrators as they shared their self-care and support narratives. It is important to note that these concepts portray the realities of living with diabetes from the struggles with lack of support from family to barriers with diabetes distress to positive self-care activities to caring and supportive environments at home and in the clinic. These concepts (presented in Table 4) are infused into the Diné diabetes self-care model that is discussed later in this chapter.

**Table 4**Core Concepts from the Diné Narrators' Themes that Emerged from the Research Questions

Concept 1 Barriers	Concept 2 Positive self-care identity	Concept 3 Relational support for self-care	Concept 4 Walking the path of self-care
Difficulty with explaining diabetes	Positive use of food for self-care management of diabetes	Positive diabetes self-care communication at home with family	Nizhonigo Ádaa áháaashyá: Healthy self-care model
Struggles with lifestyle changes	Physical activity through cultural practices and modern-day practices	<i>K'e</i> (kinship) teaching strength from relatives who have diabetes	
Diabetes distress, fatigue and anxiety with acceptance of diabetes	T'aa hwo'ajit'eego': Diné traditional communication of self-care	Loving emotional, mental, cultural, spiritual support from family	
Family communicating embarrassment and shame towards relative having diabetes	Ability to accept diabetes and share educational information with others	Kind person-centered healthcare provider communication	
Tensions from lack of support at home	Self-determination through resiliency practices	Community awareness for diabetes management	

# **Key Findings**

Through the analysis of the narratives and the three research questions, I developed 13 themes that led me to these core concepts. The key findings emerged from the themes that guided me to the core concepts, including: asserting Diné-centered well-being for diabetes self-

care; barriers with diabetes self-care, Diné peacemaking with diabetes; and walking, running, and physical activity as empowerment for diabetes self-care.

#### Asserting Diné-Centered Well-Being for Diabetes Self-Care

The narrative responses for each research question provided insights for learning how Diné narrators communicate self-care management of diabetes and how they cope with this chronic illness in their communities. The Diné narrators' narratives illuminate the need to promote patient- and cultural-centered approaches for diabetes self-care and social support. The introspective manner in which the Diné narrators shared their feelings and thoughts contribute to the reclaiming and re-constructing of health for Diné communities who are living through a disease of colonization (Bartlett et al., 2007; Joe & Young, 1993; Pilon et al., 2011; Pilon et al., 2019; Warne & Lajimodiere, 2015). In a majority of their responses, the Diné narrators revealed their perceptions of diabetes and the strategies they used for self-care, including the need for cultural, clinical, family, and community support to manage diabetes.

The use of the Navajo wellness model (Nelson, 2018) and the stages of change framework (Prochaska & DiClemente, 1982; Prochaska et al., 1992) promotes inclusive health communication practices with Diné language of self-efficacy (*t'aa hwo' ajit'eego'*) when addressing changes with eating, medication adherence, and other important aspects of a diabetes self-care regimen. Nelson (2018) and the Navajo Area Indian Health Service system use the Navajo wellness model in the curriculum *Sha'bek'ehgo As'ah Oodaal: A journey with wellness and healthy lifestyle guided by the journey of the sun* as a way to provide culturally-centered public health education and health literacy on the Navajo Nation.

The two models (Navajo wellness model and stages of change theory) are congruent with culturally centered health approaches (Dutta, 2007), which forge an alliance for diabetes self-

care in Diné communities. Modern medicine alone cannot fully address the complex and dynamic contexts of diabetes. Denzin et al. (2008) assert that decolonizing approaches in Indigenous communities prompt "cultural revitalization." Within the context of forming Diné centered approaches, I look to the empowering concepts in *Navajo Sovereignty* (Lee, 2017) through Diné scholar Larry Emerson (2017) who states, "Diné scholars and activists are actively reclaiming, restoring, reframing Diné identity, culture, language, history, and self-governance with many writers incorporating theories regarding decolonization, healing, transformation and mobilization" (p. 160). In this case, an Indigenized process is formed by applying a reframing of modern diabetes management through a culturally revitalizing self-care framework focused on the Diné lifeway wellness philosophy of *hozhó* (Austin, 2009; Benally, 1994; Kahn-John, 2010). Kahn-John (2010) states that "*Hózhó* philosophy emphasizes that humans have the ability to be self-empowered through responsible thought, speech, and behavior" (p. 24). These cultural actions for reclaiming health in an Indigenized manner provide hope and empowerment for culturally defined health practices for more positive outcomes.

### Barriers with Diabetes Self-Care

The barriers experienced by the Diné narrators evoked responses of apprehension when first being diagnosed with diabetes to the severe complications of uncontrolled diabetes.

Managing chronic illness such as diabetes can cause a range of feelings, which include being overwhelmed, angry, anxious, depressed, shock, hurt, burned out, worried, and experiencing emotional pain (Corbin & Strauss, 1988; Kretchy et al., 2020; van Smoorenburg et al., 2019). Several of their responses correlated to diabetes distress, which signifies feelings of having stress, guilt, or denial from having diabetes (Kreider, 2017). Additionally, this state of emotions can cause an individual to feel burnout from living with diabetes, and, often, they are not able to

follow through on the extensive self-care regimen from personal medical care to ways to manage the illness at home. The various forms of diabetes distress include: (1) regimen related distress, (2) emotional distress, (3) interpersonal distress, and (4) physician/provider-related distress (Lovelace Hospital, 2020).

The reality communicated by the Diné narrators' emotional and physical suffering relates to diabetes fatigue syndrome (DFS) as described by Kalra and Sahay (2018). These scholars state that this is a common symptom of living with diabetes, and it can occur during any stage of the illness. Oftentimes, the assumption may be that the fatigue from managing diabetes only occurs when it is uncontrolled. However, DFS can arise through the duration when existing with diabetes and the persistent self-care regimen. When DFS is not given the appropriate attention, it can cause harmful effects on the management of diabetes. Supportive outreach to an individual who may be experiencing DFS is needed in the collective clinical, home, and community environments. This source of support enhances the individual's adjustments for healthy changes with their lifestyle, diet, emotional and mental well-being, sleep patterns, safe glycemic control, and other medical issues such as problems with endocrine and metabolic function (Kalra & Sahay, 2018). These real emotions and feelings were expressed by the Diné individuals. Yet, diabetes distress and diabetes fatigue syndrome are represented in less prominent ways in infographics or health education materials for diabetes self-care. The Center for Disease Control and Prevention conveys a short description of diabetes distress in a section of their website entitled Diabetes & Mental Health. As a result, diabetes distress and fatigue are core themes in the Diné centered diabetes self-care model and are part of important health communication standards to discuss for physicians, nurses, diabetes health coaches, community health representatives (CHRs), and public health educators. More importantly, addressing diabetes

distress with a patient will provide support for taking initial steps to understanding the range of feelings they may experience when beginning (or during) their self-care regimen.

Adjusting to new behaviors with diabetes self-care can often feel impossible, as the Diné narrators revealed when they expressed their sincere struggles and barriers. Their narratives conveyed their perceptions of being told by a healthcare provider that they had to make major lifestyle changes impacting their respective sense of normalcy. These feelings can often become exasperated when feelings of shock and fear proliferate their thinking and their way of life. The narrators expressed how frustrated and hurt they felt with the onset of diabetes symptoms, when given prescribed medications, and with new food changes. They also expressed how it felt to share that they had diabetes with their family and the negative communication that resulted from loved ones telling them they were ashamed and embarrassed by their diagnosis. The communication of these barriers is important to note; these feelings are often experienced by other individuals who have diabetes. A key lesson to be learned from this is to assess how lifestyle changes are communicated to the patient such as creating a visual map of the safe places to walk, fitness center location, access to local gardens and farmer's markets and other key support systems. The Diné narrators shared important teachings for healthcare providers: convey diabetes information in Diné and English, listen to their needs, educate their loved ones with them about diabetes self-care, provide consistent support in person, promote participating in healthy cooking classes and share community resources. Furthermore, the explanatory narratives by the Diné narrators provided significant insights that will support other Diné community members who may find common ground with their stories about barriers when attempting to manage diabetes.

#### Diné Peacemaking with Diabetes

Communication can create a path of healing words that promote positive thinking even through the most complex aspects of their illness. Perhaps the conflicted feelings of the Diné narrators have to do with the explanations of diabetes, barriers with self-care, and distress, which provide an opening for conflict management communication that is centered in Diné peacemaking processes. Austin (2009) asserts that peacemaking language of hozhó (harmony, balance, peace), k'e (kinship unity), and k'ei (clan kinship) restores a Diné person to a healing and harmonious relationship with relatives and community. In this case, the peacemaking language can serve as a restorative language when incorporated into diabetes self-care practices for Diné people (Austin, 2009, p. 44). The Diné peacemaking language would support their conflict with food changes, reducing or eliminating sugar, daily life practices of self-care, and increasing the positive self-talk for becoming self-reliant through the concept of taa hwo ajit'eego. The Diné narrators spoke of the caring support from family members for their management of diabetes, especially from relatives who have diabetes. This form of k'e and k'ei kinship supports healthier outcomes by applying the concept of ádaa áháyá, as the Diné narrators expressed. This model creates a framework for protective factors that will serve as a restoring form of alliance with diabetes. Thus, providing Diné bilingual communication for selfcare and support creates a language path for healthy decisions and a sense of peace or hozhó through words for mental and emotional well-being.

# Walking, Running and Physical Activity as Empowerment for Diabetes Self-Care

Several Diné narrators stated they used walking as an empowering form of self-care and managing their blood pressure and glucose levels. They expressed interest, even enthusiasm, in walking one to two miles and often set further goals to walk three to four miles. Their purpose was not only to manage their diabetes, but it was frequently articulated that walking and running

aligned with the Diné expressions and cultural teachings about well-being, protection of health and happiness.

Hoskie (2010) states, "Our grandparents teach about the opportunities found in the Dawn. The Earth is soft then. It is ready to bless you with good health and leadership. This is a good time to be a leader for yourself" (p. 15). The Diné narrators shared their perspectives of this cultural teaching by walking or running at various times of the day according to their daily schedules balancing work, family, and physical activities. They spoke about walking with their grandfathers, companions, and children. This relational form of walking with family conveys they are able to create and practice healthy behaviors in their local communities. Healthcare providers who may not be familiar with the community can learn about the local resources from their patients and communicate about safe trails and fitness centers that are free versus modern forms of fitness in a commercial gym (which often means paying for a costly membership). The Diné narrators are community experts who know what areas are safe and unsafe. If they are unfamiliar with the safe areas, a local map can be made that is included with the diabetes selfcare model. (Please see Figure 2.) As I analyzed the narratives, I was surprised that the Diné narrators did not mention encountering wild dogs as they walked in the communities. Wild dogs have become a major public health issue on the Navajo Nation for local residents who find it hard to walk safely on local roads. In support of safe areas for fitness, local resources of innovation and best practices have been created by the Navajo Special Diabetes Project (SDPI), Indian Health Service, and 638 health clinics on the Navajo Nation. They have built new wellness centers that are now accessible in Window Rock, Tsehootsoi Medical Center in Ft. Defiance, Northern Navajo Medical Center in Shiprock, Winslow Indian Medical Center, and many other Diné communities. Depending on access to transportation, these wellness centers

serve as supportive resources for fitness, health promotion, and efforts for prevention and management of diabetes. In addition to the positive healing community resources from the diabetes health coaches at Chinle I.H.S. and Navajo SDPI programs have made a pivotal impact in Diné communities. More recently, the Navajo Nation has created a powerful law and funding stream to promote wellness projects in Diné chapter house communities through enacting the Healthy Diné Act which includes a 2% junk food tax (Yazzie et al., 2020). This powerful law is unique and setting a precedence for other sovereign Indigenous communities to replicate this innovation for health and well-being.

The term *naasha* or *iishal* is the Diné term for "I walk." *Nizhonigo* refers to the Diné meaning for "beautiful, healthy and feeling well," or "I am taking care of myself in a healthy way." In essence, beauty is viewed as a term for feeling healthy rather than a Westernized definition of beauty, which often connotates challenging perspectives of external, surface level beauty that often do not imply holism or well-being. When a Diné individual states *nizhonigo naashado*, they are saying "I walk in a healthy manner" or "I walk; I move with harmony and well-being, moving with health and well-being."

Chee (2010) states that part of a traditional form of Diné communication for living a healthy life is through the use of pollen (*t'ádadíín*) and sacred elements such as the earth, bluebird, sky, air, sunrise, sunset, and corn as daily expressions of self-care with the verbal phrases of walking with health, *hozhó nashaado*. Another expression is *hozhoogo naasgo iishal*, I walk in health, I move forward with healthy footsteps. As well as the phrase for forward motivation and encouragement, *naas deeniika' nahasdzaan bikaají ndeke'*, we go forward traveling upon Mother Earth. In *Diné Perspectives: Revitalizing and Reclaiming Navajo Thought*, Werito (2014), describes terms from Diné teachings from his parents. He was told,

"Nánitl'ah dóó biyáhoyee'nidii hózhóógo naasha dooleel diiní means 'although it is hard and difficult to aspire to it we want to live our lives in beauty/harmony" (p. 25).

In essence, these Diné phrases for well-being and self-care provide a path for walking and co-existing with sacred pollen words and pollen thoughts (Chee, 2010). Diné communication is not only from human to human; it is also about the communication of the earth, water, plants, and environment with all living beings, including human interaction. In an interview by Madeson (2016), Diné community knowledge keeper, food grower, and grandfather Duane "Chili" Yazzie was asked about his thoughts about the human relationship with the earth. He stated,

That's the truth. In the creation story, we were formed of mounds of earth into which the Creator blew spirit. That is our composition. That is what we are. That's the reality. We are literally of the earth. The Earth is our mother, the Spirit is our father. This is the foundation of who we are. Why we are, what we are. (Madeson, 2016, paragraph 11).

Ultimately, the communication of walking or running creates healthy action and interconnectedness with the earth and sky. Being pro-active with one's emotional, mental, cultural, and spiritual well-being embraces the term the Diné narrators spoke of referring to *t'áá hwo' ajit'eego'*. This Diné expression centers on multiple, yet synonymous, meanings, including: I am capable; I have the ability; I have self-efficacy; I am self-reliant. Benally (1994) conveyed *t'áá hwo' ajit'eego'* (if things are to be, it's up to you to complete them): "a concept of wisdom that is foundational to a good, healthy and prosperous life" (p. 27). Brown (2013) wrote about the teachings of Diné scholar, Kenneth Begishe, who spoke of a similar Diné cultural expression, *Diné t'áá bi at'éego* (a well-directed person). The narrators' narratives provided the prominence of exemplifying their actions in the Diné diabetes self-care model for living a strong life through Diné teachings and healthy activity, thus managing diabetes (Please see Table 5 and Figure 2).

The narratives about walking and fitness helped me to unite the Diné narrators' diverse perspectives with the modern diabetes self-care standards for the model. Furthermore, the motivations for walking a healthy path are evident within the Diné narrators' descriptions about what works best for diabetes self-care, including: physical activity, healthy eating through traditional foods, kinship and community support, and healthy communication.

In a Diné publication, Leading the Way, Hoskie (2010) says,

[T]raditional fitness (for males) [included activities such] as riding horses and competitive challenges for enjoyment and training through creating a bow and arrow, throwing a hoop and spear, using a sling shot (*bee aditl'ihi*), throwing a curved stick for hunting rabbits and making a club like the one Monster Slyer (*Naghe Nezghaani*, Diné twin warrior) used (*tsenil*), a rock with a groover for attaching to a stick. The club would be spun around and thrown. [T]raditional fitness for women included contest challenges through grinding corn and cooking using traditional tools for food preparation such as a stirring stick (*ee'dist'iin*) (p. 11).

Personally, my family shared stories with me about *shi masaani* (maternal grandmother) who participated in fitness challenges such as horse races and running. I recall my great-grandmother also challenging us as children to run far in the early dawn and walk as fast as she did during the day, which would often be a fast paced walk well over two to three miles to visit a relative or to care for the sheep. These types of challenges, or contests, provided teachings on being fit, healthy, and resilient. These narratives are unique to Diné and Indigenous communities that add to the modern meanings of fitness and social support with community health resources. A bridging is occurring through an alternating shift between traditional concepts of self-care and

Westernized diabetes regimen. The realization for me was that Indigenized theories and models for well-being align with what the Diné narrators shared.

# Nizhonigo Ádaa áhaashya: Diabetes Self-Care Model

The findings that emerged from the Diné narrators centered on themes and core concepts that created the bridging of cultural explanations for diabetes self-care and clinical approaches that shaped the conceptual framework (please see Table 5 and Figure 2). The findings focused on local knowledge of diabetes self-care and social support from the range of their perspectives and their lived experiences. The narratives illuminated the barriers to self-care and support as well as the positive self-care practices. The narrators' communicated important self-care and support factors that aid them with managing diabetes within their home, with family, cultural, community, and medical knowledge. Their narratives created the conceptual framework using the Navajo wellness model (Nelson, 2018) with clinical diabetes regimen and the ultimate creation of an Indigenized relational process for communicating self-care and support. This approach is a "constructivist-development worldview" (Kumugai et al., 2009) by honoring the lived experiences of the Diné narrators and how they "make meaning" through "interaction and communication" (p. 324).

The *Nizhonigo ádaa áhaashya: Diabetes self-care model* is developed from this approach and from the key findings of this study. The model incorporates Indigenous health frameworks and modern diabetes self-care models. The model is a fusion of several cultural health approaches and clinical standards including: (1) the Navajo wellness model (Nelson, 2018) through the Indian Health Service (Navajo Nation Service Unit), (2) the Decision Cycle for Person-Centered Glycemic Management (Powers et al., American Diabetes Association, 2020), and (3) the diabetes self-management education model (American Diabetes Association, 2020).

Timpel et al., (2020) state that "most care models are disease or symptom focused not accounting for individual needs;" thus, self-care models need to be redefined for Diné people in a culturally centered manner. As a result, this diabetes self-care model uses a Diné centered framework for inclusive and collectivistic targets to support Diné communities who are managing diabetes. This diabetes self-care model values the experiences of the Diné narrators by illustrating visual symbols that are described in their stories and in Diné epistemology. Each of the narratives presented a course of action the narrators took through the cultural teachings and the modern self-care management steps for diabetes. The following section and Table 5 provide explanations for the concepts that serve as a diabetes self-care communication praxis. The table shows the four sacred colors of white, blue, yellow, and black in each of cardinal directions beginning with the east, then the south, west, and north. The Diné narrators spoke about their family teachings of honoring the east with morning prayers; running aligns with the Diné philosophy of education (DPE) and the Diné philosophy of learning (DPL) known as Sa'ah Naaghái Bik'eh Hozhoon (Aronilth, 1992; Austin, 2009; Benally, 1994; Clark, 2009; Werito, 2014). The narratives for diabetes self-care are respectful of the Diné lifeways and cycles of life (Aronilth, 1992; Maryboy & Begay, 2010). Clark (2009) describes the representation of four main sacred mountains and connections with traditional stones—described as sacred gems by Kahn-John (2010). Beginning in the east with the sunrise with ha'aa'a (east) with hayoolkaal (dawn) with yoolgai (white shell), with Sisnajini (the east sacred mountain). Second, in the cardinal direction of how the sun travels to shadi'ah (south) with the dootl'iizh (blue, also known as the turquoise) for nohoodotl'iizh (the sky) with Tsoodzil (the south sacred mountain). Third, the next cardinal direction is e'ee'ah (west) represented by yellow for the diichili (abalone shell) representing nihootsoi (the sunset) for Do'koosliid (the west sacred mountain). Fourth, the cardinal direction

to *nahookos* (north) is symbolized by *baashzhini* (obsidian) for *cha'haaleel* (the evening darkness), *Dibe Nts'aa* (north sacred mountain) (Aronilth, 1992; Lee, 2014).

The Diné diabetes self-care model (Figure 2) is illustrated with symbols that were conveyed by the Diné narrators in a manner that is culturally relevant through the use of the sun (*johonaei*) and the sunrise (*hayoolkaal*) as they spoke about rising early in the morning to make an offering with a blessing and running to the east. The next symbol is the image of water representing the Diné narrators healthy practices about drinking water while reducing or eliminating sugary drinks. The third symbol in the west is symbolized by *nadaa* (corn plant) centering on the value of corn in Diné lifeway teachings for nourishment for the earth, sky, and for human beings. And, finally, the fourth symbol focuses on a trail to the north representing the narratives for walking and running as shared in the experiences of the Diné narrators. (Please see Table 5.)

 Table 5

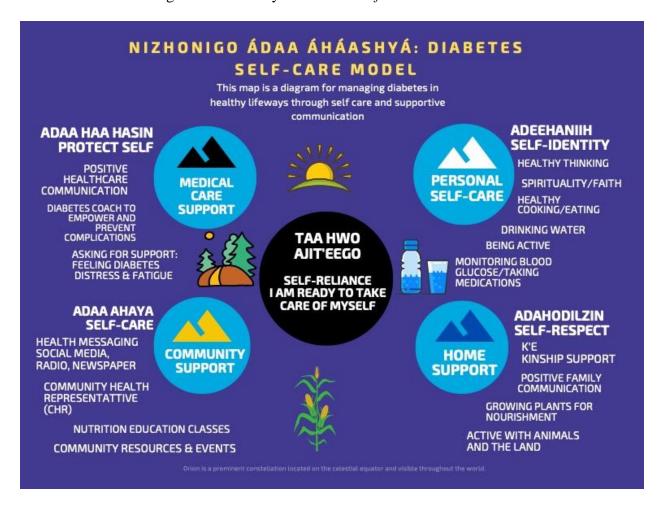
 Description of the Concepts for the Nizhonigo ádaa áhaashya: Diabetes Self-care Model

Talai (1) East Beginning with self. Personal self-care: Ádééhániih (Self-identity)	Naaki (2) South Second for home and family. Home support: Ádáhodilzin (Self-respect)	<u>T'aa (3) West</u> Third for community support. <u>Ádaa Áháyá</u> (Self-care)	<u>Díí (4) North</u> Fourth for medical care support. Ádaa Háá Hasin (Protect self)
Healthy thinking	K'e (kinship) support	Educational health messaging: radio, newspaper, social media	Positive healthcare communication
Cultural ceremonial practices and Faith	Positive family communication	Community health representative (CHR) support, mentorship, and empowerment. Teaching to prevent complications and to promote healthy outcomes through home visits	Diabetes health coach to empower and prevent complications. Provided at the clinic and through supportive e-health communication via mobile health messaging, phone calls, and video calls (if available)
Healthy cooking and eating	Planting and cultivating a garden or accessing local community garden/farmers' market	Nutrition education, cooking classes and grocery store assistance	Asking for support when experiencing diabetes distress and fatigue
Drinking water	Active movement with the land, home, and animals	Community resources and events	
Being active, daily physical movement			
Monitoring blood glucose and taking medications			

I have represented the elements of this model visually in Figure 2.

Figure 3

Visual Model: Nizhonigo Ádaa Áháashyá: Diabetes Self-Care Model



The model is a symbolic representation of the narratives conveyed by the Diné narrators. This visual praxis of Diné narratives and modern clinical diabetes self-care provide a health communication tool for Diné people who are diagnosed with diabetes as well as for family members and community and healthcare providers. This Indigenized diabetes self-care model can be used in a bilingual manner, relaying key concepts that promote self-care, positive communication, family and community support, and awareness about diabetes distress and

diabetes fatigue (which often do not appear in many of the diabetes self-care/self-management models).

In the model, supporting Diné community members by addressing barriers promotes empowerment by helping them see their illness and by providing coping strategies through the Diné language of action, hope, and resilience. The Diné narrators spoke often about *t'áá hwo' ajit'eego'*, nizhonigo nashaado, hozhó naasgo iishaal all represent holistic forms of self-care communication. It is vital to provide these terms in the model for them to be promoted at home with family, in the community, and in clinical settings. This is especially important when individuals may feel defeated, scared, or fearful when being diagnosed with diabetes. Several individuals stated that they felt hopeless or became tired of the constant self-care routine.

This model aligns with a patient-centered communication approach by Rutten et al. (2010) who present six functions:

a) Fostering healthy relationships through the development of trust, mutual understanding, empathy; b) exchanging information with the vital sensitivity to the patients' information needs, issues of literacy, numeracy and culture; c) responding to emotions by acknowledging and offering patient support for patients' emotional reactions during illness, treatment and recovery; d) managing uncertainty by assisting patients with their disease, treatment efficacy, and prognosis; e) making decisions involving patients through an open exchange of information; and f) enabling patient self-management by helping them navigate the healthcare system, by identifying community resources, and by encouraging patient autonomy, self-efficacy, and self-care outside of their clinical encounter. (p. 1440)

Furthermore, the model promotes therapeutic communication for improved patient support as stated by Kourakos et al. (2017) which includes "active listening, silence, focusing, using open ended questions, clarification, exploring, paraphrasing, reflecting, restating, providing leads, summarizing, acknowledgement, and the offering of self" (p. 10).

An important aspect to this model is related to a study conducted by Trevisi et al. (2019) and the Community Outreach and Patient Empowerment (COPE) program which focused on several strategies for supporting Diné-relevant diabetes communication using evidence-based behavior change approaches such as motivational interviewing (MI), SMART goals (i.e., specific, measurable, attainable, relevant, time bound), flipcharts with the 5A process (ask, assess, advise, assist, arrange follow-up) with culturally relevant information for diabetes self-care. As a result, the focus of the *Nizhonigo ádaa áháashyá*: Diabetes self-care model places emphasis on the community care and medical care support areas with the positive communication of diabetes self-care through community health representatives (CHRs). CHRs are community health providers from local communities and who care for Indigenous peoples through home health and social service visits. They also empower people through community engagement.

Furthermore, this model can contribute to the local Diné diabetes health coaches (used for support at Chinle Indian Health Service hospital on the Navajo Nation) and their curriculum, which uses evidence-based clinical diabetes standards of care, as they support Diné people with diabetes self-care. The model can also be used for patient care for healthcare providers who support diabetes prevention, treatment, and management in hospitals that serve Diné at other healthcare facilities near the Navajo Nation and in urban communities that serve Diné patients. The model can be adapted for use with Indigenous communities by modifying the Diné cultural

terms with the Indigenous language and cultural symbols that are appropriate for their lifeways. Ultimately, the diabetes self-care model can be used as a learning and teaching model for the families and loved ones of the Diné people who may be diagnosed with diabetes. Family members serve as a powerful support system, as do mentors, if they also have diabetes, by providing personal stories of how they manage diabetes.

#### **Narrative Shift**

The *Nizhonigo ádaa áhaashya*: Diabetes self-care model shows the intersectionality of health and cultural communication, Diné self- determination, and Indigenized health models with modern Western standards for managing diabetes. This weaving of traditional Diné self-care concepts with the modern clinical diabetes management regimen integrates an Indigenized process that honors health and well-being in a cultural and clinical centered approach. The model supports a new way of understanding diabetes self-care in Diné communities for health communication, clinical care, and family and community support.

In this study, the Diné narrators used their cultural paradigm, philosophies, and family narratives as a way to bring forth self-care in their lives, which is grounded through Diné worldview for communication. Exploring this even further, a narrative shift emerged as the narrators shifted power by locating expertise in the Diné narrators rather than in institutional and academic rhetoric. This narrative shift provides a new way of seeing diabetes self-care within the self, home practices, and clinical standards and which is grounded in ancestral lifeways with the use of the Diné language and philosophies when managing this chronic illness. The narrative shifting of power to Diné people gives voice to their knowledge which is critical to understanding their diabetes management self-care and support needs, skills and key lessons. These key lessons from the Diné narrators privilege health information that is not often given

space in dominant Western perspectives as the experts with diabetes management. According to deMaria and Rael (2018), "Narrative shift is an intentional process of shifting power that offers insight into equity-based storytelling as a means of achieving systemic change" (p. 393). This transference of power through a narrative shift with the Diné individuals supports their sovereign perspective of health by reclaiming wellness narratives through Diné-centered, equity-based storytelling (Denetdale, 2007, 2014; Emerson, 2017; Lee; 2014, 2017).

I understand more about coping with illness and finding what ádaa áháyá means through the Diné narrators' narratives as they gave voice to diabetes self-care. Their narratives created cultural congruence with Indigenous paradigms that instill commonly honored philosophies for health and well-being. Brill de Ramirez (2007) states that Indigenous people share storytelling as largely centered in the storyteller's interwoven personal, familial, and tribal worlds. Tachine (2015) provides key pillars in her dissertation on core values she created known as Cultural Threads, which include: (1) restoring your mind, (2) acknowledging the strengths within, (3) moving forward for others and self, and (4) centering your purpose. Tachine (2015) created Cultural Threads through the cultural resilience framework by Heavyrunner and Marshall (2003) who used cultural resilience theory for preventing alcohol abuse in families. They applied eight protective factors for a family education model: (1) spirituality, (2) family, (3) strength, (4) elders, (5) ceremonial rituals, (6) oral traditions, (7) tribal identity and (8) support networks (HeavyRunner & Marshall, 2003). These same values can be applied to the Diné diabetes self-care model for personal, family, and community support.

#### **Implications**

The significance of understanding the Diné narrators' narratives promote future diabetes self-care and social support recommendations in Diné and Indigenous communities. This study serves as a call to action to radically indigenize (Grouette, 2018) diseases of colonization in Indigenous communities. This study and the wisdom from the Diné narrators help us with a new way of seeing diabetes self-care within the self, in home practices, and in clinical standards. Indigenizing diabetes self-care and support provides a holistic process that is grounded in Diné language and philosophies when managing this chronic illness. It is imperative to use the wisdom from the Diné narrators' narratives through the use of the new model in teaching, training, and community health communication in tribal colleges (such as Dine College, Navajo Technical University), e-health, radio (KTNN - Window Rock), newspapers (*Navajo Times*), and social media. The conceptual framework of the Indigenized diabetes self-care model can be readily used in clinical practices, for community awareness, and as part of family support through culturally-centered health communication. Furthermore, this study teaches us to uphold and empower community health resiliency, person-first language, person-centered public health promotion, disease prevention, and the treatment and management of diabetes in Diné communities.

The findings from this study provide an understanding of important contributions for addressing diabetes self-care for Diné persons, families, and communities. As a result of these findings, and in accordance with *Healthy People 2030* (Office of Disease Prevention and Health Promotion, n.d.), health communication and health information technology messages need to be broadened for the prevention, treatment, and management of chronic illnesses such as diabetes. The Diné narrators' narratives addressed how to support this need with a focus on culturally centered and holistic approaches. Digital communication and the internet are now part of Diné

communities and households. Therefore, a bridging of traditional Diné forms of health communication (e.g., oral storytelling in person, home visits, inter-generational land-based instruction, family support) and modern digital technological mediation (e.g., mobile phone, social media, health literacy, infographics, telehealth, entertainment education/edutainment, social support networks) has the potential to address Diné-centered diabetes self-care, health promotion, and disease prevention messages (Center for Disease Control, 2020). Ultimately, this study supports the necessary bridging with Diné community health, clinical care through Indian Health Service, 638 hospitals, and health communication. Future research for diabetes self-care and support in Diné communities can contribute to and adapt new directions for health communication inquiry for the research through (1) communication in delivery of care, (2) communication and health promotion, (3) health risk communication, (4) e-health communication, and (5) communication in managing health care systems (Kreps, 2020). Health communication research needs to serve as a protective health factor for Indigenous youth, families, and communities. Thus, the departments of health and education within Indigenous communities have the opportunity to create culturally-centered health initiatives in innovative ways. Ultimately, collective health communication research and practices can serve an important role in the community to improve quality of life and prevent diabetes in children, adults, and elders.

It is imperative for researchers to listen to Diné communities for their interests, needs and wisdom with chronic illness management and support. This can be achieved through the use of qualitative research and Indigenous methodologies that honors participatory action from the community members. One of the key research approaches is community based participatory research (CBPR) (Belone et al., 2017; Hearod et al., 2019; Minkler et al., 2012) which centers

the focus on the community to drive the research agenda for their own needs. CBPR has created positive research projects within Diné and Indigenous communities (Goins et al.2011; Woodbury et al., 2019; Mendenhall et al., 2010).

#### Limitations

Among the limitations of this study, is that the analysis was conducted through de-identified secondary data. This form of analysis limited the researcher from not having met with the Diné narrators in person. Meeting with the narrators would provide several verbal and non-verbal communication interactions that would add to the personal and cultural engagement with the narrator.

Additional limitations relate to the crucial perspective for addressing limitations with how research is conducted with Indigenous communities and Indigenous scholars. It is important to discuss the realities of the tensions with the structure of the institution and Western research, academic rigors and the impact they have upon Indigenous practices, family customs and balancing of life worlds for research and community engagement. Similarly, it is imperative to address the conflict that often arises between the linear process of the institution and research process while living and upholding a cyclical, holistic way of life through Diné and Indigenous life worlds. The balancing of multi-lingual communication of Diné ancestral language, cultural non-verbal communication with the dominant, Western forms of verbal, non-verbal and academic communication. And, finally, a critical and needed shift needs to be addressed with refocusing human centric learning to land based knowledge. And understanding through ecological heart and ceremonial communication for addressing illnesses and well-being in health communication.

#### Conclusion

This research study found key understandings from the traditional and modern health practices of Diné narrators as they managed diabetes. Their narratives provided a central focus on how they perceive of modern clinical diabetes self-care regimen. The results from their narratives provide distinctive and unique personal, family, cultural and community health practices that Indigenize diabetes self-care and support. Additionally, the narratives also revealed the barriers with managing diabetes and having lack of support from family members. An important factor that emerged from the narratives is to have research and clinical providers include a wider scope of information about diabetes distress and diabetes fatigue in Diné and Indigenous communities in order to provide vital coping strategies and other approaches to support culturally- and person-centered care for emotional and mental well-being.

This study affirmed and honored the Diné language and lifeway philosophies that were shared by the Diné narrators. These narratives brought forth 13 key themes and core concepts that focused on cultural practices and health behaviors for the creation of the *Nizhonigo ádaa áhaashya*: Diabetes self-care model. This model can be used in local clinics, community health programs, family support and health communication training. Indigenous people who are impacted by current Westernized clinical approaches may find a sense of empowerment and self-efficacy through the traditional language and holistic practices of the Diné narrators and the diabetes self-care model. The narratives and the model can strengthen Diné community members who may be diagnosed with diabetes or a loved one who can learn how to support a relative who is living with diabetes. This support system with the narratives and model may also further reduce fear, stigma and distress that can be brought on by managing diabetes. Ultimately, the health and well-being of Diné communities lies in the expertise of their family traditions, cultural health practices and their decisions to balance modern clinical approaches for diabetes self-care.

# Appendix A. Interview Guide

FIRST INTERVIEW Making a Difference: The Role of Family Support in Navajo Diabetes Self Care
MBRS-SCORE Ethnographic Interview Guide

## **Diabetic Individual**

ID #	Age	Sex	Town
Interviewer	Date		f Interview

Check tape recorder once you start review consent form

CONDUCT FAMILY MAP – have tape on at the time

- I. Overview To set individual at ease, open-ended
  - 1. What individual thinks about diabetes:
  - 2. Knowledge
  - a. What individual tells kids about diabetes
  - 3. Perceptions of diabetes:
  - a. before diagnosis
  - b. present
  - c. future thoughts about going ahead in life from today
- II. Support
- / 1. Overview
  - a. in general, how do families give help/support when a person is affected by diabetes
- 2. Kinds of support individ. receives from family LISTING: FOLLOW UP ON EACH TYPE OF SUPPORT:
  - a. tell me more about . . .
  - b. who provides support and how
  - c. what do you think of this support
  - d. GO IN DEPTH if diet, ask about kinds of food, how they are cooked, who cooks, who shops
  - e. activity, kinds of activity, how often, how far(walking), for how long (other activities)
  - f. others, how often, etc.
- 3. Kinds of support that make you really well
  - a. follow up on each kind and how it makes individual feel really well.
- 4. Who helps individual the most? How?
- 5. What are the times family been really supportive for you to live with DM?
  - a. follow up on each issue get elaboration
- 6. What are the times family has not been as supportive as you would like?
  - a. follow up on each issue get elaboration
- III. Family History/responses
- 1. Who else has diabetes
- 2. What things did your family say to you when they learned you had DM?
  - a. What did family say about where does DM come from?
  - b. What did family say about how you treat DM?
- 3. From the time you were diagnosed to now, has the family had a change in thought about your DM? How?
- 4. What does individual think about things family says about diabetes?
  - a. what are those things that are said that are helpful?
  - b. what are those things that do not help?

- **IV. Traditional Practices**
- 1. way to live daily that is best
- 2. get at specific teachings, values for good living (t'11 ni 1n7t'eego)
  - a. teachings/values for overcoming problems
  - b. teachings/values for personal responsibility
- 3. What kinds of teachings do they tell their kids
- 4. get elaboration of how these teachings help, get examples on:
  - a. how these teachings help with the family and how they relate to each other
  - b. what they tell their kids about important values.
    - 1 Ask about what is said at key times in life -- married, having kids their own
  - c. how teachings help with looking at the present with diabetes
  - d. how teachings help with looking to future with diabetes
- 5. Traditional ceremonies ceremony, medicines individ. has had
  - a. ask if it's okay to talk about it
  - b. what ways did it help individual get specifics

# Appendix B. Rationale for Interview Guide

MBRS SCORE Making a Difference

Rationale for Interview Guide

#### Diabetes

#### a. Definition of Diabetes

We want to get the patient's explanatory model, and their knowledge of health issues.

However, to open the interview with a direct question asking the person to "define diabetes" is too direct. We will only get vague answers as people are unsure of their own knowledge, and it is a very blunt way of opening the interview. It will be better to make this more indirect, ask what is being said about diabetes.

Diabetes ha'n7n7g77sh ha'1t'77 11[ dei[n7? Diabetes the talk about it what is it of it they speak of?

Answers are likely to be

- 1sh88h [ikan
- naalniih
- disease
- alohk'e' doo naha'n1a da

Either what it does to you, or what causes it. They could also answer by what kind of ceremonial way is involved in the cause/cure.

Getting at the patient's own explanatory model may have to be done further on in the interview.

#### b. Knowledge of Diabetes

We need this information for hypothesis two – more knowledge of diabetes and strategies should result in better diabetes management. Perhaps we should take a look at the Michigan Diabetes Knowledge questionnaire that Frank translated for the UNM project. It might be interesting to see how we could get a more accurate take on people's knowledge levels in comparison to that. The multiple choice options are confusing and harder to distinguish in translation. We could just use it to ask a set of questions here that would get at the same information that the questionnaire attempts to elicit.

We need to do open ended questions, like how do they take care of themselves to keep themselves as healthy as possible with their diabetes. This will allow us to see what they see as important information. Questions about the underlying causes and processes will be necessary also. Frequently they respond they don't Know if asked a question that sounds a bit technical. So after they say something about how they should eat or exercise or whatever, follow up with:

!k0t'4ego 1jiy1agosh or followup their phrase with haajii['88h? What happens to you if you do? This might get at their understanding of the underlying process.

Haash yit'4ego 1daa 1dahojily1ago y1'1t'44h daan7? What are the recommendations for selfcare?

!1[ dishn7n7g77 47?
In the areas of:
Na'1d7lts'ood7g77
Ch'iy11n bee 1daa 1h1y1n7g77?
Hakee'da baa 1h1y1n7g77?
Hawoo'da baa 1h1y1n7g77?
Han1a'da baa 1h1y1n7g77?

Exercise: na'1zhd7lts'--dgo hats'77s baa 1hojily3

Diet: ch'iya1n bee 1daa 1hojily3 Foot exam: hakee' baa 1h1y3 Teeth: hawoo' baa 1hojily3 Vision: han11' baa 1hojily3

Ha't'77sh

But how can we get clear indicators that can be scored to create a variable "diabetes knowledge" that can be used to test the hypotheses?

We can ask them to design an appropriate meal, or describe an adequate exercise program, and assess it on a scale.

Try to ask a few specific questions about medications, glucose monitoring,

#### c. Perception of diabetes before diagnosis

We ask this to get at how their perceptions have changed. We start with before, then the next two questions follow that through time as they are diagnosed and look into the future. We can see the impact of diagnosis and whatever initial intervention/education/counseling etc. that was done. This is another angle on

getting at perceptions, which can then be explored in the other questions. Frank suggests that it also gets at predicting healthy behaviors.

## d. Perception/feelings of diabetes currently

# e. Future outlook of personal/family life with diabetes

This question will help us see what degree of fatalism is present, whether the future can even be discussed safely, and what sense of control the patient feels she/he has. This can also indicate something about what they have been taught, both in the sense of clinic education on managing diabetes, but also about traditional concepts of responsibility, etc. They may report that the family blames them for being a lot of trouble.

#### f. Person's definition of health

This will tell us how their vision of their own future fits with their overall vision of health.

We ask it in terms of their experience of health <h0zh=-go nijigh1>.

#### g. Ways of coping with feelings

Feelings are important underlying factors for strengths and weaknesses in support

Strong coping strategies help individuals have successful outcomes in diabetes management

"h1ni" the emotional side, how it is affected, and how the emotions become good h0zh=n7go <improve>.

# h. Problems with his/her diabetes (causes, what helps)

We ask this to find out what problems the person faces with diabetes. This list can then be referred to below in asking about support to deal with the problems, and later in what they know about management of such problems.

All the problems, difficulties, when dealing with diabetes.

# II. Support

# i. Definition of support

Ask because degree of support is critical for first two hypotheses. Explore range of support needed or desired.

Ach'8' an1h00t'i'go <towards one another problem coming to a person> a[haa 1h1y1nig77 <taking care of one another> shi[ bee h0lne' <tell me about it>

It makes no sense to ask "what is support" when in translating the question we have given a definition. We should only ask for definitions when following up on terms they have just brought to the discussion themselves in response to grand tour questions. We need to find ways to get the kind of talk going about support that might get them to give us terms that we can ask about.

Navajo Likert Scale for degree of support

!din None

t'11 1[ts'77s7go or t'11 1[ch'99d7go Small Amount

ay0o sh7k1 an1jah A lot, highly they help me

T'11 77yis77 sh7k1 an1jah or Y4ego sh7k1 an1jah Extremely very much they help me

We can get at quantitative answers by asking Haan7[tsogo n7k1 an1jah <now much do they help you>/ naa 1dahaly3 <for you they take care>?

Scale for Quality of support

Doo shi[ y1'1t'4da I did not like it.

T'1adoo shi[ 1t'4h4da I am accepting of it.

Shi[ y1'1t'44h I like it; it made me feel good.

There will be other ways people will express this, but they will generally come down to these categories.

# ii. Types of support

This question is to get taxonomy of support – examples of support, then each needs to be followed up on to get the who, how much, how often, how important, how it affects family dynamics, etc.

Danik'47 <relatives> na'1[ch7n7 <children and family> t'11 binaad66' <anyone else> how do they n7k1 an1jah <help> and naa 1dahaly3 <care> for you?

Then probe for types using Frank's translations of Navajo language for different aspects of support. Traditional is leadership, speaking for one, standing for one. Financial, money, would come under assistance, but is not considered traditional. But in-kind goods and services are kinds of traditional assistance. We should go through the initial interviews and see if all the examples of support that we find can be categorized under the taxonomy that Frank developed in Navajo.

#### iii. Who provides support

Identify who provides the different kinds of help.

What kinds of support do you get from your family and others?

#### iv. Who patient turns to most for disease mgt

Who helps you the most?

# v. Effectiveness of the types of support

Effectiveness can be 7d44[n7, bee y1'1n7t'44h. Has efficacy. Doesn't seem like it can be applied in Navajo to 'support.'

What kind of supportive activity is most helpful to you?

T'11 a['22 1t'4egosh99 naa 1h1y3 d00 n7k1 an1'11wo'. K0daat'4h7g77 h1id7g77sh ay0o bee y1'1n7t'44h?

You receive your care and assistance in many different ways. From all these kinds, which ones really make you well.

vi. What makes it easier or harder to get support

Din4 n7k1 an1jah7g77sh ha'1t'77 ay0o yin7[t'a?

- 1. transportation
- 2. pos/neg perceptions
- 3. other

#### III. Concerns

Not sure how this is different from the "problems" that we elicited at the end of the section one on diabetes. Will hold off on this section until we finish the rest and see if this section really gets at anything different.

IV. Self-Management Techniques – Ways to stay healthy

With diabetes, you can lead a long, relatively healthy life, but you have to take care of yourself. How does a person do this? Tell me about how you are taking care of yourself?

#### 1. Activities

Household - Hooghang0ne'7g77

Outdoors - T['00'g007g77

Recreational T'00 bee 1k'idahata'7g77

Religious/spiritual Sodizin bi[ naazt'i'go7g77

# 2. Diet

- 3. Medical Monitoring & Care
  - a. Taking medication
  - b. Checking blood sugar
  - c. Keeping doctor appointments
  - d. Attending classes
  - e. Following medicine man's instruction

# V. Traditional Navajo Practices/Concepts

We want to find out if you are participating in any traditional health care, and if you are participating in any forms of  $t'11\ h0\ 1j7t'4ego?$  It is taught in the traditional way that people should be very personally responsible for their life. How is that attitude helpful to you?

What helped?

Did you follow it?

T'11 h0 1j7t'4ego selfinitiating behavior. Asking for what you need 1dich'i y1t'i is part of that.

Ceremonies used: Din4j7 nahagh1 d00 azee' 1daat'4ii daats'7 [a' n1 1lyaa? For azee', zaa'ni[, taken by mouth, made for you, sweatlodge, what is dug out, azee' naasgeed are those prepared out in the field. Or peyote. The person may say yes. Or they may say the don't talk about that. Perhaps we should start by asking if it is alright to ask about it. If so, then ask how did it help you, or what changes in thinking or in condition followed that.

Bee shi[ h0lne'go0sh t'11 1ko? \$7sh 47 hait'4ego n7k1' o'oolwod? T'11sh n7k1 eelwod? Did it help you?

H1'1t'7ish t'11 1yis77 bik'ehgo joog1a[go 47 1yis77 y1'1t'44h 11?

What is the best way to live daily?

T'11 ni 1n7t'4ego daha'n7n7g77 da doodago na'nitin bik'ehgo da'iin1n7g77 11[ dishn7?

I mean those teachings and values for good living such as t'11 ni 1n7t'eego, being personally responsible.

# VI. Interventions

- 1. clinic classes
- 2. home visits
- 3. medication and medication changes.

# Appendix C. Navajo Nation Human Research Review Board Letter of Approval

# THE NAVAJO NATION

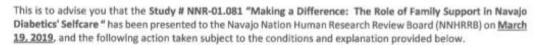
#### JONATHAN NEZ | PRESIDENT MYRON LIZER | VICE PRESIDENT



April 12, 2019

Dr. Mark C. Bauer, Ph.D. Diné College P.O. Box 580 Shiprock, NM 87420

Dear Dr. Bauer,



Reasons:

Continuation Request

Description:

Request Acceptance and Approval of Continuation Request covering

March 20, 2019 - March 20, 2020 period.

NNHRRB Action: Accepted and Approved

The Navajo Nation Human Research Review Board has added a very important additional contingency regarding failure to comply with NNHRRB rules, regulations, and submittal of reports which could result in sanctions being placed against your project. This could also affect your funding source and the principal investigator. Under Part Five: Certification, please note paragraph five wherein it states: "I agree not to proceed in the research until the problems have been resolved or the Navajo Nation Human Research Review Board has reviewed and approved the changes." Therefore, it is very important to submit quarterly and annual reports on time and if continuation is warranted submit a letter of request sixty (60) days prior to the expiration date.

The following are requirements that apply to all research studies:

- The Navajo Nation retains ownership of all data obtained within its territorial boundaries. The Principal Investigator shall submit to the NNHRRB a plan and timeline on how and when the data/statistics will be turned over to the Navajo Nation:
- 2. Only the approved informed consent document(s) will be used in the study;
- Any proposed future changes to the protocol or the consent form(s) must again be submitted to the Board for review and approval prior to implementation of the proposed change;
- If the results of the study will be published or used for oral presentations at professional conferences, the
  proposed publication, abstract and/or presentation materials must be submitted to the Navajo Research
  Program for Board review and prior approval;
- Upon Board approval, three (3) copies of the final publication must be submitted to the Navajo Research Program;
- 6. All manuscripts must be submitted to the Navajo Research Program for Board Review and prior approval;
- The Principal Investigator must submit a dissemination plan on how the results of the study and how these results will be reported back to the Navajo Nation;

# Appendix D. Resolution Approval from Northern Navajo Agency Council



# NORTHERN NAVAJO AGENCY COUNCIL RESOLUTION

NNAC-95-121518

SUPPORTING "IINA DZIIL BE' ATIIN (ON THE PATH OF A STRONG LIFE); USING HEALTH AND CULTURAL COMMUNICATION APPROACHES FOR THE STORIES FROM DINE' WOMEN AND MEN ABOUT SOCIAL SUPPORT FOR DIABETES MANAGEMENT."

#### WHEREAS:

- Pursuant to IGRD-269-05, the Northern Navajo Agency Council is a recognized political subdivision
  of the Navajo Nation and has the authority to advocate and make appropriate recommendations on
  behalf of the 20 Northern Navajo Agency Chapters to the Navajo Nation Government, Federal,
  State, and local entities for appropriate action; and
- That the health of Dine' individuals encompasses a holistic way of well-being, including how a person responds to illness and disease, particularly diabetes. It is important to understand how a person communicates their feelings about their acceptance, awareness and management of diabetes in a personal, cultural and clinical setting; and
- 3. The prospectus of Chenoa Bah Stilwell-Jensen, MS (Doctoral Candidate, Department of Communication, University of New Mexico) in partnership with Dr. Marc Bauer, Faculty, Dine' College Shiprock Campus, as the P.I. (Principal Investigator) began research collaboration in 2015, where the project was approved by the Navajo Nation Human Research Review Board (NNHRR) for NNR-01.81: Making a Difference: the Role of Family Support in Navajo Diabetics' Self Care. The study focuses on a qualitative analysis centering on health and cultural communication approaches for understanding diabetes management by two sets of interviews from 12 individuals; and
- 4. Dine' College was established by an Act of Congress in 1968 and is chartered by the Navajo Nation as an institute of Higher Education of the Navajo with the mission "... to advance quality of postsecondary student learning and development to ensure the well-being of the Dine' People,"; and
- 5. Dine' College and the Navajo Nation have identified diabetes prevention, treatment and management as priorities, demonstrated in the projects at Dine' College focusing on communitybased research, specifically training Dine' College students as interviewers for the studies on perceptions of Dine' women and men and their understanding of the causes, symptoms, and treatment of diabetes; and
- 6. Mrs. Stilwell-Jensen will explore the stories of the Dine' women and men using a qualitative analysis approach to learn what forms of communication (in Dine' and English) and health narratives inform a better understanding for patients to cope with diabetes in a culturally relevant manner. Ultimately, these stories will add to health research of how clinicians, community health educators, family care givers and individuals with diabetes can better communicate coping approaches for eating, medical care, cultural practices and emotional well-being; and
- The prospectus will be formalized into a dissertation for health and cultural communication purposes, and
- The outcomes of the qualitative analysis will be shared with the Shiprock and Northern Navajo Agency Council leadership and community members; and
- The partnership between Mrs. Stilwell-Jensen and Dine' College will support community outreach
  and engagement with health communication education for local stakeholders, comprised of tribal
  members, leaders, school board members, NNHRRB members; and

#### References

- American Diabetes Association. (2011). Standards of medical care in diabetes—2011. *Diabetes*Care, 34(1), S11-S61. https://doi.org/10.2337/dc11-S011
- Anderson, R. M. (1995). Patient empowerment and the traditional medical model: A case of irreconcilable differences? *Diabetes Care*, 18(3), 412-415. doi: 10.2337/diacare.18.3.412
- Arpan, L. M. (2002). When in Rome? The effects of spokesperson ethnicity on audience evaluation of crisis communication. *International Journal of Business Communication*, 39(3), 314-339. doi: https://doi.org/10.1177/002194360203900302
- Aronilth Jr., W. (1992). Foundation of Navajo culture. Tsaile, AZ: Diné College.
- Austin, R. D. (2009). Navajo Courts and Navajo Common Law: A tradition of tribal self-governance. Minneapolis, MN: University of Minnesota Press.
- Baltruschat, D. (2004). Television and Canada's Aboriginal communities: Seeking opportunities through traditional storytelling and digital technologies. *Canadian Journal of Communication*, 29(1), 47-59.
- Barkwell, D. (2005). Cancer pain: Voices of the Ojibway people. *Journal of Pain and Symptom Management*, 30(5), 454-465. doi: 10.1016/j.jpainsymman.2005.04.008
- Bartlett, J.G., Iwasaki, Y., Gottlieg, B., Hall, D., & Mannell, R. (2007). Framework for Aboriginal-guided decolonizing research involving Metís and First Nations persons with diabetes. *Social Science & Medicine*, 65(11), 2371-2382. doi: 10.1016/j.socscimed.2007.06.011

- Barton, S. S. (2004). Narrative inquiry: Locating Aboriginal epistemology in a relational methodology. *Journal of Advance Nursing*, 45(5), 519-526. https://doi.org/10.1046/j.1365-2648.2003.02935.x
- Barton, S. S., Anderson, N., & Thommasen, H. V. (2005). The diabetes experiences of Aboriginal people living in a rural Canadian community. *Australian Journal of Rural Health*, *13*(4), 242-246. <a href="https://doi.org/10.1111/j.1440-1584.2005.00709.x">https://doi.org/10.1111/j.1440-1584.2005.00709.x</a>
- Battiste, M. (2008). The decolonization of aboriginal education: Dialogue, reflection, and action in Canada. P. R. Dasen, & A. Akkari. In *Educational Theories and Practices from the Majority World* (pp. 168-195). Los Angeles, California: Sage.
- Becker, M. H., & Janz, N. K. (1985). The health belief model applied to understanding diabetes regimen compliance. *Diabetes Educator*, 11, 41-47.

  <a href="https://doi.org/10.1177/014572178501100108">https://doi.org/10.1177/014572178501100108</a>
- Begay, D. H. & Maryboy, N. C. (2000). The whole universe is my cathedral: a contemporary Navajo spiritual synthesis. *Medical Anthropology Quarterly*, 14(4):498-520.
- Belone, L., Orosco, A., Damon, E., Smith-McNeal, W., Rae, R., Sherpa, M. L., Myers, O.B.,
  Omeh, A. O., & Wallerstein, N. (2017). The piloting of a culturally centered American
  Indian family prevention program: a CBPR partnership between Mescalero Apache and
  the University of New Mexico. *Public Health Reviews*, 38(30). doi: 10.1186/s40985-017-0076-1
- Benally, H. (1994). Navajo philosophy of learning and pedagogy. *Journal of Navajo Education*, *XII*(1): 23-31.
- Berger, C. R. (1997). Producing messages under scrutiny. In J. Greene (Ed.), *Message production: Advances in community theory*. (pp. 221-244). Mahwah, NJ: Erlbaum.

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research* in *Psychology*, 3(2), 77-101. https://doi.org/10.1191/1478088706qp063oa
- Brill de Ramirez, S. B. (2007). *Native American Life-History Narratives: Colonial and Postcolonial Navajo Ethnography*. Albuquerque, NM: University of New Mexico Press.
- Brinson, S. L., & Brown, M. H. (1997). The AIDS risk narrative in the 1994 CDC campaign. *Journal of Health Communication*, 2(2), 101-112. https://doi.org/10.1080/108107397127815
- Brody, H. (1999). Taking the words from their mouths. *Index of Censorship*, 28(4), 41-47. https://doi.org/10.1080/03064229908536619
- Brown, G. (2013). Diné T;áá Bi At'éego, Wholeness as a well-directed person: Navajo narratives that revisit the work of Kenneth Begishe. Disseration

  (<a href="http://hdl.handle.net/10150/272835">http://hdl.handle.net/10150/272835</a>)
- Carter, J. S., Gilliland, S. S., Perez, G. E., Levin, S., Broussard, B. A., Valdez, L., & Davis, S. M. (1997). Native American diabetes project: Designing culturally relevant education materials. *The Diabetes Educator*, 23(2), 133-139. doi: 10.1177/0145721797702300203
- Carter, J. S., Pugh, J. A., Monterossa, A. (1996). Non-insulin-dependent diabetes mellitus in minorities in the United States. *Annals of Internal Medicine*, 125(3), 221-232. https://doi.org/10.7326/0003-4819-125-3-199608010-00011
- Cavanaugh, C. L., Taylor, C. A., Keim, K. S., Clutter, J. E., & Geraghty, M. E. (2008).

  Cultural perceptions of health and diabetes among Native American men. *Journal of Health Care for the Poor and Underserved*, 19(4), 1029-1043. doi: 10.1353/hpu.0.0083

- Chee, D. (2010, July). Early dawn and the beginnings of learning. *Leading the way: The wisdom of the Navajo people*, 8(7), p. 20.
- Centers for Disease Control and Prevention. (2020, Feb. 11). *National Diabetes Statistics report*. <a href="https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf">https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf</a>
- Centers for Disease Control and Prevention. (2017). *National diabetes statistics report*.

  <a href="https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf">https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf</a>.
- Centers for Disease Control and Prevention. (2015). Traditional Foods in Native America: A

  compendium of stories from the Indigenous Food Sovereignty Movement in American

  Indian and Alaska Native communities Part IV.

  <a href="https://www.cdc.gov/diabetes/ndwp/pdf/Part\_IV\_Traditional\_Foods\_in\_Native\_America.">https://www.cdc.gov/diabetes/ndwp/pdf/Part\_IV\_Traditional\_Foods\_in\_Native\_America.</a>

  pdf
- Centers for Disease Control and Prevention. (2013). Traditional Foods in Native America: A compendium of stories from the Indigenous Food Sovereignty Movement in American Indian and Alaska Native communities Part I.

  <a href="https://www.cdc.gov/diabetes/ndwp/pdf/part-i---traditional-foods-in-native-america-april-21.pdf">https://www.cdc.gov/diabetes/ndwp/pdf/part-i---traditional-foods-in-native-america-april-21.pdf</a>
- Clark, F. (2009). In becoming Sa'ah Naaghai Bik'eh Hozhoon: The historical challenges and the triumphs of Diné College (Publication No: 3360201) [Doctoral dissertation, University of Arizona]. University Libraries, University of Arizona.
- Clarke, J. N., & Everest, M. M. (2006). Cancer in the mass print media: Fear, uncertainty and the medical model. *Social Science & Medicine*, 62(10), 2591-2600. doi: 10.1016/j.socscimed.2005.11.021
- Compher, C. (2006). The nutrition transition in American Indians. *Journal Transcultural*

- Nursing, 17(3): 217-223. https://doi.org/10.1177/1043659606288376
- Corbin, J., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco, CA: Jossey-Bass
- Coulehoun, J. (2003). Metaphor and medicine: Narrative in clinical practice. *Yale Journal of Biology and Medicine*, 76(2), 87-95. PMCID: PMC2582695
- Cragan, J. F., & Shields, D. C. (1998). *Understanding communication theory: The communicative forces for human action*. Boston, MA: Allyn and Bacon.
- Creswell, J. W. (1994). *Research design: Qualitative & Quantitative Approaches*. Thousand Oaks, CA: Sage Publications.
- Creswell, J. W. (2003). Research design: Qualitative, quantitative, and mixed methods approaches. Thousand Oaks, CA: Sage Publications.
- Deloria, V. & Wildcat, D. R. (2001). *Power and place. Indian education in America*. Golden, CO: Fulcrum Publishing.
- Deloria, V. (1999). *Spirit and reason: The Vine Deloria Jr. reader*. Golden CO: Fulcrum Publishing.
- deMaria, J., & Rael, R. (2019). Shifting narratives for behavioral health justice. In Page-Reeves (Ed.), Wellbeing as a Multi-Dimensional Concept: Understanding Connections Between Culture, Community and Health, (pp. 393-). Lantham, MD: Lexington Books of Rowman & Littlefield.
- Denetdale, J. N. (2014). The Value of Oral History on the Path to Diné/Navajo Sovereignty.

  In L. L. Lee (Ed.), *Diné Perspectives: Revitalizing and reclaiming Navajo thought*.

  Tucson: The University of Arizona Press.
- Denetdale, J. N. (2007). Reclaiming Diné history: The legacies of Navajo Chief Manuelito

- and Juanita. Tucson, Arizona: University of Arizona Press.
- Denzin, N. K., & Lincoln, Y. S. (Eds.) (1994). *Handbook of qualitative research*. Thousand Oaks, CA: SAGE.
- Denzin, N. K., Lincoln, Y. S., & Tuhiwai Smith, L. (2008). *Handbook of critical and Indigenous methodologies*. Thousand Oaks, CA. Sage Publications.
- Denzin, N. K., & Lincoln, Y. S. (Eds.) (2011). *Handbook of qualitative research*. 4<sup>th</sup> Edition. Thousand Oaks, CA: SAGE.
- Dignan, M., Michielutte, R., Blinson, K, Wells, H. B., Case, L. D., Sharp, P., Davis, P., Koren, J., & McQuellon, R. P. (1996). Effectiveness of health education to increase screening for cervical cancer among Eastern-Band Cherokee Indian women in North Carolina. *Journal of National Cancer Institute*, 88(22), 1670-1676. doi: 10.1093/jnci/88.22.1670
- Dutta, M. J. (2007). Communicating about culture and health: theorizing culture-centered and cultural sensitivity approaches. *Communication Theory*, *17*(3), 304-328. doi: 10.1111/j.1468-2885.2007.00297.x
- Edwards, E., & Patchell, B. (2009). State of the science: A cultural view of Native

  Americans and Diabetes Prevention. *Journal of Cultural Diversity*, 16(1), 32-25. PMCID:

  PMC2905172
- Emerson, L. (2014). Diné culture: Decolonization, and the politics of hózhó. In L. L. Lee, *Diné*\*Perspectives: Revitalizing and reclaiming Navajo thought. Tucson: The University of Arizona Press.
- Fischhoff, B., Bostrom, A., & Quadrel, M. J. (1993). Risk perception and communication.

  Annual Review of Public Health, 14(1), 183-203.

  https://doi.org/10.1146/annurev.pu.14.050193.001151

- Fisher, W. R. (2000). The standpoint of storyteller. *Qualitative Health Research*, 10(3), 254-365. doi: 10.1177/104973200129118499
- Fisher, W. R. (1987). *Human communication as narration: Toward a philosophy of reason, value, and action.* Columbia, SC: University of South Carolina Press.
- Fisher, W. R. (1985). The narrative paradigm: In the beginning. *Journal of Communication*, *35*(4), 74–89. doi: 10.1111/j.1460-2466.1985.tb02974.x
- Frank, L. A. (2020). History on a plate: How Native American diets shifted after European colonization. www.history.com, Updated December 30, 2020.
- Ganga, D., & Scott, S (2006). Cultural 'insiders' and the issue of positionality in qualitative migration research: Moving 'across' and moving 'along' researcher-participant divides.

  \*Qualitative Social Research\*, 7(3): 1-7. <a href="https://doi.org/10.17169/fgs-7.3.134">https://doi.org/10.17169/fgs-7.3.134</a>
- Glanz, K., Rimer, B. K., & Viswanath, K. (Eds). (2008). *Health behavior and health education: Theory, research, and practice* (4th ed.). San Francisco, CA: John Wiley & Sons.
- Glanz, K., Rimer, B. K., & Lewis, F. M. (2002). *Health behavior and health education: Theory, research, and practice* (3rd ed.). San Francisco, CA: Jossey-Bass.
- Glanz, K., Lewis, F.M. and Rimer, B.K. (eds) (1997). *Health Behavior and Health Education: Theory, Research and Practice*, 2nd edition. Jossey-Bass, San Francisco, CA.
- Glanz K., & Oldenburg B. (1997) Relevance of Health Behavior Research to Health
  Promotion and Health Education. In D.S. Gochman (Ed.) *Handbook of Health*Behavior Research IV, (pp. 143-161). Boston, MA: Springer.
  - https://doi.org/10.1007/978-1-4899-0484-3\_8
- Goins, R. T., Garroutee, E. M., Fox, S. L., Geiger, S. D., & Manson, S. M. (2011).

- Theory and practice in participatory research: Lessons from the Native elder study. *The Gerontologist*, 51(3): 285-294. https://doi.org/10.1093/geront/gnq130
- Gray, J. B. (2009). The power of storytelling: Using narrative in the healthcare context.

  \*\*Journal of Health Communication, 2(3), 258-273.\*\*

  https://doi.org/10.1179/cih.2009.2.3.258
- Green, M. C. (2006). Narratives and cancer communication. *Journal of Communication*, *56*, 163-183. <a href="https://doi.org/10.1111/j.1460-2466.2006.00288.x">https://doi.org/10.1111/j.1460-2466.2006.00288.x</a>
- Greymorning, S. (2004). A will to survive: Indigenous essays on the politics of culture, language and identity. Boston, MA: McGraw-Hill Humanities.
- Guisinger, S., & Blatt, S. J. (1994). Individuality and relatedness: Evolution of a fundamental dialectic. *American Psychologist*, 49(2), 104-111. https://doi.org/10.1037/0003-066X.49.2.104
- Hearod, J. B., Wetherill, M. S., Salvatore, A. L., & Jernigan, V. B. B. (2019). Community-based participatory intervention research with American Indian communities: What is the state of science? *Current Developments in Nutrition*, *3* (2), 39-52.

  <a href="https://doi.org/10.1093/cdn/nzz008">https://doi.org/10.1093/cdn/nzz008</a>
- HeavyRunner, I., & Marshall, K. (2003). Miracle survivors: Promoting Indian students. *Tribal College Journal*, 14(4),
- Hinyard L. J., & Kreuter, M. W. (2007). Using narrative communication as a tool for health behavior change: A conceptual, theoretical, and empirical overview. *Health Education & Behavior*, 34(5): 777-792. Doi: 10.1177/1090198106291963
- Hodge, D. R., Limb, G. E., & Cross, T. (2009). Moving from colonization toward

- balance and harmony: A Native American perspective on wellness. *Social Work*, *54*(3), 211-219. doi: 10.1093/sw/54.3.211
- Hood, E.E., Witcher, D.R., Maddock, S., Meyer, T., Baszczynski, C., Bailey, M., Flynn, P.,
  - Register, J., Marshall, L., Bond, D., Kulisek, E., Kusnadi, A., Evangelista, R., Nikolov.,
    - Z., Wooge, C., Mehigh, R. J., Hernan, R., Kappel, W. L., Ritland, D., Li, C. P., &
    - Howard, J. A. (1997). Commercial production of avidin from transgenic maize:
  - characterization of transformant, production, processing, extraction, and
  - purification. *Molecular Breeding 3*, 291–306.
    - https://doi.org/10.1023/A:1009676322162
- Hoskie, A. (2010, July). Challenging yourself. *Leading the way: The wisdom of the Navajo People*, 8(7), p. 11.
- Hymes, D. H. (1974). *Foundations in sociolinguistics: An ethnographic approach*. Philadelphia, PA: University of Pennsylvania Press.
- Indian Health Service (2020). Health topics: diabetes. https://www.ihs.gov/forpatients/healthtopics/diabetes/
- Janz, N. K., & Becker, M. H. (1984). The Health Belief Model: A decade later. *Health Education Quarterly*, 11(1), 1–47. https://doi.org/10.1177/109019818401100101
- Jernigan, V. B. (2010). Community-based participatory research with Native American communities: The chronic disease self-management program. *Health Promotion Practice*, 11, 888-899. doi: 10.1177/1524839909333374
- Joe, J. R., & Young, R.S. (1993). Diabetes as a disease of colonization: The impact of Culture Change on Indigenous Peoples. New York: De Gruyter Mouton.
- Joe, J. R. (1988). Breaking the Navajo Family: Governmental interference and forced

- relocation. Diné Be'iina', 1(2): 1-21.
- Jones, C. M. (2010). The moral problem of health disparities. *American Journal of Public Health*, 100(1), S47-S51. https://doi.org/10.2105/AJPH.2009.171181
- Jones, D. S. (2006). The persistence of American Indian health disparities. *American Journal of Public Health*, 96(12), 2122-2134. doi: 10.2105/AJPH.2004.054262
- Joslin, E. P. (1940). The university of diabetes. *Journal of the American Medical Association*, 115, 2033-2038.
- Kahn-John, M. (2010). Concept analysis of Diné Hózhó: A Diné wellness philosophy. *Advanced Nursing Science*, 33(2), 113-25. doi: 10.1097/ANS.0b013e3181dbc658
- Kahn-John, M., & Koithan, M. (2015). Living in health, harmony, and beauty: The Diné (Navajo) Hozhó Wellness Philosophy. *Global Advances Health Medicine*, 4(3), 24-30. doi: 10.7453/gahmj.2015.044
- Kalra, S., & Sahay, R. (2018). Diabetes fatigue syndrome. *Diabetes Therapy*, 9(4): 1421-1429. doi: 10.1007/s13300-018-0453-x
- Kopp, J. (1986). Cross cultural contacts: Changes in the diet and nutrition of the Navajo Indians.American Indian Culture and Research Journal. 10(4), 1-30.doi: 10.7453/gahmj.2015.044
- Kourakos, M., Fradelos, E. C., Papathanasiou, I. V., Saridi, M., & Kafkia, T. (2017).

  Communication as the basis of care for patients with chronic diseases. *American Journal of Nursing Science*, 7(3): 7-12. doi: 10.11648/j.ajns.s.2018070301.12
- Kreider, K. E. (2017). Diabetes distress or major depressive disorder? A practical approach to diagnosing and treating psychological and comorbidities of diabetes. *Diabetes Therapy*, 8(1): 1-7. DOI: 10.1007/s13300-017-023-1

- Krieger N. (2012). Methods for the scientific study of discrimination and health: an ecosocial approach. *American journal of public health*, *102*(5), 936–944. https://doi.org/10.2105/AJPH.2011.300544
- Krieger, N. (2009). Putting health inequities on the map: Social epidemiology meets medical/health geography—an ecosocial perspective. *GeoJournal*, 74(2), 87-97. doi: 10.1007/s10708-009-9265-x
- Kreiger, N. (2005). Embodiment: A conceptual glossary for epidemiology. *Journal of Epidemiology of Community Health*, 5 9(5), 350-355. doi: 10.1136/jech.2004.024562.
- Kreiger, N. (2001). Theories for social epidemiology in the 21<sup>st</sup> century: Ecosocial perspective. *International Journal of Epidemiology*, *30*(4), 668-677. https://doi.org/10.1093/ije/30.4.668
- Kretchy, I. A., Koduah, A., Ohene-Agyei, T., Boima, V., & Appiah, B. (2020). The Association between diabetes-delated distress and medication adherence in adult patients with type 2 diabetes mellitus: A cross-sectional study. *Journal of Diabetes Research*, 2020, 1-10. doi: 10.1155/2020/4760624
- Kulhawy-Wibe, S., King-Shier, K. M., Barnabe, C., Manns, B. J., Hemmelgarn, B. R., & Campbell, D. (2018). Exploring structural barriers to diabetes self-management in Alberta First Nations communities. *Diabetology & metabolic syndrome*, 10(87), 1-7. <a href="https://doi.org/10.1186/s13098-018-0385-7">https://doi.org/10.1186/s13098-018-0385-7</a>
- Kumugai, A. K., Murphy, E. A., & Ross, P. T. (2009). Diabetes stories: use of patient narratives of diabetes to teach patient-centered care. *Advances in Health Sciences Education Journal*, 14: 315-326. doi: 10.1007/s10459-008-9123-5

- LaDuke, W. (2005). *Recovering the sacred: The power of naming and claiming*.

  Cambridge, MA: South End Press.
- LaFromboise, T. D., Trimble, J. E., & Mohatt, G. V. (1990). Counseling interventions and American Indian tradition. *The Counseling Psychologist*, *18*(4), 628-654. https://doi.org/10.1177/0011000090184006
- Laing, R. D. (2018). *The politics of the family, and other essays* (Vol. 5). New York: Routledge.
- Landzelius, K. (2006). *Native on the net: Indigenous and diasporic peoples in the virtual age*. New York, NY: Routledge.
- Lee, L. L. (2017). Navajo sovereignty: Understandings and visions of the Diné People.

  Tucson, AZ: The University of Arizona Press.
- Lee, L. L. (2014). *Diné Perspectives: Revitalizing and reclaiming Navajo thought*. Tucson: The University of Arizona Press.
- Lindlof, T. R., & Taylor, B. C. (2002). *Qualitative communication research methods*. Thousand Oaks, CA: Sage Publications.
- Lipkus, I. M., & Hollands, J. G. (1999). The visual communication of risk. *Journal of National Cancer Institute Monographs*, 1999(25), 149-163. https://doi.org/10.1093/oxfordjournals.jncimonographs.a024191
- Lipkus, I. M. (2007). Numeric, verbal, and visual formats of conveying health risks:

  Suggested best practices and future recommendations. *Medical Decision Making*, 27(5), 696-713. https://doi.org/10.1177/0272989X07307271
- Lovelace Hospital (n.d). *Diabetes distress: A common occurrence in patients with diabetes*.

  <a href="https://lovelace.com/news/blog/diabetes-distress-common-occurrence-patients-diabetes">https://lovelace.com/news/blog/diabetes-distress-common-occurrence-patients-diabetes</a>

- Madeson, F. (2016, Feb. 10). The Pain of the Earth: and interview with Duane "Chili" Yazzie.

  \*Counterpunch. <a href="https://www.counterpunch.org/2016/02/10/the-pain-of-the-earth-an-interview-with-duane-chili-yazzie">https://www.counterpunch.org/2016/02/10/the-pain-of-the-earth-an-interview-with-duane-chili-yazzie</a>
- Mattson, M., & Hall, J. B. (2011). *Health as communication nexus: A service-learning approach*. Dubuque, IA: Kendall Hunt.
- McCabe, M., Morgan, F., Smith, M., Yazzie, E., Spencer, A., Curley, H., Begay, R., & Gohdes, D. (2003). Lessons learned: Challenges in interpreting diabetes concepts in the Navajo language. *Diabetes Care*, 26(6), 1913-1914. doi: 10.2337/diacare.26.6.1913
- McLaughlin, S. (2010). Traditions and diabetes prevention: A healthy path for Native

  Americans. *Diabetes Spectrum*, 23(4), 272-277.

  https://doi.org/10.2337/diaspect.23.4.272.
- Mendenhall, T. J., Berge, J. M., Harper, P., GreenCrow, B., LittleWalker, N., WhiteEagle, S., & BrownOwl, S. (2010). The family education diabetes series (FEDS): community-based participatory research with a midwestern American Indian community. *Nursing Inquiry*, 17(4), 359-372. doi: 10.1111/j.1440-1800.2010.00508
- Minkler, M., Garcia, A. P., Rubin, V., & Wallerstein, N. (2012). Community-based participatory research: A strategy for building healthy communities and promoting health through policy change. *National Collaborating Center for Determinants of Health*.

  <a href="https://nccdh.ca/resources/entry/community-based-participatory-research">https://nccdh.ca/resources/entry/community-based-participatory-research</a>
- Misselbrook, D., & Armstrong, D. (2002). Thinking about risk. Can doctors and patients talk the same language? *Family Practice*, 19(1), 1-2. <a href="https://doi.org/10.1093/fampra/19.1.1">https://doi.org/10.1093/fampra/19.1.1</a>
  National Congress of American Indians. (2020, Feb.). *Tribal Nations and the United States: An*

Introduction.

https://www.ncai.org/attachments/PolicyPaper\_VmQazPEqbvZDMeaDvbupWTSZLmzyzBKOknQRXnUyoVMoyFkEWGH\_Tribal%20Nations%20and%20the%20United%20States\_An%20Introduction.pdf

- Narayan, K. M. V. (1996). Diabetes Mellitus in Native Americans: The problem and its implications. In G.D. Sandefur, R.R. Rindfuss, & B. Cohen (Eds.), *Changing Numbers, Changing Needs: American Indian Demography and Public Health,* (pp. 262-288.
  Washington, (DC): National Academic Press (US).
- NCAI Policy Research Center. (2015). Translating science: Research and communities addressing diabetes in American Indian and Alaskan Native populations.

  <a href="https://www.ncai.org/policy-research-center/research-data/prc-publications/DiabetesResearchBrief.pdf">https://www.ncai.org/policy-research-center/research-data/prc-publications/DiabetesResearchBrief.pdf</a>
- Nelson, M. (2018, Jan. 4). Navajo wellness model: Keeping the cultural teachings alive to improve health. *Indian Health Service*. <a href="https://www.ihs.gov/newsroom/ihs-blog/january2018/navajo-wellness-model-keeping-the-cultural-teachings-alive-to-improve-health/">https://www.ihs.gov/newsroom/ihs-blog/january2018/navajo-wellness-model-keeping-the-cultural-teachings-alive-to-improve-health/</a>
- O'Connell, J., Yi, R., Wilson, C., Manson, S. M., & Acton, K. J. (2010). Racial disparities in health status: a comparison of the morbidity among American Indian and U.S. adults with diabetes. *Diabetes care*, *33*(7), 1463–1470. <a href="https://doi.org/10.2337/dc09-1652">https://doi.org/10.2337/dc09-1652</a>
- Office of Disease Prevention and Health Promotion. (n.d.) *Social determinants of health*. https://health.gov/healthypeople/objectives-and-data/social-determinants-health

- Pilon, R., Bailey, P. H., Montgomery, P., & Bakker, D. (2011). The future is the present: diabetes complication stories. *Journal of Nursing and Healthcare of Chronic Illness*, 3 (3), 234-244. doi: 10.1111/j.1752-9824.2011.01095.x
- Pilon, R., Benoit, M., Maar, M., Cote-Meek, S., Assinewe, F., & Daybutch, G., (2019).

  Decolonizing diabetes. *International Journal of Indigenous Health*, 14(2), 253-275. doi: 10.32799/ijih.v14i2.32958
- Porter, R. O. (2004). *Sovereignty, colonialism, and the Indigenous nations*. Durham, NC: Carolina Academic Press.
- Poudrier, J., & Mac-Lean, R. T. (2009). "We've fallen into the cracks:" Aboriginal women's experiences with breast cancer through photovoice. *Nursing Inquiry*, *16*(4), 306-317. <a href="https://doi.org/10.1111/j.1440-1800.2008.00432.x">https://doi.org/10.1111/j.1440-1800.2008.00432.x</a>
- Powers, M. A., Carstensen, K., Colon, K., Rickheim, P., & Bergenstal, R. M. (2006).

  Diabetes BASICS: Education, innovation, revolution. *Diabetes Spectrum*, 19(2), 90-98.

  <a href="https://doi.org/10.2337/diaspect.19.2.90">https://doi.org/10.2337/diaspect.19.2.90</a>
- Prochaska, J.O. (1994). Strong and weak principles for progressing from precontemplation to action based on twelve problem behaviors. *Health Psychology*, *13*(1): 47-51. doi: 10.1037//0278-6133.13.1.47
- Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1992). In search of how people change: Applications to addictive behaviors. *American Psychology*, 47, 1102-1114. doi: 10.1037/006x.47.9.1102
- Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy toward a more integrative model of change. *Psychotherapy Theory Research Practice*, *19*, 276-287.
- Prochaska, J. O. (1979). Systems of psychotherapy: A transtheoretical analysis. Pacific,

- CA: Brooks-Cole.
- Prochaska, J. O., & Velicer, W. F. (1997). The transtheoretical model of health behavior change.

  \*American Journal of Health Promotion, 12(1), 38-48. doi: 10.4278/0890-1171-12.1.38
- Rallis, S. F., & Rossman, G. B. (2003) Learning in the field: An introduction to qualitative research (2nd ed.). Thousand Oaks, CA: SAGE
- Ravussin, E., Valencia, M. E., Esparza, J., Bennett, P. H., & Schulz, L. O. (1994). Effects of a traditional lifestyle on obesity in Pima Indians. *Diabetes Care*, *17*(9), 1067-1074. https://doi.org/10.2337/diacare.17.9.1067
- Reaney, M., Eichorst, B., & Gorman, P. (2012). From acorns to oak trees: The development and theoretical underpinnings of diabetes conversation map education tools. *Diabetes Spectrum*, 25(2), 111-116. https://doi.org/10.2337/diaspect.25.2.111
- Riessman, C. K. (2008). Narrative methods for the human sciences. Sage Publications, Inc.
- Rosenstock I. M. (1990). The health belief model: Explaining health behavior through experiences. In K. Glanz, F. M. Lewis, & B. K. Rimer (Eds.), *Health behavior and health education: Theory, Research, and practice* (pp. 39-62). San Francisco, CA: Josey-Bass/Wiley.
- Rosenstock I. M. (1974). The Health Belief Model and Preventive Health Behavior. *Health Education Monographs*. 1974;2(4):354-386. doi: 10.1177/109019817400200405
- Rutten, L. J. F., Hesse, B. W., Sauver, J. L. S., Wilson, P., Chawla, N., Hartigan, D. B.,
  Hartigan, D. B., Moser, R. P., Taplin, S., Glasgow, R., Arora, N. K. (2016). Health self-efficacy among populations with multiple chronic conditions: the value of patient-centered communication. *Advances id Therapy*. 33: 1440. doi: 10.1007/s12325-016-

- Saldana, J. (2008). *Coding manual for qualitative researchers*. Los Angeles, CA: Sage Publications.
- Satterfield, D.W. (2001). "So that the people may live Hecel lena oyate nipi kte:" Women as reservoirs of knowledge about health protection and diabetes prevention. [Doctoral dissertation, The University of Geogia].

  https://getd.libs.uga.edu/pdfs/satterfield\_dawn\_w\_200112\_phd.pdf
- Satterfield, D. S., DeBruyn, L., Francis, C.D., & Allen, A. (2014). A stream is always giving life:

  Communities reclaim Native science and traditional ways to prevent diabetes and promote health. *American Indian Culture and Research Journal*, 38(1), 157-190.

  <a href="https://doi.org/10.17953/aicr.38.1.hp318040258r7272">https://doi.org/10.17953/aicr.38.1.hp318040258r7272</a>
- Scarton, L., & de Groot, M. (2016). Emotional and behavioral aspects of diabetes in

  American Indian/Alaskan Natives: A systemic literature review. *Health Education & Behavior*, 44(1), 70-82. doi: <a href="https://doi.org/10.1177/1090198116639289">https://doi.org/10.1177/1090198116639289</a>
- Sequist, T. D., Cullen, T., & Acton, K. J., (2011). Indian health service innovations have helped reduce health disparities affecting American Indian and Alaska Native people. *Health Affairs*, 30(10), 1965-1973. doi: 10.1377.hlthaff.2011.0630
- Sharf, B. F., & Vanderford, M. (2003). Illness narratives and the social construction of health. In A. Dorsey, K. L. Miller, R. Parrott, & T. Thompson (Eds.), *Handbook of Health Communication* (pp. 9-34). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Shinitzky, H. E., & Kub, J. (2001). The art of motivating behavior change: The use of motivational interviewing to promote health. *Public Health Nursing*, *18*(3), 178-185. doi: 10.1046/j.1525-1446.2001.00178.x.

- Shrivistava, S. R., Shrivistava, P. S., & Ramasamy, J. (2013). Role of self-care in management of diabetes mellitus. *Journal of Diabetes Metabolic Disorder*, *12*(14), 1-5. doi: 10.1186/2251-6581-12-14
- Smith, L. T. (2012). *Decolonizing methodologies: Research and indigenous peoples* (2nd Ed). London and New York: Zed Books.
- Tachine, A. R. (2015). *Monsters and weapons: Navajo students' stories on their journeys toward college* (Publication No: 3704873) Doctoral dissertation, University of Arizona].

  University Libraries, University of Arizona.
- Timpel, P., Lang, C., Wens, Contel, J., & Schwarz, P. E. (2020). The Manage Care Model-Developing and evidence-based and expert-driven chronic care management model for patients with diabetes. *International Journal of Integrated Care*, 20(2): 1-13. doi: http://doi.org/10.5334/ijic.4646
- Todacheene, H. L. (2014). She saves us from monsters: The Navajo creation story and modern tribal justice. *Tribal Law Journal*. *15*(1), 30-66.

  <a href="https://digitalrepository.unm.edu/tlj/vol15/iss1/2">https://digitalrepository.unm.edu/tlj/vol15/iss1/2</a>
- Tom-Orme, L. (1993). Traditional beliefs and attitudes about diabetes among Navajos and Utes. In J. R. Joe & R. S. Young (Eds.), *Diabetes as a disease of civilization: The impact of culture change on Indigenous peoples* (pp. 272-291). New York, NY: Mouton de Gruyter.
- Trevisi, L., Orav, J.E., Atwood, S., Brown, C., Curley, C., King, C., Muskett, O., Sehn, H., Nelson, K. H., Begay, M., & Shin, S. S. (2020) Community outreach for Navajo people living with diabetes: Who benefits most? *Preventing Chronic Disease*, 17(200068): 1-9. http://dx.doi.org/10.5888/pcd17.200068

- Trevisi, L., Orav, J. E., Atwood, S., Brown, C., Curley, C., King, C., Muskett, O., Sehn, H., Nelson, K. H., Begay, M., & Shin, S. S. (2019). Integrating community health representatives with health care systems: clinical outcomes among individuals with diabetes in Navajo Nation. *International Journal for Equity in Health*, *18*(183): 1-23. <a href="https://doi.org/10.1186/s12939-019-1097-9">https://doi.org/10.1186/s12939-019-1097-9</a>
- Tucker, G. (2006). First person singular: The power of digital storytelling. *Screen Education*, 42, 54-58.
- Turner, B. S. (2000). The history of the changing concepts of health and illness: Outline of a general model of illness categories. In G. Albrecht, R. Fitzpatrick, & S. C. Scrimshaw (Eds.), *Sage Handbook of Social Studies in Health and Medicine* (pp. 9-22). Thousand Oaks, CA: Sage Publications.
- Turner, M. M., Skubisz, C., & Rimal, R. N. (2011). Theory and practice in risk communication: A review of the literature and visions for the future. In T.

  L.Thompson, R. Parrott, & J. F. Nussbaum (Eds.), *The Routledge Handbook of Health Communication* (2<sup>nd</sup> Ed., pp. 146-164). New York, NY: Routledge.
- van Smoorenburg, A. N., Hertroijs, D. F. L., Dekkers, T. et al. (2019). Patients' perspective on self-management: type 2 diabetes in daily life. *BMC Health Serv Res*earch, 19, 605. https://doi.org/10.1186/s12913-019-4384-7
- Wagner, E. H., Bennett, S., Austin, B. T, Greene, S. M., Schaefer, J. K., & Vonkorff, M, (2005).
  Finding Common Ground: Patient-Centeredness and Evidence-Based Chronic Illness
  Care. The Journal of Alternative and Complementary Medicine, 11(1), S-7-S-15.
  <a href="https://doi.org/10.1089/acm.2005.11.s-7">https://doi.org/10.1089/acm.2005.11.s-7</a>
- Walters, K. L., Mohammed, S., Evans-Campbell, T., Beltrán, R., Chae, D., & Duran, B. (2011).

- Bodies don't just tell stories, they tell histories: Embodiment of historical trauma among American Indians and Alaska Natives. *Du Bois Review*, 8(1), 179–189. doi: 10.1017/S1742058X1100018X
- Warne, D., & Lajimodiere, D. (2015). American Indian health disparities: Psychosocial influences. Social and Personality Psychology Compass, 9(10): 567-579. doi: 10.1111/spc3.12198
- Werito, V. (2014). Understanding *Hozhó* to achieve critical consciousness: A contemporary Diné interpretation of the philosophical principles of *hozhó*. In L. L. Lee, *Diné Perspectives: Revitalizing and reclaiming Navajo thought*. Tucson: The University of Arizona Press.
- Whitegoat, W., Vu, J., Thompson, K. & Gallagher, J., (2017). Mental health in diabetes
   prevention and intervention programs in American Indian/Alaska Native Communities.
   Washington University Journal American Indian Alaska Native Health, 1(1): 1-15.
   PMID: 28451652
- Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Black Point, Nova Scotia: Fernwood Publishing.
- Womack, R. B. (1993). Measuring the attitudes and beliefs of American Indian patients with diabetes. *The Diabetes Educator*, *19*(3), 205-209. https://doi.org/10.1177/014572179301900307
- Woodbury, R. B., Ketchum, S., Hiratsuka, V.Y., & Spicer, P. (2019). Health related participatory research in American Indian and Alaska Native Communities: A Scoping Review.

  International Journal of Environmental Research and Public Health. August: 16(16): 2969-2995. doi: 10.3390/ijerph16162969

Yazzie, D., Tallis, K., Curley, C., Sanderson, P. R., Eddie, R., Behrens, T. K., Antone-Nez, R., Ashley, M., Benally, H. J., Begay, G. A., Jumbo-Rentila Ma, S., & de Heer, H. D. (2020). The Navajo Nation healthy Dine Nation Act: A two percent tax on foods of minimal-to-no nutritious value, 2015-2019. *Preventing disease*, *17*(E100). <a href="https://doi.org/10.5888/pcd17.200038">https://doi.org/10.5888/pcd17.200038</a>