2015

Cultural Beliefs and Experiences of Formal Caregivers Providing Dementia Care to American Indians

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Abstract

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Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Public Health

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Abstract

Alzheimer's disease (AD) is a significant public health concern for all elders in the United States. It is a particular concern for the American Indian (AI) population, which is one of the fastest-aging populations in the United States and the smallest, most underrecognized, and most culturally-diverse group in the country. A formal caregiver understanding of AD in the AI population is scarce. This phenomenological study was designed to discern what is known about AD in the AI population by exploring the cultural beliefs and experiences of formal caregivers who provide care for AI dementia patients. Specifically, this study sought to document formal caregiver and AI dementia beliefs about AD. Data came from 4 in-depth interviews that included 3 Western and one AI formal caregiver. These interviews explored the variability of cultural beliefs regarding AD and dementia among a sample of formal caregivers who minister to AI patients; in the interviews, these participants also provided examples of challenges they faced, providing a better cultural understanding of AI dementia. Results suggested that challenges include adopting a bicultural approach to AD, illuminating interactions between patient and provider, and fostering awareness of cultural competency. Research on this topic is critical in advancing cultural, public health, and evidence-based health practices regarding AI dementia patients. The potential implications for social change include enhancing cross cultural provider-patient interactions and advancing public health policy and practice for this underserved population. Many of the issues and challenges explored may have implications for other ethnocultural minority groups.

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Dedication

In memory of my parents, Rae and James. Words cannot express the Love and Gratitude I have for both of you.

In memory of my undergraduate mentors, Daisy M.L. Tagliacozzo, PhD and Gerald R. Garrett, PhD, and of two of my grammar school teachers, Sister Mary Geraldine O'Connor, SND and Sister Mary Cornwell, SND, and of my high school teacher Sister Gertrude Smith SCN. Each of you taught me to do my best and nurtured me academically. All of you have had a positive impact on my life, and I am forever grateful to each of you.

To my benefactors, Judy and Doug Fitzsimmons, your belief, love, and support have been a mainstay in helping me finish this dissertation. I don't know what I would have done without your generous assistance.

I want to thank Dr. Lewis Mehl-Madrona, who encouraged me to make this study a reality. Through many twists and turns, I was able to seek his advice. I will never forget his kindness and belief in me and the topic of this study. A very special Kinana'skomotin'waw!

I also want to thank the Reverend Anne Berry Bonnyman. Your words in your last sermon at Trinity Church have been a godsend and a real consolation to me. "Remember who you are and where you came from." I have had to repeat these words over and over.

Acknowledgments

Kinana’skomotinKisemanito (I Thank You God-Great Spirit) for all your help throughout this journey and for the gift to assist in imparting this information. I also say Kinana’skomotin’ waw (I Thank You People) to my Cree and non-Cree ancestors.

A special Kinana’skomotin’ waw to the formal caregivers who consented to participate in this study.

It takes a village to produce a PhD, and I am grateful to the many people who supported me throughout the completion of this dissertation. I am especially grateful for the support of my dissertation committee: Dr. C.J. Schumaker Jr., Dr. Ronald Hudak, and Dr. Gary J. Burkholder. I could have not made it through this laborious and arduous task if it weren’t for the following people: my APA Editors, John and Sue Morris; Youssef Kamil, who helped me with all the technical aspects of completing this study; to my cousin, Gail Marshall Williams, for her excellent transcription of all of the interviews for this study; and to Janis A. Pryor for her expertise on editing the Indigenous cultural and worldview aspects of this study.

I also want to thank the individuals of what I refer to as “Damon’s Support Team,” these individuals include: Reverend Dr. William Rich, Reverend Rainey Dankel, Judith and Warren Radkte, My aunt Margaret Proulx and my uncle Joseph Proulx, Dona Luisa and Wayne Pembreton, Irene Reiss, Dr. Sandra Rasmussen, Dr. Patricia J. Scott, Ruth Knopf, and Cora Lewis

Table Of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the Study

Introduction

The incidence of Alzheimer's disease is increasing rapidly throughout the United States (Alzheimer's Association, 2014). Alzheimer's disease is a type of dementia that can affect people regardless of race or ethnicity, and Alzheimer's disease is the predominant form of dementia in the United States and worldwide (Alzheimer's Association, 2014). Dementia is a disorder of the brain that prevents individuals from being able to participate in normal activities of daily living (Alzheimer's Association, 2014). Alzheimer's disease is a progressive and degenerative neurological disease that severely impairs memory function and for which there is no known cure (Alzheimer's Association, 2014). Prior epidemiological and genomic research has suggested "that the allelic architecture of American Indians can confer protection against the disease" (Benedet et al., 2012, p. 311). However, Weiner, Hynan, Beekly, Koepsell, and Kukull (2007) argued that researchers must be cautious when interpreting genetic and blood quantum data because of issues of acculturation into Western society, and because American Indians (AIs) do not always self-report being AI as their primary racial classification.

Current literature on dementia in the AI population suggests that this population is heterogeneous in its cultural beliefs and has a prevalence of dementia. The epidemiological and caregiver literature on AIs remains underdeveloped and AIs are under recognized as a heterogeneous population (Goins et al., 2011; Jervis & Manson, 2002). Additional qualitative and exploratory studies are needed that not only focus on cultural beliefs about Alzheimer's disease in the AI dementia population, but also on the role of cultural factors of formal caregiving to the AI dementia population (Goins et al., 2011; Jervis & Manson, 2002). This study explored these factors to address a gap in the literature.

Background

This study employs American Indian (AI) to refer to the original population in the United States before the arrival of the Europeans. It further uses the term *Indigenous* with a capital I to refer to this population's worldviews and cultural nuances (Clarke, 2012; Yuan, Bartigis, & Demers, 2014). The related terms *Aboriginal* and *First Nation* refer to the original populations of Australia and Canada; they appear in direct quotations where these terms were used in scholarly literature.

History has not been kind to the AI population of the United States (Zinn, 2005). For more than five centuries, AIs have been labeled as savages, barbarians, demons, and beasts by Westerners and early European settlers (Weidensaul, 2012). The labels have led to widespread oppression, misunderstanding, and disparities in virtually every aspect of AI lives (Satter, Randall, & Solomon, 2014). Because of fragmented healthcare systems, government underfunding, and access to healthcare and healthcare services, AIs continue to suffer some of the highest rates of chronic health conditions in the United States (Centers for Disease Control and Prevention [CDC], 2010, 2012; E. R. Rhoades & Rhoades, 2014). Alzheimer's disease is emerging steadily in AI populations because AIs are living longer and are the fastest growing population in the age 65+ category (U.S. Department of Commerce, Economics and Statistics Administration, 2010).

AIs have some of the highest disease comorbidities and lifestyle risk factors associated with dementia in the United States (Goins & Pilkerton, 2010). Jervis and Manson (2002) found disparities in tracking AI cases of Alzheimer's disease and dementia because of the fragmented healthcare systems between reservations, in rural and urban AI populations.

Limited information is available regarding formal caregiver and AI understanding of Alzheimer's disease. This lack has also provided an incomplete picture of the experience of formal dementia caregivers. Researchers have suggested common reasons for the lack of information including: (a) differences in access and the types of medical care available for AI rural, and urban, populations; (b) lack of appropriate information regarding the heterogeneity of AI beliefs of disease and formal caregiving duties; (c) limited studies that address Alzheimer's disease among AIs; (d) racial misclassifications of AIs; (e) indistinct racial classification between AIs and Alaskan Natives; and (f) incomplete automated reporting systems on diagnosis and discharge diagnosis (Goins et al., 2011; Henderson & Henderson, 2002; Jervis & Manson, 2002).

Problem Statement

Prior theoretical and conceptual frameworks have focused on understanding Alzheimer's disease from health and sociocultural coping models (Goins et al., 2011; Knight & Sayegh, 2010; Knight, Silverstein, McCallum, & Fox, 2000). These frameworks have not addressed or included formal caregivers, AI dementia patient, or cultural beliefs regarding Alzheimer's disease (Jervis & Manson, 2002). This lack of information has slowed needed research and delivery of needed healthcare for disease-specific illnesses (Goins & Pilkerton, 2010; Goins & Spencer, 2005; Goins et al., 2011; Jervis & Manson, 2002; Portman & Dewey, 2003). AIs have been used either as a comparison or contrast group in the limited genomic and epidemiological literature (Weiner et al., 2003) and as a limited contrast group in cultural studies (Dilworth-Anderson, Williams, & Gibson, 2002).

According to the U.S. Department of Commerce, Economics and Statistics Administration (2012) 2.2% of the 5.2 million American Indian and Alaska Natives (AI/AN) reside on reservations and land trusts. The U.S. Office of Management and Budget and the U.S. Census Bureau uses AI/AN to federally report AI and Alaska Native racial groupings. The Henry J. Kaiser Family Foundation (2013) further reported that many AIs and their caregivers live in poverty, suffer from poor health, and do not have access to adequate care.

The Indian Health Service (IHS) is the main operating health care agency that provides medical and public health services to the 114,000AI/AN persons who live on reservations and land trusts (U.S. Department of Health and Human Services, Indian Health Services [IHS], 2014a). At the time of this study, the IHS also funded Urban Indian Health Programs (OUIHP) programs through grants and contracts, and in total provided all health care to 33 Hospitals, 59 health centers, and 50 health stations, in addition to supplementing funding to 34 urban Indian Health projects (IHS, 2014a). Twelve IHS service areas throughout the United States provide both traditional and Western forms of health care. However, geriatric care funding is severely underfunded or nonexistent in the IHS budget (U.S. Commission on Civil Rights, 2004). As a result, IHS facilities are not able to deliver AD and dementia specialty care. Some rural and urban AI dementia patients choose not to receive specialty care from Western providers because of their distrust of providers who do not respect or possess knowledge and understanding of AI dementia cultural health issues (M. L. Castro et al., 2006; Goins et al., 2011; Jervis & Manson, 2002).

This study addressed a problem of culturally biased perspectives, assessments, and measurements, and historical factors relating to Alzheimer’s disease treatment involving AIs. It specifically these factors in relation to the beliefs of formal caregivers, AI dementia patients on Alzheimer’s disease, access to culturally sensitive healthcare, and the types of healthcare used by AI dementia patients that have resulted in a misunderstanding of the interaction between culture and disease (Dilworth-Anderson et al., 2002; Goins & Pilkerton, 2010; Goins & Spencer, 2005; Goins et al., 2011). Goins et al. (2011) emphasized the need to focus on the cultural notions of formal caregivers, the cultural factors that may influence how formal caregivers provide care, and their own understanding of what it means to be a formal caregiver. It addressed a research gap consisting of a lack of knowledge regarding the cultural beliefs and experiences of Alzheimer’s disease among the AI population.

Purpose Statement

The purpose of this study was to explore the cultural beliefs and experiences of formal caregivers who provide dementia care to AI demented patients. Specifically, this study sought to understand formal caregiver’s cultural beliefs about Alzheimer’s disease and dementia, and how these beliefs define the course of care developed by the formal caregivers to AI dementia patients. Limited literature was available on this topic and extant studies on this population lacked cultural understanding of the nuances of formal caregivers and AI dementia patients (Goins & Pilkerton, 2011; Goins et al., 2011; Henderson & Henderson, 2002; Jervis & Manson, 2002). By approaching formal caregiving in this manner, I sought to identify cultural differences specific to the AI dementia population. Of particular interest was whether formal caregivers choose traditional medicine, Western medicine. The research questions in this study were answered using a phenomenological approach. These questions appear in the next section.

Research Questions

The three research questions guiding the study were:

1. What are the understandings of formal caregivers for American Indians about their patients' cultural beliefs about Alzheimer's disease and dementia?
2. What are the cultural beliefs about Alzheimer's disease and dementia of formal caregivers for American Indians?
3. How do formal caregivers for American Indians use their cultural beliefs about Alzheimer's disease and dementia, to develop courses of care for their patients?

Conceptual Framework

At the center of the indigenous worldview is a belief that all things in nature are imbued with spirit (Deloria, 2003; Lowe, 2002). However, Westerners' worldviews often emphasize a Creator, the natural world, and human beings as separate and distinct from one another, and value individuality and independence as viable means of achieving harmony and balance (Lowe & Struthers, 2001). AIs, in contrast, generally view relationship and accountability to all of creation as the means of achieving harmony and balance in one's life. Because of AIs'emphasis on balance and harmony, "each person possesses special gifts and talents and makes contributions through these gifts and talents to the whole of creation and universe" (Lowe, 2002, p. 6). It is when these talents, gifts, and contributions become imbalanced that harmony is not achieved, thereby leading to what AIs refer to as disease.

This conceptual framework was constructed to address a negative historical perception by American Indians of research conducted by Western researchers on AI persons (Humphrey, 2001; L. T. Smith, 2012). The AI conceptual framework honors AI cultural beliefs and cultural notions regarding Alzheimer's disease. For the purpose of this discussion, the medicine wheel served as the example by which AIs have come to understand disease and have relied on the oral tradition to find healing (see Figure 1).

The traditional medicine wheel represents the circle of life and how all living things in the universe are connected, related, and intertwined (Lowe & Struthers, 2001; Struthers & Eschiti, 2005; Struthers, Eschiti, & Patchell, 2004). Since 1985 to the present, a corpus of literature has emerged focusing on nursing and holistic healing that uses the medicine wheel as a conceptual framework for AI and Western nurses who care for the AI population (Arnold & Bruce, 2005; Hunter, Logan, Goulet, & Barton, 2006; Lowe, 2002; Lowe & Struthers, 2001; Struthers & Littlejohn, 1999; Struthers & Lowe, 2003). The traditional medicine wheel and the conceptual framework of nursing in the AI culture aid in the exploration of understanding of AI health and medicine. The medicine wheel has been used by AI nurses “to draw upon their own particular health world view in situations of health and illness” (Lowe & Struthers, 2001, p. 280).

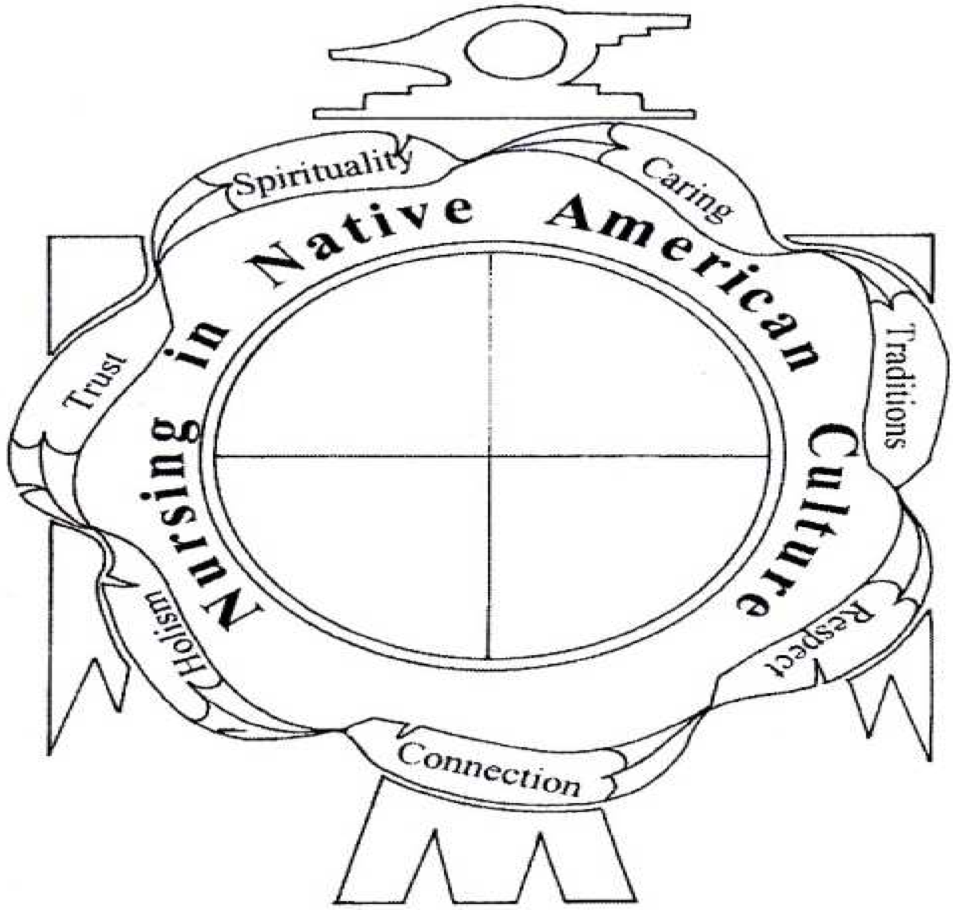

Figure 1. Conceptual model of nursing in American Indian culture.
Note. Adapted from “A Conceptual Framework of Nursing in Native American Culture,” by J. Lowe & R. Struthers, 2001, *Journal of Nursing Scholarship*, *33,* p. 282. Copyright 2001 by *Journal of Nursing Scholarship*. Reprinted with Permission.

The medicine wheel, also known as the circle of life, can also be used by non-AI practitioners not only to understand AI worldviews on health and illness; it can also be used by these practitioners to build necessary trust with the AI population to care for their health needs (Hunter et al., 2006). Figure 1 is a visual depiction of how nurses may engage AI patients in traditional healing practices, while the AI patient may be receiving Western biomedical interventions for a particular disease.

The essence of AI nursing lies in healing and caring (Lowe & Struthers, 2001; Struthers & Littlejohn, 1999). These two factors are of utmost importance as they relate to the Indigenous worldview of nursing and health. It is this notion whereby AI nursing and medicine diverge from Western biomedical medicine. The emphasis for AI nurses is on healing, rather than on curing. Lowe and Struthers (2001) identified seven dimensions that are essential to AI nursing: (a) caring, (b) traditions, (c) respect, (d) connection, (e) holism, (f) trust, and (g) spirituality. These dimensions may be further categorized into a medicine wheel or circle of life and form the basis for AI holistic healing on an individual, family, community, and global level, based on the AI world view of health and illness (Figure 1; Hunter et al., 2006). Little Bear (2009) states:

> The function of Aboriginal values and customs is to maintain the relationships that hold creation together. If creation manifests itself in terms of cyclical patterns and repetitions, then the maintenance and renewal of those patterns is all-important. Values and customs are the participatory part that the aboriginal people play in the maintenance of creation. (p. 81)

Hunter et al., (2004) documented that it is these dimensions, along with the varying levels of holistic healing that form the basis of understanding AI nursing.

The conceptual framework for this study was also guided by previous work of Roter and Hall (1989) regarding formal caregiver and patient interaction. This framework is particularly important for both AI and Western formal caregivers providing dementia care to AI patients. Roter and Hall (1989) outlined two categories of formal caregiver's skill and behavior as essential to developing trust with AIs. The first of these is technically based skills which are "skills used in problem solving that comprise the expertness for which the provider is consulted" (p. 171). The second category includes the affective and socioemotional behavior between the formal caregiver and dementia patient. These behaviors include intrinsic behaviors "such as small talk, joking, and nonverbal behaviors" and "tone of voice and smiling and other behaviors that gain affective significance by their interpretation" (Simonds, Christopher, Sequist, Colditz, & Rudd, 2011, p. 837). It is these skills and behaviors that determine the trust and success of the relationship between AI and Western formal caregivers and their AI dementia patients. Figures 2 and 3 show visual depictions of this process.

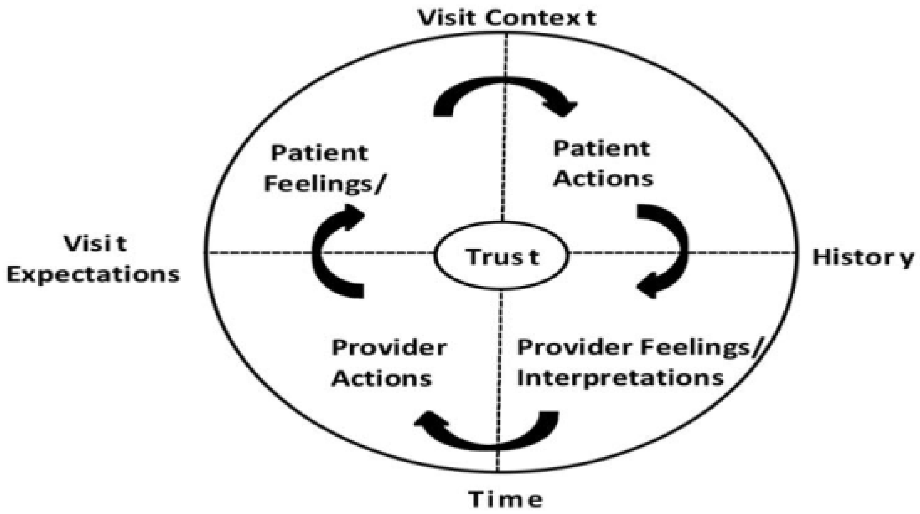

Figure 2. Model of patient-provider interaction.
Note. Adapted from "Exploring Patient Provider Interaction in a Native American Community," by V. Watts-Simonds, S. Christopher, T. D. Sequist, G. A. Colditx, & R. E. Rudd, 2011, *Journal of HealthCare for the Poor and Underserved, 22,* p. 840. Copyright 2011 by Meharry Medical College. Reprinted with permission.

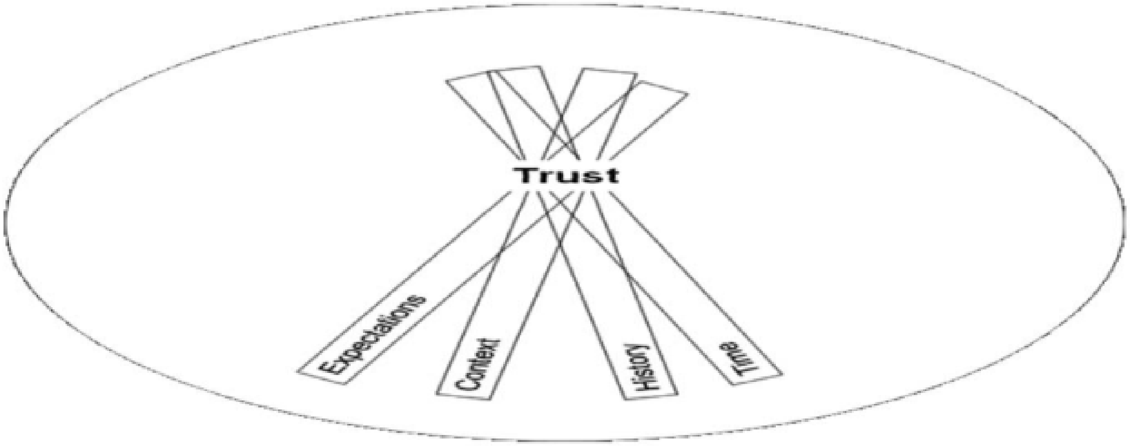

Figure 3. Model of patient-provider interaction using a culturally significant symbol. *Note.* Adapted from “Exploring Patient-Provider Interactions in a Native American Community,” by V.Watts-Simonds, S. Christopher, T. D. Sequist, G. A. Colditz, & R. E. Rudd, 2011, *Journal of Health Care for the Poor and Underserved, 22,* p. 841.Copyright 2011 by Meharry Medical College. Reprinted with permission.

Nature of the Study

To answer the questions posed in this study, I collected data from a combination sample (*N*=4) of AI and Western formal caregivers providing dementia care and services to AI demented patients in rural northern New England. A formal caregiver is a paid medical provider (Family Caregiver Alliance, 2014). For purposes of this research study, this sample was drawn using purposive sampling. I recorded individual interviews with these formal caregivers’ responses. These semi structured semi structured interviews facilitated the gathering of information on formal caregivers’ understanding of AI cultural beliefs of Alzheimer’s disease and dementia as reported by their AI dementia patients, as well as formal caregivers ’cultural beliefs about AI and dementia, and how formal caregivers use these cultural beliefs to develop a course of care for their AI dementia patients.

Because researchers showed that phenomenological research has been a culturally accepted method in conducting research with AI populations, the qualitative method was used for this study (Struthers & Peden-McAlpine, 2005). Qualitative research methods assist in exploring, understanding, and describing formal caregiver cultural beliefs and AI dementia patient cultural beliefs and how these cultural beliefs shape the experiences of Alzheimer's disease and dementia in the AI population (Creswell, 2009). Prior research did not explore and describe the formal dementia caregiver, AI dementia patient care experience; the lack of cultural understanding of AI Alzheimer's disease and a lack of cultural understanding of AI dementia patients by the Western population led me to choose the qualitative method as an appropriate methodology. Additionally, to date, no previous research was conducted with AI populations in the United States regarding formal provider care and AI dementia specific care. Qualitative research is chosen when there is a little is known about a topic or phenomenon (Creswell, 2009; Struthers & Peden-McAlpine, 2005). "Qualitative research methods are used when little is known about the topic and allows the researcher to explore meanings and interpretations of constructs rarely observed in quantitative research" (Jeanfreau & Jack, 2010, p. 613).

Definitions

The following list provides definitions for terms used in this study:

Aboriginal: A person descended from the original populations of Canada and Australia.

Activities of daily living: "Assistance with bathing, dressing, feeding, toileting, and transferring from bed to chair" (Aldrich, 2009, p. 4).

Alaska Native: Refers to “Alaska’s many diverse native cultures” (AI/Alaska Heritage Center, 2012, p. 1).

Alzheimer’s disease (AD): A type of dementia and brain disorder that is progressive and that eventually causes memory loss. “AD is the most common form of dementia” (Alzheimer’s Association, 2014, p. 1).

American Indian (AI): Another term for Native American. A person descended from the original population of North America.

Amerindian: An anthropological term to describe original Natives before Columbus arrived in Central and South America (Contreras et al., 2010).

Axiology: “Axiology is the ethics or morals that guide the search for knowledge and judge which information is worthy searching for” (S. Wilson, 2008, p. 35).

Caregiver: A person who performs basic care and looks out for the safety of another person.

Cree: One of the largest American Indian tribes in North America (Chippewa Cree Nation, 2013).

Dementia: “Memory loss that impairs a person’s ability to carry out daily activities” (Alzheimer’s Association, 2014, p. 2).

Formal providers: Health care professionals who provide medical care.

First Nation: Refers to Tribes and Nations of the original Aboriginal population in Canada.

Indigenous: “The original inhabitants of Australia, Canada and other countries worldwide. Indigenous is also used as an adjective to describe these people” (S. Wilson, 2008, p. 34).

Informal caregiver: A family member or friend caring for an individual who is either temporarily or permanently physically impaired (Family Caregiver Alliance, 2010).

Medicine wheel: “A holistic integration of humans and the natural world” (P. Walker, 2001, p. 19).

Rural American Indians: AIs who live on reservations and tribal lands in rural areas.

Shema: The White way.

Tribal epistemology: Knowledge pertaining to a particular tribe.

Urban Indians: AIs who reside in urban and metropolitan areas.

Verstehen: Understanding, comprehension, or meaning (Olutayo, 2012)

Assumptions

The assumptions of this study were as follows:

1. AIs are living longer and the incidence of Alzheimer’s disease in this population will increase. This has been a recurring assumption made in Healthy People 2010 (U.S. Department of Health and Human Services, 2010), Healthy People, 2020 (U.S. Department of Health and Human Services, 2013), and U.S. Census Data (U.S. Department of Commerce, Economics and Statistics Administration, 2010).

2. The number of formal dementia caregivers caring for AI dementia patients will rise.
3. Chronic disease in the AI population will continue to increase until issues of health disparities are addressed. This assumption has been cited in Healthy People (U.S. Department of Health and Human Services, 2010) and proposed goals for Healthy People 2020 (U.S. Department of Health and Human Services, 2013).

Scope and Delimitations

Although there are some census and epidemiological data on AI reservation and urban AIs, there are no empirical data of the numbers of AIs diagnosed with either Alzheimer's disease or dementia (Jervis & Manson, 2002). There are however, data on mortality rates from Alzheimer's disease among AIs. The U.S. Department of Health and Human Services (2010) reported .042 per 100,00 mortality rate from Alzheimer's disease among AI males, .083 per 100,000 mortality rate from Alzheimer's disease among AI females for a total of 0.62 per 100,000 mortality rate among the AI population in 2010. These data represent an increase of 1.5% among female AI death rates from Alzheimer's disease from the years 1999–2009 (Espey et al., 2014). The exact number of formal caregivers providing dementia care in the AI population remains virtually unknown (Garrett et al., 2010). The delimitations of this study include (a) the formal caregiver is presently caring for AI dementia patients with a clinical diagnosis of Alzheimer's disease or dementia; (b) formal caregivers included in this study must be from northern rural New England only; (c) formal caregivers must not be caring for a AI dementia patient or be a informal caregiver that is a family member (i.e. in-law, cousin, niece, nephew or other extended family member). Formal caregivers were excluded from participation in this study if they had been diagnosed with any form of cognitive impairment. Formal caregivers were asked if they had any form of cognitive impairment. Researchers must assume participants are being truthful and reliable in their responses.

Limitations

The following is a list of potential limitations for this study:

1. This study focused on formal caregivers providing care to AI dementia patients in one geographical location only.
2. Rates of comorbidities and lifestyle factors vary depending on tribal affiliation and geographical location.
3. Purposive sampling does not enable generalization to all tribal affiliations across the United States. Because there is limited research on AIs and Alzheimer's disease, a purposive sample enables the researcher to explore and understand a phenomenon where there is limited information in the literature.
4. The sample size (*N*=4) was too small to generalize to the entire AI dementia population. The research was limited to formal caregivers providing care to AI dementia patients where no known studies have been conducted on Alzheimer's disease.

Significance of the Study

The study fills a void in the existing AI Alzheimer's disease and dementia formal caregiver literature and research by providing qualitative data on a topic of marked importance (Goins & Pilkerton, 2010; Jervis & Manson, 2002). Evaluation of evidence-based, self-management, and community-based participatory research is scarce for Alzheimer's disease and dementia in the AI population (Daley et al., 2010; Jernigan, 2010; Orom & Gage, 2013). Current literature has not kept pace with cultural differences of Alzheimer's disease and dementia in the AI population (Alzheimer's Association, 2014; Dixon & Iron, 2006; Goins et al., 2011; Jervis & Manson, 2002).

The potential implications for positive social change include construction of programs aimed at the cultural understanding of Alzheimer's disease and dementia in the AI population, among formal providers caring for AI dementia patients, as well as to initiate responsive programs for AI dementia patients. Additional research may also focus on extending the seminal literature using quantitative and mixed-methods approaches, with the potential of providing data needed to develop AI explanatory models of Alzheimer's disease in the AI population and cultural beliefs of formal caregivers, and AI dementia patients (Dilworth-Anderson et al., 2002; Goins et al., 2011; Hennessy, 1996; Janevic & Connell, 2001; Parveen, Morrison, & Robinson, 2011). In addition, this research paves the way for future research on (a) Alzheimer's disease in the AI population; (b) research specifically focused formal caregiving with AI dementia patients, and (c) research on the cultural nuances of caregiving in the AI population. Further, this study may also pave the way for research in other populations where Alzheimer's disease is less understood.

Summary

This chapter presented an overview of how AIs understand Alzheimer’s disease. It included an introduction to the problem that culturally biased assessments and historical factors relating to the access of healthcare have resulted in the misunderstanding of culture and disease. I also presented the problematic issues of limited literature on Alzheimer’s disease in the AI population. Additionally, I reviewed problematic issues regarding formal caregivers and AI dementia patients, as well as the use of a culturally relevant conceptual framework to begin to explore and understand Indigenous worldviews. Such a conceptual framework is important to understanding the health behaviors of AIs, and more specifically to the course of care provided to AI dementia patients.

Chapter 2: Literature Review

Introduction

The purpose of this phenomenological study was to explore the cultural beliefs and experiences of formal caregivers who provide dementia care to AI dementia patients. It was specifically designed to document formal caregiver cultural beliefs about Alzheimer's disease and dementia, and how these beliefs define the courses of care developed by formal caregivers to American Indian dementia patients. It addressed a literature gap concerning the cultural understanding of the nuances of formal caregivers and AI dementia patients (Goins & Pilkerton, 2011; Goins et al., 2011; Henderson & Henderson, 2002; Jervis & Manson, 2002). By approaching formal caregiving in this manner, I sought to identify cultural differences specific to the AI population. Of particular interest was whether formal caregivers choose traditional medicine, Western medicine, or a combination.

The problem investigated by this study was that culturally biased perspectives, culturally biased assessments and measurements, and historical factors relating to the beliefs of AI formal dementia caregivers on Alzheimer's disease, access to culturally sensitive healthcare, and the types of healthcare used by AIs and their formal caregivers have resulted in a misunderstanding of the interaction between culture and disease (Dilworth-Anderson et al., 2002; Goins & Pilkerton, 2010; Goins & Spencer, 2005; Goins et al., 2011). Goins et al. (2011) discussed the need to focus on the cultural notions of AI formal caregivers as well; cultural factors that influence how AI formal dementia caregivers provide care, and these caregivers' own understanding of what it means to be a formal caregiver. The general problem investigated was a lack of knowledge regarding the cultural beliefs and experiences of Alzheimer's disease among the AI population.

Literature Search Strategy

In the search for relevant literature, I accessed electronic databases through the Walden University Library, the University of Massachusetts–Boston, and the Boston Public Library. Google Scholar was the main search engine that I used. The search used the following key terms to identify literature related to Alzheimer's and dementia among AIs and formal dementia caregiving among AIs: *Alzheimer's disease and American Indians*, *dementia and American Indians*, *Urban American Indians*, *help seeking choices*, *cultural notions about caregiving*, *cultural values and American Indians*, *traditional healing and American Indians*, *Western medicine and American Indians, formal and formal caregiver support services used*, *Apolipoprotein (APOE) and American Indians*, *APOE4 and American Indians*, *American Indian cultural beliefs disease*, *American Indian cultural beliefs Alzheimer's disease*, *American Indian cultural beliefs dementia*, *American Indian genomic literature*, *American Indian lifestyle risk factors*, and *American Indian leading diseases*. The search spanned literature published 1980–2014 because of the limited literature on the research topic and to provide a comprehensive literature review of what was available. All of the abovementioned search terms were used in the following databases: MEDLINE, Nursing Academic, Academic Search Premier, ERIC ProQuest, CIAIHL, CIAIHL SELECT, CIAIHL PLUS, PsycARTICLES, PsycINFO, and SocINDEX.

This search for relevant literature only identified a limited body of available information on Alzheimer's disease and dementia among AIs as well as on formal caregiving with AI dementia patients in the United States. I supplemented these results by reviewing literature on the Institute of Medicine, National Institutes of Health, Indian Health Services, and Alzheimer's Association websites. I also examined related literature on First Nation and Aboriginal populations in Canada and Australia. The literature in Canada and Australia has kept current pace with the needs of its native populations, so this literature was used when (a) the literature was deficient in the United States and (b) there was comparable information regarding the Alzheimer's disease and dementia literature among AI, First Nation, and Aboriginal populations and their formal and informal caregivers. In other instances, when appropriate, I also consulted books, articles, and texts written by AI. This material was particularly helpful in discerning AI worldviews, spirituality, science, religion, healing, and familism.

Conceptual Framework

I selected the medicine wheel as the conceptual framework for this study because of its prominence in AI medicine. Unlike biomedicine and Western medicine, which uses the scientific method, AI medicine incorporates both a biomedical and holistic approach. The medicine wheel has been used for centuries by AIs to provide a holistic understanding of disease (DiStefano, 2006), and to diagnose and treat disease, bringing the body and mind back to restored balance and harmony (Deloria, 2006; P. Walker, 2001). From an AI perspective, balance and harmony are the representation of someone being disease free, whole, and healthy (Deloria, 2006).. The oral tradition is the manner in which AI practitioners use the medicine wheel to talk about disease and the manner in which AIs find healing, based on the laws of nature, traditional medicine, and a way to achieve harmony and balance (Deloria, 2006).

Historically, Westerners have viewed AI medicine and traditional healing with contempt, with Western scientists categorizing these as forms of quackery (Lane, Bopp, Bopp, & Norris, 2002; Walker, 2001).The more recent notion that Westerners must develop an empathetic understanding of the AI worldview underscores these negative impressions of native medicine and traditional healing (Pollio, Henley, & Thompson, 2006). This empathetic understanding is based on the German concept of *verstehen*, which means understanding and comprehension (Waiter, 1989). It is this understanding by Westerners, imbued with the AI worldview that facilitates a greater meaning and understanding of the cultural beliefs and experiences of AIs caring for a family member with Alzheimer’s disease and dementia (Deloria, 2006; Mehl-Madrona, 2007).

In the context of this study, the concept of *verstehen* was used to aid in understanding the meaning of Alzheimer’s disease and dementia in the everyday lives of formal dementia caregivers and AI dementia patients. The concept of *verstehen* was developed by Dilthey, a 19th-century sociologist and philosopher (Harrington, 2001). This concept was developed to focus more on human studies and disciplines, rather than natural sciences (Helle, 1995). *Verstehen* has also appeared in the writings of Schutz and Luckmann in the 20th century. Dilthey, Luckmann, and Schutz agreed that *verstehen* is the basis for understanding meaning in everyday life (Olutayo, 2012). Within the context of this study, *verstehen* is essential, because the focus of Alzheimer's disease is on human studies rather than natural studies (Helle, 1995).

Demographics of Native Americans

At the time of this study, there were 5.2 million AIs and ANs in the United States (U.S. Department of Commerce, Economics and Statistics Administration, 2010), according to the racial classification used by the U.S. federal government to classify anyone with American Indian or Alaskan Native ancestry. The number of AIs and Alaskan Natives is expected to increase to 8.6 million by 2050 (U.S. Department of Commerce, Economics and Statistics Administration, 2010). According to the IHS (2014b), there are 566 Federally Recognized Tribes in the United States. The life expectancy for AIs is "six years lower than the U.S. average" (American Psychiatric Association, 2010, p. 1). The leading causes of death ranked in order among AIs include (a) heart disease, (b) cancer, (c) unintentional injuries, (d) diabetes, (e) chronic liver disease and cirrhosis, (f) chronic respiratory disease, (g) stroke, (h) suicide (i) nephritis, nephritic syndrome, and nephrosis, (j) influenza and pneumonia (CDC, 2012).

It is estimated that more than half of AIs live off of reservations in rural, urban, and suburban areas (U.S. Department of Commerce, Economics and Statistics Administration, 2012). According to the CDC (2012), health disparities are still a significant concern in AI rural and urban communities. The Institute of Health, Board on Health Science Policy (2003) reported that health disparities among the AI population exist because of genetic predisposition, socioeconomic factors, and access to health care.

American Indians in Rural and Urban Settings

Rural American Indians

For purposes of this study, the term rural AI was used to refer to AIs living on federally recognized AI reservations land trusts and in the general rural U.S. population. Today, there are 2.2 million AI/ANs who live on federally recognized reservations and land trusts (IHS, 2014b). In 1887, Congress passed the Dawes Act, which according to Yazzie (2009) was “a scheme to civilize Indians by dividing up reservations into small, individually owned parcels of land called allotments” (p. 40). Since the inception of the reservation system, AIs have suffered the highest amounts of poverty, health care disparities, and highest rates of cardiovascular disease, cancer, and diabetes type II which are comorbid conditions associated with Alzheimer’s disease and lead to early mortality (Kim, Bryant, Goins, Worley, & Chiriboga, 2012; Jones, 2006; U.S. Department of Commerce, 2013; U.S. Department of Health and Human Services, 2012). The economic, social, and physical isolation of life on reservations is suboptimal, with reservations sometimes referred to as underclass areas (Burton, Lichter, Baker, & Eason, 2013). Despite these circumstances, the elderly AIs continue to live on reservations because of their fear of losing healthcare benefits (CDC, 2009).

The state of AI health care is a fragmented system, and one that has been fraught with many broken promises, inequalities, and disparities as compared with the health care in the general population. The Snyder Act of 1921, the Transfer Act of 1954, and the Health Care Improvement Act of 2010 all included language about the federal government’s federal responsibility to provide health care to AI/ANs and to “ensure the highest possible health status for Indians and urban Indians and to provide all resources necessary to effect that policy" (as cited in Warne & Frizzell, 2014, p S263). The IHS was created to ensure this care was provided for (a) tribal reservations, (b) independently tribal operated health care facilities, and (c) the urban Indian health care program is the IHS. Warne and Frizzell (2014) discussed that unlike Medicare and Medicaid programs that automatically receive federal funding, IHS services are subject to available funding per fiscal year. In a 2013 article that appeared in *Indian Country Today*, Gale Courey Toensing reported that the IHS 2013 budget was reduced by $800 million. This reduction represented a substantial percentage of the IHS budget for that fiscal year. A report by the U.S. Commission on Civil Rights (2004) cited a number of disparities that existed and continue to exist in the IHS as it relates to AI and AN health. These issues include: (a) lack of access to quality health care, (b) lack of providers, (c) lack of availability of culturally company health services, (d) social and cultural barriers, and (e) lack of federal funding. Sequist et al. (2011) found "little is known about the potential impact of limited resources on the quality of care for American Indians" (p. 480). Soeng and Chinitz (2010) reported that AIs who experience long wait times to see providers are at greater risk for chronic disease and have a higher rate of mortality from other comorbid conditions associated with one or more chronic conditions.

One area of the IHS budget where there is a major unmet need is in geriatric health. Many AI elders lack access to long-term care services, and lack culturally competent health care services aimed at treatment and prevention and other needed educational resources. This is particularly problematic because the AI population is the fastest growing population among persons 65 and over (U.S. Department of Health and Human Services, 2013), the rise of dementia is increasing, however, little is known about Alzheimer's disease, which may well result in the misdiagnosis and under diagnosis of Alzheimer's disease in the AI population. (*Alzheimer's Disease*, 2014; Finke, 2013; Griffin-Pierce et al., 2008; IHS, 2011). There is an increased need for formal dementia caregivers (Aldrich, 2009; Jervis, Boland, & Fickenscher, 2010; Jervis, Jackson, & Manson, 2002). As the AI population increases, chronic disease will also continue to increase, as well as the need for non-institutional and culturally appropriate services for advanced Alzheimer's disease and dementia care. Yet barriers continue to exist for such long-term care services which include: (a) education and awareness, (b) IHS underfunding, remote location of reservations and tribal lands, and (c) training and retention of caregivers. According to Baldridge and Aldrich (2010):

> Family members provide an estimated 90% of elder care in Indian country. Taking care of an elder is a continuation of a long cultural tradition of extended family and lifelong care for family, and is generally not regarded as a "burden." (p. 1)

Long-term care services are a viable addition to the informal activities of daily learning that AI informal dementia caregivers provide to family members, as well as may serve as an extension to the care provided in a non-institutional setting.

Urban Indians

AIs have lived in urban areas after the European colonization of the New World (National Urban Indian Family Coalition, 2008). The push for urbanization of AIs began in 1953 when Congress enacted House Concurrent Resolution 108 (Forquera, 2001; Steeler, 2001). This bill was put into law because of Congress' dissatisfaction with the Bureau of Indian Affairs handling of housing shortages and high rates of poverty on reservations (Forquera, 2001; National Urban Indian Family Coalition, 2008; Steeler, 2001). The purpose was to move a group of 200,000 AIs off federally recognized reservations and assimilate them into urban life (National Urban Indian Family Coalition, 2008). As a result of this relocation, the literature revealed that "American Indians [through assimilation] suffer from the indifference and misconception of their surroundings" (National Council on Indian Health, 2011, p. 1). As a result, of these indifferences AIs have lived in marked poverty; are more susceptible to depression, mental illness, and alcoholism; and suffer greater disparities in healthcare (Goins & Spencer, 2005; Mann, 2011, 2012; Morgan, 2012; Weidensaul, 2012; Zinn, 2005).

Currently there are 2.5 million AIs who live in major metropolitan areas throughout the United States (Fox, 2013). The largest percentages of AIs live in the following cities: New York, Los Angeles, Phoenix, and Chicago (National Urban Indian Family Coalition, 2008). There are also a high percentage of AIs living in cities throughout the western and southwestern parts of the United States (U.S. Department of Commerce, Economics and Statistics Administration, 2010). Urban AIs live in poverty and thus are susceptible to much shorter life spans than the average White person in the general urban population (National Council on Indian Health, 2011; Urban Indian Health Institute, 2011; U.S. Department of Commerce, Economics and Statistics Administration, 2010). AI informal dementia caregivers living in urban are defined as:

> individuals of American Indian and Alaska Native ancestry who may or may not have direct and or active ties with a particular tribe, but who identify with and are at least somewhat active in the Native community in their urban area. (National Urban Indian Family Coalition, 2008, p. 7)

Central to AI cultural identity was the formation of AI health and cultural centers in metropolitan areas across the United States. After the major resettlement efforts of the 1950s, many natives lost touch with their specific tribes and thus tribal identity was severely compromised (National Urban Indian Family Coalition, 2008). These AI health and cultural centers were formed to help AIs living in metropolitan areas with needed social service resources and healthcare services, and provided a drop-in-center-like environment for AIs remain connected to their specific tribal identities and to other AI persons living in a particular urban area. For those long-term AI residents, these Urban Indian Organizations have been the only means to learn about their tribal identity, history, and culture. The National Urban Indian Family Coalition (2008) used four categories to define Urban Indians:

1. Long-term residents: Lived in cities for several generations.
2. Forced residents: Persons forced to relocate to urban areas because of healthcare needs or abject poverty.
3. Permanent residents: Relocated for better opportunities.
4. Medium- and short-term visitors: Persons who visit for specific purposes but don’t intend to stay (p. 6).

Prevalence of Alzheimer’s Disease and Dementia in the United States

The prevalence of Alzheimer’s disease and dementia among the non-AI population is well documented (Alzheimer’s Association, 2014). There are 5.2 million people in the United States with Alzheimer’s disease (Alzheimer’s Association, 2014) and Alzheimer’s disease ranks as the most common form of dementia in the non-AI population (Alzheimer’s Association, 2014). Additionally, the Alzheimer’s Association (2014) reported there were 15.5 million caregivers providing 17.7 billion hours of care among the general population of the United States in 2012. Alzheimer’s disease rose from being the seventh leading cause of death in the United States in 2012 to the sixth leading cause of death in the United States in 2014 (Alzheimer’s Association, 2014).

Heart disease ranks as the leading cause of death in the general U.S. population, with stroke ranking as the fourth leading cause (CDC, 2013b). This has raised significant concerns for all age groups; individuals with cardiovascular disease are more susceptible to vascular dementia, which is ranked the second leading cause of dementia. Research undertaken by the Alzheimer’s Association and CDC has revealed that an individual may have both vascular dementia and Alzheimer’s disease (as cited in Martins et al., 2006). The Alzheimer’s Association (2014) has undertaken research initiatives to target cardiovascular diseases in an effort to slow the progression of vascular dementia among younger groups (CDC, 2013a, 2013b; Martins et al., 2006).

Approximately 16,000 persons aged 65 and older have been diagnosed with Alzheimer’s disease and related dementias (these figures do not include early-onset patients) and there are formal and informal caregivers in northern rural New England caring for elders with Alzheimer's disease and dementia (Alzheimer's Association, 2014). These statistics include AIs; however, there are no data specifically reporting numbers or percentages of AIs by racial category.

American Indian Population and Alzheimer's Disease

Prevalence rates for Alzheimer's disease and dementia among the AI population are not well documented (Griffin-Pierce et al., 2008; Jervis & Manson, 2002; Weiner et al., 2007, 2008). There are no known estimates of prevalence among this population (Griffin-Pierce et al., 2008; Jervis, Boland, & Fickenscher, 2010; Jervis & Manson, 2002; Randall, 2014). It is assumed that AIs comprise a percentage of the 5.2 million AD and dementia cases in the United States (Alzheimer's Association, 2014; U.S. Department of Health and Human Services, 2012). To date, few studies have addressed Alzheimer's disease and dementia in the AI population (*Alzheimer's Disease*, 2014; Jervis & Manson, 2002).

The state of scholarship in this area remains limited. Only three studies focused on Alzheimer's disease among AI tribes. The first of these studies was conducted by Hendrie et al. (1993), who compared Alzheimer's disease rates in a Manitoban rural Cree tribe and English-speaking non-AIs in the Winnipeg urban area (Hendrie et al., 1993). The sample for the Cree tribe was 216 and the sample size for the English-speaking non-AI sample was 252. The first stage of the research focused on screening participants for dementia using the Community Screening Interview for Dementia (Hendrie et al., 1993; Jervis & Manson, 2002). The second phase of the research focused on a sample size of 91 ($n = 91$) for Cree participants and 67 ($n = 67$) for English-speaking participants who had low cognitive scores on the cognitive screening instrument. The findings varied among the two populations. For the Cree, there was a 0.5% rate of Alzheimer's disease, compared to an age-adjusted rate of 3.5% of Alzheimer's disease among English-speaking participants (Hendrie et al., 1993; Jervis & Manson, 2002). Particularly among Cree participants, multi-infarct dementia and alcohol-related dementia were rated highest. However, the study had several limitations, including (a) sample bias—English-speaking participants were both community and institutional whereas the Cree were not, (b) educational differences in each sample, (c) differences in language, that is, Cree understandings of words were different from those of their English-speaking counterparts, (d) high vascular dementia rates among the Cree, which may be indicative of vascular dementia coexisting with Alzheimer's disease, (e) a small sample size, and (f) only one AI tribe was studied; therefore, results were not homogenous to each AI tribe (Benedet et al., 2012; Jervis & Manson, 2002).

The second study was conducted by Rosenberg et al. (1996). This study looked at Alzheimer's disease in the Cherokee tribe in Oklahoma. This study primarily focused on the degree of AI ancestry as a protective factor against developing an Apolipoprotein E (APOE) allele for Alzheimer's disease. This study's research participants included 26 persons with Alzheimer's disease and 26 control-group members. The Alzheimer's disease group was aged 65 years and older. The group with Alzheimer's disease included more women than men and was older than the control group (Rosenberg et al., 1996). In addition, the Alzheimer's disease group had a lower degree of Cherokee ancestry than the control group. The findings of the study revealed that those with a higher rate of

Cherokee genetic ancestry were less likely to develop Alzheimer's disease, compared with those who had lower rates. The study did not consider lifestyle risk factors that give rise to Alzheimer's disease; research participants were self-reporters of degree of Cherokee ancestry; and there was no discussion of AI health, spiritual practices, and other traditional healing practices that may have a role in the protection against Alzheimer's disease (Jervis & Manson, 2002).

A third and more recent study conducted by Benedet et al. (2012) suggested that the role of Amerindian genetic ancestry protects Amerindians against Alzheimer's disease. This study is similar to the findings of Rosenberg et al. (1996). The major difference was that this study was conducted in Brazil and researchers looked at the parental ancestry and genetic structure of three ethnic groups: European, African, and Amerindian. The researchers in this study used 12 autosomal ancestry markers (AIMs) to estimate ancestry proportions among the three groups. AIMs assisted the researchers when distinguishing Alzheimer's disease risk groups from different genetic backgrounds (Benedet et al., 2012). Researchers compared parental contributions to genetic ancestry between the group with Alzheimer's disease and the non-cognitively impaired group as a means to determine late-onset Alzheimer's disease. Comparisons included (a) a description of AIMs (b) descriptions of AIM alleles, (c) chromosome positions among the European, African, and Amerindian parental groups, and (d) continuous and categorical variables among Alzheimer's disease patients and control, un-demented subjects as a baseline. The data were then analyzed using covariance and log-transformed ancestry estimates (Benedet et al., 2012). Differences in covariances and ancestry estimates were significant because the differences resisted adjustments to late-onset Alzheimer’s disease, especially for literacy, age, and gender. Another significant finding was that ancestry proportions were higher among European and African groups while Amerindians remained low. This study showed major differences between Alzheimer’s disease patients and non-cognitively impaired subjects, as well as Amerindians with “an average content of Amerindian genetic ancestry threefold lower (5.6% versus 16.2%; $p < .001$) than the average corresponding, average content in cognitively normal adults” (Benedet et al., 2012, p. 315). These data suggested that Amerindians may have an allelic architecture protecting them against Alzheimer’s disease (Benedet et al., 2012).

Though in its infancy, this corpus of literature shows promise. However, early mortality, misclassification of race at time of death, and inadequate diagnosis are prevalent: AIs are usually treated for a presenting illness such as for stroke or cardiovascular disease, whereas Alzheimer’s disease or dementia symptoms may be overlooked (CDC, 2013b). Thus access to culturally competent specialized services for AI elders in rural and urban areas is needed. Typically AI health services which are run under the direction of the IHS and Urban Indian Health Services (UIHS) only cover walk-in, emergency care and urgent care as well as primary-care services (in urban settings), usually with high copayments, and AI elders and their informal dementia caregiver are left on their own to pay for medical specialty services. Even though Alzheimer’s disease may be less prevalent among AIs, dementias associated with chronic health problems (cardiovascular disease, diabetes, and alcoholism), and lifestyle risk factors need to be explored and documented (Hendrix, 2003).

The emphasis of studies conducted on the AI population have focused on the APOE polymorphism related to cardiovascular disease, diabetes, stroke, and alcoholism and the coexistence of dementia (Demarchi et al., 2005; Goins & Pilkerton, 2010; Griffin-Pierce et al., 2008; Leduc et al., 2012; Rosenberg et al., 1996; Weiner et al., 2007, 2008, 2011). Additionally, extensive research has focused on AI lifestyle factors as they relate to the incidence of dementia associated with the effects of cardiovascular disease, diabetes, and stroke (Casper et al., 2005; Galloway, 2005; Haan et al., 2003; Hanley et al., 2003; Stoner, Stoner, Young, & Fryer, 2012; Urban Indian Health Institute, 2011; U.S. Department of Health and Human Services, National Institutes of Health, National Heart, Lung, and Blood Institute, 2001). These risk factors include excessive smoking, excessive drinking of alcohol, and changes from traditional AI diets to more Westernized diets. Although the Alzheimer's Association (2014) reported that Alzheimer's disease can only be definitively detected at time of death as a result of an autopsy of the brain, there are certain dementia types that are more prevalent in AIs. These include vascular dementia, multi-infarct dementia, Korsakoff Syndrome (alcohol-related dementia), mixed dementia, as well as growing research on the link between Alzheimer's disease and Type 2 diabetes. Therefore, AIs, like others in the non-AI population, may have the potential to develop Alzheimer's disease or dementia by way of health and lifestyle-related risk factors (Dixon & Roubideaux, 2001; Goins & Pilkerton, 2010; Griffin-Pierce et al., 2008).

Indigenous Knowledge

This section of the literature review focuses on Indigenous knowledge of oral tradition, science, and medicine. The literature is quite limited on the cultural beliefs of AIs on Alzheimer's disease and dementia. Therefore, this section includes AI texts written by AI authors and Western authors familiar with AI knowledge systems to provide a backdrop. Here, I explore Indigenous knowledge systems and how these systems impact formal dementia caregiver and AI understanding of Alzheimer's disease and dementia.

Western and AI views of Alzheimer's disease and dementia are different. Alzheimer's disease and dementia vary in "how sickness is culturally constructed with particular significance to old age" (Henderson & Henderson, 2002, p. 198). Cultural construction of how AIs view growing older and losing memory are different from that of Western views (Hulko et al., 2010): "Elders hold differing views about memory loss, including the traditional 'going through the full circle' [of life] and the *shema* [White] way—'*your* dementia' with the latter being more common" (p. 318). Researchers indicated that Alzheimer's disease and dementia are not words used or understood in AI communities. "Dementia is basically a western diagnostic category" (Pollitt, 1996, p. 1062) and other researchers reported Alzheimer's disease and dementia is not connected with negative attributions in the AI population (Henderson & Henderson, 2002; Hulko et al., 2010; Traphagan, 2005). Cognitive changes in behavior are accepted by the AIs as a normal process of aging as well as a completion of the full circle of life before entrance into the spirit world (Jacklin, Walker, & Shawande, 2013; Lanting, Crossley, Morgan, & Cammer, 2011). Culture and cultural perceptions of Alzheimer's disease and dementia are not viewed negatively among AIs; however, AIs are one of the fastest growing aged populations, posing new challenges as to how the AI population will address the incidence of new cases of Alzheimer's disease and dementia.

The Oral Tradition

At the center of Indigenous knowledge is the oral tradition (Hart, 2010; J. Poupart, Baker, & Red Horse, 2009; Starks, Ofahengaue-Vakalahi, H. F., Comer, M. J., & Ortiz-Hendricks, 2010; Struthers & Peden-McAlpine, 2005). Through the oral tradition, AIs disseminate knowledge and wisdom and define an AI worldview of science and medicine (Cajete, 2000; Deloria, 1997; Getty, 2010; Peat, 2002). The oral tradition is the way tribal elders teach and tribal members learn (Lowe & Struthers, 2001; L. M. Poupart, 2003; Struthers & Peden-McAlpine, 2005). In contrast to written teachings, oral traditions are stories that have existed and will continue to exist from generation to generation (L. A. Benson, 2003; W. F. Benson, 2009; Porter, 2003; Starks et al., 2010). These traditional forms of storytelling include all aspects of tribal life and address matters of science, medicine, health, spiritual matters, and other matters important to teaching life lessons (Banks-Wallace, 2002; Bailey & Tilley, 2002; Ollerenshaw & Creswell, 2002).

Traditional storytelling has been shown to have a positive impact on health and wellness in AI communities (Schanche, Pasqua, Marquez, & Geishirt-Cantrell, 2002; Struthers & Eschiti, 2005; Struthers et al., 2004). These traditional stories, narratives, and oral histories have been shown to be effective in promoting wellness among AIs in the form of talking and sharing circles about specific health problems and traditional forms of healing (Broome & Broome, 2007; Loppie, 2007; Mattingly & Lawlor, 2000; Mehl-Madrona, 2007), as well as issues relating to alcoholism, substance abuse, and mental health (Coyhis & Simonelli, 2008; Dickerson et al., 2011; Rieckmann et al., 2012). In addition, there have been a number of evidence-based and community participatory-research programs that have used American oral histories and trained AI leaders in promoting workshops that focus on AI disease self-management and living healthy lifestyles (S. Castro, O'Toole, Brownson, Plessel, & Schauben, 2009; Fleischhacker, Vu, Ries, & McPhail, 2011; Johnson & Lorig, 2011; R. D. Walker & Bigelow, 2011). Two other areas are the impact oral tradition has on science and medicine. In the context of science and medicine, AI authors and texts aid understanding of the meaning of science and medicine and their relationship to the individual, the formal dementia caregiver, and the community.

Indigenous Science

Indigenous science and Indigenous physics (Cajete, 2000; Peat, 2002) are considered to be the story of creation and the backbone of AI knowledge (Cajete, 2000; Four Arrows, Cajete & Jongmin, 2010; Peat, 2002). According to Peat (2002) the ancient definition of physics is the study of the true nature of reality. Essential to any culture is their story of creation and how it came to be. For Peat (2002) and Bohm (2004) any culture's worldview is a reflection of that reality. Each tribe (or nation) has its own story of creation that has been handed down from generation to generation, but AIs believe that true knowledge and life are based on a holistic view of nature, which includes all things animate and inanimate. This is similar to Christianity in the Western world. Although all

Christians share fundamental beliefs, each denomination teaches Christian tenets differently. Cajete (2000) and Peat (2002) described Western science as objective and based on reason and a rigid value system; in contrast, Indigenous science is not based on a value system, but rather is aligned to nature to achieve integration, harmony, and balance in an individual's life as well as in the world.

Western scientists base their thinking on reason and independent truth, in contrast to the AI way of seeing, listening, and reflecting as pathways to ways of learning (Fixico, 2003). In other words, Western science is perceived by AI thinkers to be a product rather than a process (Cajete, 2000; Elliot, 2009; Peat, 2002). Western ways of thinking about science traditionally have included linear, binary, and categorical ways of thinking (Fixico, 2003). AIs, in contrast, see science and all that comprises life in a circular pattern. AI science is predicated on direct experience, interconnectedness to all living things, and interdependency on true knowing, which is based on a natural worldview (Cajete, 2000).

Since the Renaissance, science has been dominated by the Western worldview, Such domination has excluded AI ways of thinking from consideration; this has resulted in a lack of belief in AI viewpoints or a refusal to believe that the AI worldview may have something to offer (Durie, 2004; Mazzocchi, 2006; Smylie et al., 2003). Bala and Joseph (2007), in their discussion of indigenous knowledge and Western science reported:

> traditional and local knowledge systems, as dynamic expressions of perceiving and understanding the world, can make, and historically have made, a valuable

> contribution to science and technology and that there is a need to preserve, protect, research and promote this cultural heritage and empirical knowledge. (p. 41)

Bala and Joseph (2007) advocated that scientists should begin “acknowledging that there are two systems of knowledge both of which are empirically testable and both of which are concerned with understanding and guiding practical activity within the same domain of phenomena” (p. 42).

Over the past several decades, the most significant dialogues between Western and Indigenous scientists addressed the way Western and Indigenous science converge. AI dialogue has been the traditional way elders of tribes seek to resolve problems and implement new initiatives. According to the late esteemed physicist Bohm (2004), dialogue is a free flowing, nonjudgmental conversation used to discuss a range of tribal matters, to arrive at a deeper understanding of a problem, issue, or insight. The first of these dialogues to explore similarities among Western and Indigenous scientists took place in May 1992. Participants included quantum/consciousness physicists (represented by David Bohm, David Peat, Sam Kounoso, Al Ford, and Buff Parry as well as Indigenous scholars Sa’ke’j Henderson, Leroy Little Bear and others; Alford, 1993). At the conclusion of these dialogues, the physicists and Indigenous scholars came to nine points of agreement between Western and Indigenous science: (a) everything that exists vibrates, (b) everything is in flux, (c) the part enfolds the whole—it is not just a sum of the parts, (d) there is an implicate order to the universe, (e) earth’s ecosphere is basically friendly, (f) AI culture can be taught new tricks, (g) there is a quantum potential and spirit, (h) the principle of complementarily holds true, and (i) everything is interconnected.

Conference attendees also agreed that Indigenous thought mirrors many aspects of quantum theory and that the essence of quantum theory regarding the traditional Indigenous worldview and way of being in the world embraces the concept of the whole and being in relationship. Lowe (2002) stated, “Connectedness occurs through the dynamics of relationship. This relationship exists between everything and every person within the creation/universe” (p. 5). This is the foundation of the traditional way of being among AIs. In addition, physicists also discovered concepts and theories that the Indigenous world has known for centuries. For example, quantum theorists have found that ancient religions are mirrors of quantum theory. Through dialogue, this has been explored (Bohm, 2004; Peat, 2002). Specifically this has been proven by Bohm in an exploration of the tenets of traditional dialogic practice (Bohm, 2002, 2004, 2005). According to Bohm (2002),

> In a dialogue … nobody is trying to win. … There is a different sort of spirit to it. In a dialog there is no attempt to win points or a particular view prevails. Rather, whenever any mistake is discovered on the part of anybody, everybody gains. (p. 7)

A tacit example of how dialogue is applied specifically to AIs was developed by Bohm (2004):

> Some time ago there was an anthropologist who lived a long while with a North American tribe. It was a small group of about fifty people. … Now from time to

> time that tribe met like this in a circle. They just talked and talked and talked, apparently to no purpose. They made no decisions. There was no leader. And everybody could participate. There may have been wise men or wise women who were listened to a bit more—the older ones—but everybody could talk. The meeting went on, until finally it seemed to stop for no reason at all and the group dispersed. Yet after that everybody seemed to know what to do, because they understood each other so well. Then they could get together in smaller groups and do something or decide things. (pp. 18–19)

Mazzocchi (2006) addressed the continued need for dialogue among differing cultures as it relates Western and traditional knowledge. Specifically Mazzocchi stated,

> This dialogue should take place with the unknown and the otherness. By shifting our perspective, and looking for other parts of knowledge that humans have developed and lived, we might create the necessary conditions for hitherto unknown knowledge to be revealed. (p. 465)

Such knowledge may be gleaned from an exploration of medicine, medical treatment, and the beliefs of AI people regarding disease.

Indigenous Medicine

The terms Indigenous medicine, traditional medicine, and Indian medicine have been used to describe a holistic healthcare system used by AIs. Struthers et al. (2004) reported that Indigenous medicine has been in North America for 12,000 to 40,000 years. Portman and Garrett (2006) described an Indigenous construct of medicine that focuses on the healing of the inner power with the overall goal of promoting preventive healthcare through harmony and balance of the physical, spiritual, and emotional self. Although each has its own creation story, the essence of each member's life and the connection to the earth is clearly understood and shared by all tribes. Indigenous medicine differs from Western medicine. The purpose of Western medicine is to eradicate a disease. According to Duran (2012), AIs cosmology dictates that "the doctor forms a relationship with the whole life-world including sickness, which is understood as a loss of harmony in the person, family, and tribe" (p. 126). This radical difference is the AI belief that people use Indigenous medicine for AI diseases and *White medicine* for *White diseases* (Devi, 2011; Hodge & Nandy, 2011; Johnston, 2002; Mehl-Madrona, 2007; Struthers, 2001; Struthers et al., 2004). A more detailed discussion of medical treatment choices will follow in the discussion on caregivers.

At the center of Indigenous medicine is the medicine wheel, also known as the sacred hoop (Allen, 1992; DiPace, 2006). Each tribe has a different medicine wheel that can be used for a variety of purposes (spiritual, mental, physical, and emotional). The medicine wheel is comprised of four directions: east, west, north, and south and each direction is represented by a different color, according to tribal affiliation. The medicine wheel also represents (a) stages of life, (b) seasons of the year, (c) aspects of life, (d) elements of nature, (e) animals, and (f) ceremonial plants (Cajete, 2000; McGaa, 2004; Peat, 2002). The medicine wheel represents "a holistic integration of humans and the natural world, including all beings, processes, and creations" (P. Walker, 2001, p.18). It is when one is fixed in one area (physical, spiritual, emotional, and mental) that it is determined by a medicine person that a being is *dis-eased* and out of harmony and balance (Deloria, 2006, 2009; Duran, 2012). It is at this point that an individual or caregiver makes the deliberate decision to be healed traditionally, healed medically, or a combination of both (Garroutte & Westcott, 2008).

Informal Caregiving Among American Indians

Limited scholarship is available on informal dementia caregiving and how AI dementia patients understand Alzheimer’s disease (Goins et al., 2011; Henderson & Henderson, 2002; Jervis et al., 2010) even though AIs are one of the fastest growing elder populations in the United States (Miller-Cribbs, Byers, & Moxley, 2009; U.S. Department of Commerce, Economics and Statistics Administration, 2010), AIs have been referenced as the “invisible minority” (Kramer, 1992; Marrone, 2007). Hartmann and Gone (2012) found that AIs who reside on reservations and in urban settings have similar levels of health disparities. Jervis et al. (2010) indicated that there is a paucity of dementia research on AIs. This absent body of literature is surprising in that Baldridge and Aldrich (2010) found that 90% of AI family members are engaged in some form of informal caregiving and elder care. Given the paucity of information, I discuss the AI formal dementia caregiver experiences in relation to what is known about the role of the AI family and the types of medical treatment accessed by AI elders and their informal dementia caregivers, the lack of cultural competency in dealing with AI groups, and the scant literature available on dementia caregiving in Aboriginal and First Nation populations in Canada and Australia. This approach bridges the gap and provides a frame of reference about what was missing in the body of literature on AI informal dementia caregiving.

The Role of American Indian Families

The core unit of AI society is the family, which includes both immediate- and extended family members. In the AI family system, family members provide informal caregiving tasks for elders (CDC, 2009). “The term ‘elder’ has a special meaning in Indian communities, because it is related to the personal contributions to their community, to their perceived value and wisdom” (CDC, 2009, p. 1). The role of family is of particular importance to AIs, who, through relocation, may or may not have lost their understanding of tribal traditions through acculturation and assimilation into the dominant White society (Lucero, 2010). The manner in which AI families have developed a positive and strong sense of American identity has not been previously explored in the literature (Cheshire, 2001; Lucero, 2010). AI elders both rural and urban are more likely to seek services from AI health centers than from non-AI healthcare providers (Urban Indian Health Commission, 2007). Garwick, Jennings, and Theisen (2002) found that AI families seek care from IHS facilities and Urban Indian Health Organizations because these providers tend to be more culturally sensitive to familial needs and concerns as opposed to Western specialty providers who advocate more of a biomedical approach. Research has not focused on culturally competent care from a family caregiver’s point of view (Garwick, 2000). This finding is congruent with research conducted by Jervis et al. (2010) and Lucero (2010) who found that filial obligation in AI families supersedes any level of burden that AI caregivers may encounter.

Cultural Competence

Over the past several decades, researchers have conducted abundant research on cultural competence with little emphasis on the AI culture (Caldwell et al., 2005; Sanchez, Plawecki, & Plawecki, 1996; U.S. Department of Health and Human Services, Office of Minority Affairs, 2013; Weaver, 1997a, 1997b, 2004). AIs have been used largely as contrast groups in major studies on racial, cultural, and ethnic issues (Dilworth-Anderson et al., 2002, 2005; Janevic & Connell, 2001; Joe, 2014; Leung, 2012; O'Connell & Gibson, 1997; Randall, 2014). Additionally, in a review of racial and ethnic caregiver literature from 2000–2010, only 10 articles specifically addressed AI dementia patients. Goins et al. (2011), Scharlach et al. (2006), and Weaver (2004) found cultural competence for the AI population has not been clearly articulated in the AI caregiver literature. The Office of Minority Health (U.S. Department of Health and Human Services, 2013) defined cultural competence as "cultural and linguistic competence is a set of congruent behaviors, attitudes and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations" (p. 1). Because of this lack of cultural values, beliefs, and worldviews, those AIs who accept traditional values are reticent to accept help from Westerners; in contrast, those who are have become more assimilated and acculturated into Western society (in urban areas) may be more willing to accept help from Westerners (Griffin-Pierce et al., 2008; Jervis et al., 2010; Struthers et al., 2004).

One area of significant challenge in cultural competence is in the area of health practices and beliefs. Buchwald, Beals, and Manson (2000) found that AIs who identify more with AI culture are more likely to use traditional practices, whereas Gurley et al. (2001) found that AI dementia patients will incorporate Western and traditional medicine based on the accessibility of services. Several have reported that, due to the lack of data on AI health conditions, racial misclassifications, and frequent mobility in and out of metropolitan and reservation areas, health data on AIs and their informal caregivers are often incomplete and inaccurate (Buchwald, Furman, Ashton, & Manson, 2001; Cardinal, 2006; Goins & Pilkerton, 2010; D. A. Rhoades, Manson, Noonan, & Buchwald, 2005; K. Wilson, Rosenberg, & Abonyi, 2011).

One major area where literature has been developed on AI dementia patients and their formal caregivers is within the area of in patient–provider interactions and choice of medical care (Garroutte, Kunovich, Buchwald, & Goldberg, 2006; Fadiman, 1998; Garroutte, Sarkisian, Arguelles, Goldberg, & Buchwald, 2006; Garroutte, Sarkisian, Goldberg, Buchwald, & Beals, 2008;Gryczynski & Johnson, 2011; Johansson, Jacobsen, & Buchwald, 2006; Koithan & Farrell, 2010; Simonds, Christopher, Sequist, Colditz, & Rudd, 2011; Simonds, Goins, Krantz, & Garroutte, 2013). Their evidence suggested that most AIs seek traditional healers, medicine men and medicine women, to address matters of disharmony in their physical, spiritual, and emotional being (Hartmann & Gone, 2012; Hunter et al., 2006; Schneider & DeHaven, 2003). Use of traditional healing was also dependent on geographical location and accessibility to services for AI dementia patients (Struthers et al., 2004). Most AI elders and their caregivers seek both traditional and Western medicine (Buchwald et al., 2000; Gurley et al., 2001). However, most AI elders seek traditional medicine for matters of disharmony and imbalance, and seek Western medicine practices for more long-term and complicated physiological conditions (Earle, 2011; K. Wilson et al., 2011). AI dementia patients may only seek Western medical treatment in combination with traditional medicine for health conditions including heart disease, diabetes, and other long-term chronic diseases not associated with Alzheimer's disease or dementia (Earle, 2011).

The greatest source of anxiety among AI dementia patients stems from perceived discrimination in healthcare, lack of understanding of Western practitioners concerning traditional medicine, and lack of AI understanding of Western prognosis, diagnosis, and treatment (Garroutte, Kunovich, et al., 2006; Garroutte, Sarkisian, et al., 2006; Garroutte & Westcott, 2008; Gonzales et al., 2015; Herbert, 2001; Towle, 2006). Common AI complaints of interactions with Western providers include (a) poor communication, (b) lack of relationship, (c) lack of trust, and (d) limited understanding (Simonds et al., 2011). Garroutte et al. (2008) Johansson et al. (2006), Lowe (2002), and Struthers et al. (2004) also reported instances when AIs incorporate traditional healing, but most would not disclose this to Western practitioners for fear of being misunderstood.

American Indian Informal Dementia Caregivers

The literature on Alzheimer's disease, dementia, and formal dementia caregiving insufficiently addressed AIs in the United Sates, First Nations in Canada, and Aboriginal populations in Australia (Henderson & Henderson, 2002; Hulko et al., 2010; Jervis & Manson, 2002; Lanting et al., 2011; K. Smith et al., 2011). Knowledge and understanding of dementia is lacking in First Nation populations (Hulko et al., 2010; Lanting et al., 2011). Finkelstein, Forbes, and Richmond (2012), Lanting et al. (2011), and K. Smith et al. (2011) also cited remarkably different cultural beliefs of dementia between Western and AI populations, as well as cultural beliefs on aging to be major factors in the underrecognition and underdevelopment of Alzheimer's disease and dementia in these populations. The following two quotations from Hulko et al. (2010) are illuminating examples of the cultural differences and cultural perceptions of Alzheimer's disease and dementia in First Nation communities:

> For us it is an accepted part of our culture or conditions, accepted part of our family circle. If we see an Elder or a person losing their memory, they were not condemned as, as such, you know like hey you're going crazy or something. You're losing it or something. It was part of our growing up; we believe in our traditions, we come as a baby independen[t] of our mother, parents, extend[ed] family that's how we, we … and then going through the full circle we once again, you call memory loss, we once again go back to full circle as a—as a baby once again, so we have always had great respect for our Elders, I don't recall many of them [having memory loss] really. (p. 329)
>
> Because in the Native community, the Elders are highly respected. Where I see across the river [in White society] they are not, not treated the same as Elders here are treated; they are almost forgotten over there [in White society]. Here we try to deal with our Elders as much as we can. Those of us that can go around and visit and sometimes we, we take some of the Elders to go visit the ones that are in the homes, like, like what's that place [residential care facility in city 80 km away]. (p. 330)

These examples provide the backdrop of barriers and challenges facing researchers. In essence, AI populations view Alzheimer's disease and dementia as a Western disease; not an AI one (Garvey et al., 2011; Herbert, 2001; Hulko et al., 2010; Lanting et al., 2011; Taylor, Lindeman, Stothers, Piper, & Kuipers, 2012). However these views become more problematic as the incidence of Alzheimer's disease and dementia increases, especially in Australian Aboriginal populations where dementia is five times that of the non-Aboriginal population (Garvey et al., 2011; K. Smith et al., 2011; Taylor et al., 2012). Additional research is needed and should focus on culturally sensitive care, culturally sensitive knowledge regarding traditional healing practices, and the possibility of forming a converging relationship with traditional and Western worldviews on Alzheimer's disease and dementia (Arnold & Bruce, 2005; Hunter et al., 2004; Lowe & Struthers, 2001; K. Smith et al., 2011).

Critique of Methods

In this section I discuss the appropriateness of choosing a phenomenological and Indigenous research method, as evidenced in the literature.

Phenomenology

Phenomenology focuses on meaning and experience (Moustakas, 1994;Vagle, 2014; van Manen, 1990, 2014). Qualitative methods, unlike quantitative methods, seek to find meaning as it occurs in the experience and lifeworld (Giorgi, 2005). For the purposes of this study, the experience of formal dementia caregivers shaped individual feelings about caregiving. According to Finlay (2009a, 2009b), phenomenological research methods are appropriate when trying to describe and understand lifeworld and experience. Phenomenology has been used to capture the meaning and essence of what it means to be a formal dementia caregiver (Upton & Reed, 2006) and to capture the subjective nuances of AI culture, which remain virtually a mystery to the Western thinker (Little Bear, 2009). vanManen (2001) posited:

> Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences…[it] does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us in more direct contact with the world. (p. 9)

Indigenous Research Method

Triangulating indigenous research methods with phenomenological research methods honors indigenous worldviews. "As long as methods fit the ontology, epistemology, and axiology of the Indigenous paradigm, they can be borrowed from each other" (S. Wilson, 2008, p. 17). Indigenous research methods also provide a way to decolonize and validate differences in the experiences of AI dementia patients from normally accepted Western beliefs concerning Alzheimer's disease and dementia (Denzin, Lincoln, & L.T. Smith, 2008; L. T. Smith, 2012). Deloria (1999) stated,

> strangely there has been very little attention paid to Indian methodologies for gathering data, and, consequently, the movement is primarily an ad hoc, personal preference way of gathering new ideas and attempting to weld them to existing bodies of knowledge. (as cited in Kovach, 2010, p. 23)

Moreover, phenomenology is a methodology compatible with Indigenous research methods because it allows for meaning in narratives and traditional forms of storytelling (Bagele, 2012; Hornung, 2013; Ignacio, 2013; Kovach, 2010; Lambert, 2014).

Summary

This chapter summarized what is known and what is not known about Alzheimer's disease and dementia among AIs, and the state of research regarding formal dementia caregiving and Alzheimer's disease in the AI population. This literature review identified a gap in a lack of previous research on how formal dementia caregivers experience AI Alzheimer's disease and dementia in their everyday world. This chapter described the demographics of AIs; profiled rural and urban Indians; described the prevalence of Alzheimer's disease and dementia; and discussed indigenous knowledge, the oral tradition, science, medicine, and informal caregiving among AIs. Major gaps in the literature were a lack of understanding about AI Alzheimer's disease and dementia and a lack of understanding regarding AI beliefs about Alzheimer's disease and dementia, and a lack of understanding of AIs' perceptions of Alzheimer's disease and dementia among Westerners who care for AIs with Alzheimer's disease and dementia.

Chapter 3: Research Method

Introduction

This study utilized phenomenology as a research method to explore the lived experience and meaning of formal caregivers who provides dementia care to American Indians. Empirical methods cannot adequately investigate meaning within the context in which it occurs (Struthers, 1999). Therefore, a qualitative method such as phenomenology is required. Further, this study is interested in documenting formal caregiver lived experiences.

Phenomenologists have stressed the importance of understanding human perspectives and experiences Prior theoretical and conceptual frameworks have focused on understanding Alzheimer's disease from health and sociocultural coping models (Goins et al., 2011; Knight & Sayegh, 2010; Knight, Silverstein, McCallum, & Fox, 2000). These frameworks have not addressed or included formal caregivers, AI dementia patient, or cultural beliefs regarding Alzheimer's disease (Jervis & Manson, 2002). This lack of information has slowed needed research and delivery of needed healthcare for disease-specific illnesses (Goins & Pilkerton, 2010; Goins & Spencer, 2005; Goins et al., 2011; Jervis & Manson, 2002; Portman & Dewey, 2003). AIs have been used either as a comparison or contrast group in the limited genomic and epidemiological literature (Weiner et al., 2003) and as a limited contrast group in cultural studies (Dilworth-Anderson, Williams, & Gibson, 2002).

This study used a phenomenological approach to answer a set of research questions on formal caregivers providing dementia care to AIs. This study was designed to understand the experiences of formal dementia caregivers and the lack of caregiver services for the AI dementia population as well as the lack of Western understanding concerning the cultural beliefs and experiences of formal caregivers providing dementia care to AIs. This chapter discusses the following: (a) research design and rationale, (b) role of the researcher, (c) methodology, and (d) issues of trustworthiness.

Research Design and Rationale

The research questions posed in this study were:

1. What are the understandings of formal caregivers for American Indians about their patients' cultural beliefs about Alzheimer's disease and dementia?
2. What are the cultural beliefs about Alzheimer's disease and dementia of formal caregivers for American Indians?
3. How do formal caregivers for American Indians use their cultural beliefs about Alzheimer's disease and dementia, to develop courses of care for their patients?

This study used phenomenology as a research method to reveal the meaning or lived experiences about formal caregivers developing a course of care for AI dementia patients. For this study, the central phenomena were the cultural beliefs and experiences of formal caregiver and, AI dementia patients, on Alzheimer's disease and dementia. The remainder of this discussion of phenomenology will focus on phenomenology as the chosen method. This discussion includes an overview of phenomenology and the philosophy of phenomenology. Little Bear (2009) noted that qualitative researchers often merely describe the customs of AIs but pay little attention to the meaning behind the customs. Rather than describe the customs, this study documented the lived experiences of formal caregivers caring for AI dementia patients.

Phenomenology is a philosophical movement and a research methodology. The philosophical base of phenomenology grew from the work of numerous philosophers including Brentano (1838–1917), Husserl (1859–1938), Heidegger (1889–1973), Sartre (1905–1980), Merleau-Ponty (1908–1961), and Spiegelberg (1904–1990). Each of these philosophers impacted the philosophy and method of phenomenology. Husserl is considered the forefather of the phenomenological movement (Groenewald, 2004; Paul, 1999; Penner & McClement, 2008; Reiners, 2012). Husserl's work was challenged by a number of philosophers such as Heidegger, Sartre, Merleau-Ponty, and Spiegelberg (McCann, 1993; Penner & McClement, 2008; Sokolowski, 2000). Struthers (1999) posited that "these disputes has afforded a refinement and reexamination to the method of phenomenology" (p. 40). These refinements and reexaminations resulted in two distinct schools of phenomenological thought: transcendental (descriptive) and hermeneutic (interpretative).

Choosing a Phenomenological Method

I chose phenomenology as the qualitative method for studying the cultural beliefs and experiences of formal caregivers and their AI demented patients (Todres, 2005). Creswell (2009) stated that "a phenomenological study examines the meaning for several individuals of their lived experience or phenomenon" (p. 57). The phenomenon in this research study is the lived experience of formal caregivers providing dementia care to AIs. The goal of this research study was to describe the universal essences or commonalities of participants. For Husserl, phenomenology includes openness to the phenomenon as well as suspending preconceived notions, assumptions, and judgments (Creswell, 2009; Moustakas, 1994; Sokolowski, 2000). Within the context of this study a reflexive journal and bracketing was used to ensure that I suspended my bias during the interview and data analysis stages. A major component of the phenomenological approach is that the reality of an experience is perceived and given meaning by the individual (McCann, 1993; Moustakas, 1994; Willis, 2007). Willis (2007) stated,

> Phenomenology [is] focused on the subjectivity and relativity of reality, continually pointing out the need to understand how humans view themselves and the world around them…Phenomenologist distinguish…phenomena (the perceptions or appearance from the human point of view) from the noema (what the thing really is). (p. 53)

Choosing a correct phenomenological approach to explore a phenomenon can be challenging (Lopez & Willis, 2004; Reiners, 2012; Wojnar & Swanson, 2007). The descriptive phenomenological approach has been documented as more suited to studies where little is known about the phenomenon (Swanson-Kaufmann & Schonwald, 1988). Because little is known about the cultural beliefs of formal caregivers and AI dementia patients, phenomenology was the best-suited qualitative approach, according to the steps laid out by Creswell (2009), Edwards (2010), and Finlay (2009a, 2009b). These steps include: (a) identifying a phenomenon and its philosophical underpinnings to the phenomenon studied (cultural beliefs and experiences of formal caregivers, and AI demented patients); (b) collecting data from research participants who have experienced the phenomenon (formal caregivers who provide dementia care to AI dementia patients; (c) engaging in the data collection and analysis; and (d) writing the results and presenting the findings. A challenge common for phenomenological researchers is their ability to suspend judgment, personal reactions and beliefs (Moustakas, 1994). As previously mentioned, a reflective journal and bracketing was used to avoid bias in the interview and data analysis stages of this study.

The specific phenomenological approach chosen for this study was transcendental phenomenology. Central to this approach is a researcher's ability to engage in a process called *epoche*. Epoche is the suspension of one's personal judgments, reactions, beliefs and assumptions, and listening attentively to the participants' experiences being recorded. Epoche is achieved through a process called phenomenological reduction (bracketing) (Moustakas, 1994; van Manen, 1990). I took steps to beware of my personal biases during this research and used reflexive journaling and memoing to express them. These bracketing exercises were designed to assists me in eliminating my preconceptions, while at the same time eliminating the possibility of changing meanings and experiences described by research participants (Chan, Fung, & Chien, 2013; Drew, 2004; Tufford & Newman, 2010).

Ultimately, I selected a phenomenological method because it is the best method to research lived experience, and it allows for an open attitude needed to let new meanings emerge (Appelbaum, 2011; Lopez & Willis, 2004; Pascal, Johnson, Dore, & Trainor, 2011). This method presented me with the opportunity to describe, explore, and identify cultural and lived experiences that are essential in providing an accurate description of an explanatory description of AI Alzheimer’s disease and dementia Paul, 1999; Penner & McClement, 2008; Upton & Reed, 2006). It was also useful because phenomenology involves storytelling, which is a significant part of AI culture. Oral tradition and storytelling are innate and inherent techniques that AIs use to educate and impart important information (Schanche, Pasqua, Marquez, Geishirt-Cantrell, 2002). Formal caregivers also use storytelling in their interactions with AI dementia patients and their formal caregivers (Mehl-Madrona, 1997, 2005, 2007).

Role of the Researcher

As a Cree male, I became interested in the topic of AI Alzheimer’s disease from caring for a mother of Cree ancestry who had Alzheimer’s disease. In addition, I observed personal friends of AI ancestry who also cared for a family member with Alzheimer’s disease. Personal involvement included (a) interaction with the participant during the interview process, and (b) seeing one’s own past caregiver experience when transcribing the interviews: a mother who had Cree ancestry and Alzheimer’s disease (Fontana & Frey, 2008; Horsburgh, 2003). I used traditional AI and Westernized caregiver and medical approaches to caregiving with my mother who had Alzheimer’s disease and Cree ancestry.

My role in this study was that of a reflexive researcher (Horsburgh, 2003). Specifically, the role of an insider and outsider was used: an AI adult child who cared for an AI mother and that of a researcher and PhD student. The reflexive researcher role was advocated by a number of AI and Western researchers (Kovach, 2010; Mahoney, 2007; Maxwell, 2005; Watt, 2007; Wilson, 2008). According to Watt (2007), reflexive research "entails careful consideration of the phenomenon under study, as well as the ways a researcher's own assumptions and behavior may be impacting the inquiry" (p. 82). Morse (2006) found that social location is important to reflexive researchers, because social location can affect meanings assigned to a particular event or experience as well as impose significant value on claims made in the research.

Researching one's own community (in this case AIs) allowed not only social proximity but also an understanding of unspoken language and idiosyncratic cultural nuances of AIs (Ganga & Scott, 2006). This is particularly important as it relates to AI body and eye language that has been commonly misunderstood by Western researchers (Kovach, 2010; Little Bear, 2009; S. Wilson, 2008).

In contrast, as an outsider/researcher, there are a number of challenges facing researchers in accessing a specific AI community and the manner in which Western researchers have misunderstood AI culture (Kerstetter, 2012; Mercer, 2007). Historically Westernized approaches of research have been viewed with suspicion in AI communities (Kovach, 2010; Wilson, 2008). Ganga and Scott (2006) also found that being an AI researcher from the outside also sets up a dynamic that may discourage participation in research studies. This was particularly important in the context of this study. As discussed in the literature review, most AI communities view Alzheimer's disease and dementia with esteem rather than with negative connotations. Therefore Alzheimer's disease and dementia are rarely discussed or seen as an AI health problem. For this reason, AIs view Alzheimer's disease and dementia as part of normal aging and are reticent to discuss it with others. One area of health research that has been somewhat successful is a grassroots effort to discuss Alzheimer's disease and dementia in community-based participatory research and tribal-based participatory research. Here, there is mutual collaboration among Western/AI university researchers and AI communities. Therefore, it was essential in this study that I identify my AI ancestry (to gain trust) and develop a collaborative effort (rapport). For this phenomenological study, being an outsider may have been circumvented by shared AI ethnicity and shared AI experiences.

The potential for bias in phenomenological and qualitative research has been well documented (Creswell, 2009; Maxwell, 2005; Mehra, 2002; Norris, 1997; Onwuegbuzie, Leech, & Collins, 2008). In this study, I was known to have AI ancestry and have been a caregiver to an AI with Cree ancestry who had Alzheimer's disease. Because my experience was very close to the study, there was a need to use phenomenological procedures that addressed potential bias. These procedures included the use of epoche and bracketing, memoing, keeping fieldwork notes, and keeping a reflexive journal.

One of the most underlying examples of potential research bias in this study was my prior and contextual knowledge of the lived experience of being a formal dementia caregiver to AIs and their informal caregivers. Second, because I had personal knowledge of the phenomenon under study, the potential for failing to understand and validate the perspectives of research participants could have proven to be a methodological danger. The nature of this descriptive study had the potential for me to record what I wanted to hear instead of what was actually there. The potential for creating a preresearch bias was also evident in the context of this study. Possible researcher bias may also include examples of subconscious and conscious opinions and feelings (Fontana & Frey, 2008). An example of this could include preferential validation of one's own tribal and nation affiliation, which could prejudice the data. Strategies used in this research study to address potential bias include bracketing and keeping a reflexive journal. A component essential to phenomenology is bracketing (phenomenological reduction or epoche) According to Moustakas (1994), "in epoche, the everyday understandings, judgments, and knowings are set aside, and phenomena are revisited, freshly, naively, in a wide open sense, from the vantage point of a pure or transcendental ego" (p. 33).

The next step in bracketing was the transcendental phenomenological reduction. A phenomenon is presented in a new an open way (Moustakas, 1994), which allows the research question(s) to be answered by phenomenological reduction or bracketing. Epoche eliminates and suspends all preconceived notions, assumptions, and judgments and thus allows the phenomenon to be viewed and revealed in its truest forms, without bias (Moustakas, 1994; van Manen, 1990, 2014). I was aware of possible biases during the research and used a reflexive journal to express them.

Bracketing and using a reflexive journal is a crucial stage in the research process. Drew (2004) stated, "bracketing allows the task of sorting out the qualities that belong to the researcher's experience of the phenomenon" (p. 215). In this study, bracketing my prior experience was important to presenting participants' accounts and experiences exactly as they were and with an open mind (Tufford & Newman, 2010). Throughout the research process, I maintained a reflexive journal containing field, observation, and methodological notes (Groenewald, 2004). These notes were kept by date and in the form memos that accounted what I heard, experienced, and saw throughout the research process (Miles, Huberman, & Saldana, 2014). These memos are an important part of this study, because they helped "the researcher maintains a balance between descriptive notes and reflective notes such as hunches, impressions, feelings, and so on" (Groenewald, 2004, p. 13). The reflexive journal also allowed me to make notes on the reason for the research, issues of reflexivity throughout the research process, particularly those that dealt with insider/outsider research issues. Bracketing in this research study also facilitated transcendental intersubjectivity and allowed for a dialectical dialogue between the researcher, the research participant, and the research methodology. Further, it was essential in helping uncover the meanings and essences of the phenomenon (Moustakas, 1994).

In this study, member checking and participant and researcher debriefing were extremely important to the overall design and protocol of the research methods and interpretation of the data. Interviewing and preparing narratives posed challenges with human thought, human memory, and interpretation that are continuous and subject to change (Carlson, 2010).

Methodology

Participant-Selection Logic

Participants in this study met the following criteria: (a) formal caregiver was presently providing Alzheimer's disease or dementia care to AI demented patients and their informal caregivers; (b) the formal caregiver had never been diagnosed with cognitive impairment; and (c) the formal caregiver and AI dementia patient in northern rural New England. The setting of this study was in northern rural New England.

A sample size of (*N* = 4) AI and Western formal caregivers was chosen from a purposive sample of AI and Western formal caregivers practicing in northern rural New England. In purposive sampling, the researcher "selects a sample on the basis of knowledge of a population, its elements, and the purpose of the study" (Babbie, 2007, p. 184). Sample size depends on the purpose of the study, how much time is available, and the researcher's resources (Al-Busaidi, 2008; Creswell, 2009; Crouch & McKenzie, 2005). Snowball sampling was also used to choose the inclusion of other AI and Western formal caregivers. According to the University California Davis Center for Research (2011),

> A subset of a purposive sample is a snowball sample -- so named because one picks up the sample along the way, analogous to a snowball accumulating snow. A snowball sample is achieved by asking a participant to suggest someone else who might be willing or appropriate for the study. Snowball samples are particularly useful in hard-to-track populations, such as truants, drug users, etc. (p. 1)

For purposes of this research, snowball sampling was used to obtain referrals and inclusion of other formal caregivers into the study. Locating formal caregivers providing care to AI dementia patients was particularly time consuming. Referrals from other formal caregivers were essential in recruiting a large enough sample. Creswell (2009), Maxwell (2005), and Crouch and McKenzie (2005) advocated for smaller sample sizes

(10–20), especially when using a phenomenological method that includes rich description, coding, and longer and more informative interviews to find meaning and understanding of a given phenomenon.

In addition, data saturation was used to determine the sample size, considering that participants may have left the study. Data saturation occurs when narratives contain no new information, insights, or new ideas; at this juncture, further narratives are likely to yield the same data (Babbie, 2007; Creswell, 2009; Onwuegbuzie & Leech, 2007; J. L. Walker, 2012). Groenewald (2004) and Mason (2010) reported that a sample size of 10–20 research participants is a “sufficient number to reach saturation” (Groenewald, 2004, p. 11). Small sample sizes in phenomenological research allow for longer and detailed descriptions of the phenomenon (Creswell, 2009; Maxwell, 2005). However other qualitative researchers advocate for sample sizes large enough to answer the research question and provide an accurate account of the phenomenon under investigation (Abrams, 2010; Bonevski, et al., 2014; Englander, 2012; Marshall, Cardon, Poddar, & Fontenot, 2013; Whiting, 2001).

The recruitment strategy included contacting a AI medical doctor who is also a public health researcher. I knew this person from previous communications throughout the dissertation process. Numerous phone calls were placed to this contact who had close relationships with other formal caregivers providing care to AI dementia patients. A verbal commitment to assist in providing possible participants was received from this AI medical doctor indicating his desire and ability to assist me with locating participants. The AI doctor provided me with email addresses and telephone numbers of possible participants, which I contacted by email and followed-up with phone calls. Only four out of eight formal caregivers referred consented to participate in the study. Because of the small sample, I sent out 20 additional requests by email to locate formal caregivers throughout the rural and urban New England area to request their participation in the study. After a month, I followed up with phone calls to see if there was an interest in participating. This recruitment strategy took place over a two month period. These requests included contacting health care facilities located on tribes throughout the New England area, contacting individual formal caregivers in heavily populated areas where AIs reside and receive healthcare, and I tried to use snowball sampling with previous formal caregivers already interviewed to locate additional formal caregivers. I either received no response from these formal caregivers or I was contacted indicating that formal caregivers declined to participate because they either had no experience with AI dementia or in most cases had never seen or were not currently seeing AI patients with dementia. Subsequently, only four formal caregivers consented to participate. A more detailed discussion follows in Chapter 5.

Approval was granted from Walden University's Institutional Review Board (IRB) in November 2014. The approval number issued from Walden University IRB to conduct this study is 03-17-16-0106750. Recruitment logistics took place over several months. Formal caregivers were recruited by the AI medical doctor, and I followed up with a letter of invitation letter describing the study (see Appendix C). A copy of the dissertation proposal was also sent to the AI medical doctor to familiarize him with the intricacies of the proposed study. Once the sample was obtained was obtained, the invitation letter (see Appendix C) the Informed Consent Form (see Appendix D) and Provider Demographic Sheet (see Appendix E) were sent via email or by fax to the formal caregiver depending upon their delivery preference. The formal caregiver already has prior knowledge that I would be contacting them. The first point of contact with the research participants of the study was the time of their interviews.

Instrumentation

In phenomenology, the researcher is immersed in the phenomenon (Englander, 2012; Moustakas, 1994; van Manen, 1990, 2014). The researcher and the participants are viewed as co researchers. For this study, audiotaped semistructured interviews, observations, and analysis of the memos and reflexive journal were the instruments.

This study was based on three semistructured interview questions that assisted in identifying and understanding the cultural beliefs of formal caregivers and AI dementia patients, and the cultural aspects of the course of care provided (R Atkinson, 1998). According to Jacob and Furgerson (2012), semistructured interviews allow researchers to use “prompts and probe deeper into the given situation” (p. 3). Semistructured interviews that include open-ended questions allow participants to describe in detail as much information as they desire (Turner, 2010), and allow researchers to ask and document the same information from each participant (Turner, 2010). Probes such as “tell me about,” “tell me more,” “what was it like,” “can you give me an example,” and “I don’t understand,” allow participants to give thick and rich descriptive examples of the phenomenon of AI formal dementia caregiving. The reflexive journal, memos and field notes provide the researcher with cues in body language, voice, and “extra information that can be added to the verbal answer of the interviewee on a question" (Opdenakker, 2006, p. 3).In a phenomenological study, researchers ask few questions (Groenewald, 2004; Hycner, 1985; Moustakas, 1994). The three semistructured interview questions for this study follow:

1. What is your understanding about AI cultural beliefs about AD and dementia?
2. What are your cultural beliefs as a formal caregiver about AD and dementia?
3. How do you use these cultural beliefs to develop a course of care with your AI dementia patients?

Another qualitative method used in this study was using me as an instrument to extract meaning from the data (Barrett, 2007; Pezalla, Pettigrew, & Miller-Day, 2012; Xu & Storr, 2012). In this study I was immersed in the data through semistructured interviews, interviewer reflexivity, researcher self-awareness of the data, and collaboration between research participants and me (Finlay, 2012; Watt, 2007). In essence, I took an active role in the research and became what Pezalla et al. (2012) referred to as an empirical interpreter in the research process. As an instrument, I guided the collection of data, data analysis, and trustworthiness of the data (Creswell, 2009; Kovach, 2010; van Manen, 1990; S. Wilson, 2008).

An informed-consent form was obtained from each participant. In addition, the researcher completed a participant demographic sheet (see Appendix D). Each participant was informed that their participation in the study was voluntary and that they could withdraw at any time without any risks. Ample opportunity was given to participants to ask questions and complete the participant demographic sheet. All research participants were asked the same identical open-ended questions. All data were coded to ensure confidentiality, appropriate reporting, and data analysis.

Procedure for Recruitment, Participation, and Data Collection

I conducted all interviews and performed all data collection and data analysis. In instances when some research participants may have been reticent to answer questions individually, interviews were conducted using appropriate probes and prompts, allowing participants to expand their responses as appropriate. In this study, probes and prompts were used to avoid defensive responses by participants and to authenticate “meaning making” from the interviewer to the participant (Seidman, 2006, p. 84). Because so much of the caregiver literature was studied by Western researchers, probes and prompts such as “tell me more,” “what was it like,” and “tell me your story” helped decolonize the Western approach, and provided a decolonizing lens when approaching Indigenous issues in the context of Western research; using principles of Indigenous research allowed me to use a decolonizing lens (Kovach, 2010; L. T. Smith, 2012; S. Wilson, 2008).

All interviews were conducted by phone, were semistructured, and were 60 minutes in length. The interviews were audio recorded and if the formal caregiver objects to being recorded, accurate interview notes were kept, and entered into the researcher’s computer using Microsoft Word. Transcription was done using and outside transcriptionist, and a Confidentiality Agreement was obtained and signed by the transcriptionist (see Appendix F). Recordings were downloaded on the researcher’s computer and sent via email to the transcriptionist. Audio files and a completed transcript were returned to the researcher as well as Microsoft Word files for those formal caregivers who declined to be recorded. All transcripts were sent to each formal caregiver to verify accuracy of the interviews. These were sent to formal caregivers by email. Formal caregivers were either asked to track any changes using Microsoft Word or editing by hand. The researcher asked formal caregivers to either email or fax any changes. In the event changes were made by the formal caregiver, these changes were either emailed back to the transcriptionist to include formal caregiver changes. If no changes needed to be made, formal caregivers were asked to respond and say no changes were needed. An instruction sheet for interview accuracy was also emailed along with the transcript to the formal caregiver (see Appendix G). Prior to all transcriptions, the transcriptionist completed a confidentiality agreement (see Appendix F). At the conclusion of the accurate transcript a thank you letter was sent to each formal caregiver for their participation and input (see Appendix H).

Data-Analysis Plan

Giorgi (2006, 2011) discussed several variations to the application of the phenomenological data-analysis method. Which variation was used depended on the type of phenomenological method used (descriptive or interpretative) (Giorgi, 2006). In this study, the phenomenological method most able to capture a descriptive approach was used in the data-analysis phase. A phenomenological analytical technique facilitated analysis of responses from the face-to-face interviews and narrative conversations. Groenewald (2004) and Hycner (1985) referred to this phase as the explication rather than the data-analysis phase. According to Hycner (1985) “the term analysis is avoided because it usually means a breaking in parts and explication implies the investigation of the constituents of a phenomenon, while keeping the context of the whole" (as cited in Groenewald, 2004, p. 17). It was important to maintain the essence of the experience without breaking the data into smaller parts. This is particularly important as it relates to capturing the essence of formal caregiving to AI dementia patients. Hycner (1985) proposed the following guidelines be used in the data-analysis (explication) process:

1. Bracketing and reduction
2. Delineating units of meaning; these units include general meaning such as "words, phrases, or para-linguistic which express a unique and coherent meaning" (Hycner, 1985, p. 282)
3. Clustering units of meaning to form themes (in this case participant responses). Portions of the interview transcript were read to determine clusters of meaning. At this stage of the research, it was important to bracket and suspend judgment, assumptions, and presuppositions, and to present the phenomenon as openly as possible. Significant statements and descriptions were extracted and categorized (clustered units of meaning). Themes were identified as they emerged from the data. Significant statements, thematic descriptions, and verbatim quotes were organized around each theme.
4. Summarizing each interview, validating it, and where necessary, modifying it.
5. Extracting general and unique themes from all the interviews and making a composite summary. (Hycner, 1985)

ATLASti7©, a qualitative computer program, allowed me "to collect organize and analyze content from interviews, focus groups discussions, and surveys" (Friese, 2014 p. 4). ATLASti7© has been used in numerous qualitative doctoral dissertations (Hwang, 2008; Rambaree, 2007).

Issues of Trustworthiness

To maintain credibility in this study, several strategies were used. The first, triangulation, involves the use of phenomenological and Indigenous research methods to capture the essence of formal caregivers and AI dementia cultural beliefs, Triangulation was used at the data-collection and data-analysis stages (Ghrayeb, Damodaran, & Vohra, 2011). Data were collected in participant interviews, analyzed (explicated) using Hycner's phenomenological method for data analysis, and narratives constructed, providing rich and thick descriptions of the similarities and differences of formal caregiver dementia care experiences (P. Atkinson, 2005). The use of member checks was also used in this study. These included instant checks during interviews as well as after the transcription of the interviews. Member checks ensured I had authentically captured formal caregiver's correct words. Finally, audit trails were used to confirm findings. These were carried out between an outside expert and me on AI health and culture.

Transferability was achieved in this study by providing enough detail about methods, data collection, and data analysis to provide other researchers ample opportunity to replicate this study (Bowen, 2005; Shenton, 2004). Throughout this study, thick descriptions of the phenomenon under study were used. Dependability and conformability were used simultaneously in this study; this was accomplished specifically by using audit trails to verify the accuracy of research participant interview information.

Ethical Considerations

A file was created for each research participant and all hard copies of transcripts, tape recordings, external data-storage devices, researcher notes, diaries, and data were kept in a locked strong box throughout the data-collection phase. My home computer, lap top, and any pertinent software programs where the data were stored are password protected to ensure confidentiality. All of the aforementioned data were kept in a locked box and housed in a safe deposit box in a Boston bank for a period of 7 years after the study is complete. After that time, all hard copies and tape recordings will be destroyed.

Historically, much of the research conducted by non-AIs has not been conducted and managed in an appropriate manner (Nielsen & Gould, 2007; Struthers, 1999). In preceding centuries, European (Western)-based scientific method has been used (Nielsen & Gould, 2007). As a result, AI lives have been invaded and AI persons have been treated with disrespect and have had their personal and tribal lives invaded. AIs have been treated as research subjects rather than participants or collaborators. Intellectual property rights have been stolen as AIs were treated in culturally unacceptable ways (Weaver, 1997b). Not only have these errors been made with tribal communities, but they have also included AI urban communities as well. Much of the research undertaken on AIs by Western researchers has focused on specific problems rather than on strengths or solutions, and has come from a lack of understanding of AIs and AI culture.

To ensure that ethical considerations among formal caregivers in this study were met, the following were considered: (a) each formal caregiver was provided an informed-consent form to sign, and the form was explained to each participant; (b) the research study was submitted for approval from the university Institutional Review Board; (c) each formal caregiver was provided a complete copy of the transcribed interview and narrative at the member check and final stages of transcription to assure accuracy; and (d) because of the sensitive nature of the research topic, each formal caregiver was provided the opportunity to identify information not to be shared in the published research study. Adherence to this protocol helped support collaboration and future entrance into AI communities (Struthers, 1999; Weaver, 1997b).

Future research needs to be conducted by AI researchers. It is paramount they collaborate with tribal elders rather than seeking the advice of consultants (Nielsen & Gould, 2007; Struthers, 1999). Also, researchers need to focus their attention on the oral knowledge imparted by elders rather than merely on written information and findings. Oral knowledge enhances the presence of a holistic, natural, and spiritual response to any research context on AIs.

Summary

This chapter provided an overview of the methods of the study. Detailed recruitment strategies, data instruments used, and ethical researcher/research participant considerations were provided. In addition, data-collection techniques, data analysis, and trustworthiness relating to the data were presented. Ethical considerations were discussed to relate the importance of research being carried out by AI researchers.

Chapter 4: Results

Introduction

As stated beforehand, the purpose of this research was to explore the cultural beliefs and experiences of formal caregivers who provide dementia acre to American Indian dementia patients. An in-depth portrayal of the nature and lived experiences of formal caregivers was quested through data generated utilizing a dialogic open ended semistructured approach. All interviews were conducted on the phone. The interviews were then transcribed by a hired transcriptionist. Each formal caregiver received a copy of their transcript for review. Data analysis then ensued. Themes were extracted from formal caregiver responses and then related back to each of the research questions.

The research questions in this study were answered using a phenomenological approach. The research questions guiding this study were:

1. What are the understandings of formal caregivers for American Indians about their patients' cultural beliefs about Alzheimer's disease and dementia?
2. What are the cultural beliefs about Alzheimer's disease and dementia of formal caregivers for American Indians?
3. How do formal caregivers for American Indians use their cultural beliefs about Alzheimer's disease and dementia to develop a course of care for their patients?

The remainder of this chapter focuses on the following: (a) the research setting, (b) participant demographics, (c) data collection, (d) data analysis, (e) evidence of trustworthiness, and (f) the results of the data collection and data analysis.

Setting

The setting for this study was northern rural New England. New England is home to 16 American Indian tribes (University of Massachusetts, Boston, 2012). The target population consisted of formal caregivers who provided dementia care to AIs and who resided in northern rural New England. According to the U.S. Census Bureau (2014), AIs represent roughly 91,000 persons living in the New England area. This figure represents a combination of rural and urban AI dwellers, but only includes only AIs who reported AI as being their only race; it does not include AIs who reported belonging to more than one race. Thus, population estimates for AIs living throughout New England remain incomplete (US Census Bureau, 2014). To date, there are no known estimates for AIs living with dementia in New England. However, there is a significant presence of American Indian organizations throughout New England that provide medical, counseling, and behavioral health services to AIs (University of Massachusetts, Boston, 2012).

All four formal caregivers interviewed for this study lived and worked with AIs living in northern rural New England. I recruited them for this study, and had each formal caregiver complete a Patient Demographic Sheet and fax it to me (Appendix E). All interviews were conducted by telephone and lasted approximately 60-90 minutes. Signed informed consent forms were obtained from each formal caregiver and faxed to me (Appendix D). I emailed interview transcripts to each of the participants for accuracy review, and the participants returned these to me in the same manner reviewing the transcripts for accuracy. At the conclusion of the study, I also emailed each participant a copy of the completed study.

Demographics

There were four formal caregivers who participated in this study. All four formal caregivers were medical professionals, and had varying levels of medical expertise. The composition of the formal caregivers selected included: (a) one AI family practice/psychiatrist medical doctor with 40 years of medical experience; (b) one Western physician assistant with 35 years of medical experience; and (c) two Western nurse practitioners with 7 and 20 years of medical experience, respectively. At the time of the study, each was caring for AI demented patients. The two nurse practitioners provided care on reservations in northern rural New England, while the medical doctor and physician assistant provided care in rural cities and towns in northern rural New England.

Data Collection

Interviews, narrative case studies, and focus groups have been cited as appropriate forms of data collection in phenomenological studies (Creswell 2009; Groenwald, 2004; Hycner, 1985). Semistructured, open ended question interviews were used in this study to capture the cultural and lived experiences of AI formal caregivers, and AI demented patients, as reported by the interviewees. Three interview questions were asked of each formal dementia caregiver in this study:

1. What is your understanding of AI cultural beliefs about Alzheimer's disease and dementia?

2. What are your cultural beliefs as a formal caregiver about Alzheimer’s disease and dementia?
3. How do you use these cultural beliefs to develop a course of care with your AI demented patients?

In addition to these three main interview questions, I also used an interview protocol with secondary questions centered on these main questions (see Appendix F).

I maintained a reflexive journal as part of this phenomenological study. The purpose of the reflexive journal was to keep reflective notes and memos regarding what I heard and experienced throughout the process, as suggested by Miles, Huberman and Saldana (2014). This reflexive journal was an important tool that assisted me in suspending my assumptions and biases. All recorded data were transcribed verbatim. Reoccurring statements and quotes were used to describe and convey the formal caregivers’ cultural beliefs and experiences of being a formal dementia caregiver. In addition, I was immersed in the data through semistructured interviews, interviewer reflexivity, and research self-awareness of the data (Finlay, 2012; Patton, Tobin, & Begly, 2003; Watt 2007). According to Green et al. (2007), “data immersion brings about clarity of the part played by both the interviewer and research participant, and lays the foundation for connecting disjointed elements into a clearer picture of the issue being investigated” (p. 547). The fact that I have Cree heritage and was a former AI informal dementia caregiver, gave me an active role in the research, making me become what Pezzalla et al. (2012) referred to as an empirical interpreter in the research process.

All interviews were electronically recorded and subsequently transcribed by an outside transcriptionist (see Appendix G) into Microsoft Word, then were imported into Atlas ti7© for coding and analysis. Upon receipt of the transcribed interviews, I emailed each formal caregiver a copy of the transcript to ensure accuracy. This step was repeated until each formal caregiver emailed me and indicated that the interview transcripts reflected the essence and thoughts of each formal caregiver. I began the data analysis immediately after this verification.

The formal caregivers for this study discussed their cultural beliefs, and the experiences centered on what their individual experience was like being a formal caregiver to AI demented patients. The differences in answers were based upon their particular experiences of working with certain tribes, and in some cases on working with members from a group of tribes. In addition, these answers were also based upon differences in the cultural approaches used by formal caregivers in caring for their AI dementia patients. Another factor that added to the richness of the discussion was the number of years' experience each formal caregiver had working with the AI community.

Data Analysis

The corpus of literature on phenomenological data analysis and methods chosen to execute phenomenological data analysis is vast (Giorgi 2006, 2005; Hycner, 1985; Moustakas, 1994; van Manen, 2014, 1990; Vagle, 2014). The specific method that I chose for this study was developed by Hycner (1985):

1. Bracketing and reduction.

2. Delineating units of meaning; these units include general meaning such as "words, phrases, or para-linguistic which express a unique and coherent meaning" (Hycner, 1985, p. 282).
3. Clustering units of meaning to form themes (in this case participants' responses). The interview transcripts were read to determine clusters of meaning. At this stage of the research, it was important to bracket and suspend judgment, assumptions, and presuppositions, and to present the phenomenon as openly as possible. Significant statements and descriptions were extracted and categorized (clustered units of meaning). Themes were identified as they emerged from the data. Significant statements, thematic descriptions, and verbatim quotes were organized around each theme.
4. Summarizing each interview, validating it, and where necessary, modifying it.
5. Extracting general and unique themes from all the interviews and making a composite summary. (Hycner, 1985)

This method was chosen because it provided a structured approach to explore and describe the whole phenomenon of cultural beliefs and experiences as it relates to formal caregiving with AI dementia patients. It also provided me with the opportunity for "systematic procedures to identify essential features and relationships" (Coffey & Atkinson, 1996, p. 6), a procedure identified by Hycner (1985) and Groenwald (2004) as *explication*. In addition to employing phenomenological reduction, a systems approach has been documented as appropriate when researching cultures unfamiliar to a researcher (Bradley, Curry, & Devers, 2007, Kodish & Gittelsohn, 2011; Lowe & Struthers, 2001, Leininger, 1988; Patton, 1999; Polaschek, 1998; Pope, Ziebland, & Mays, 2000), and it has been additionally used by highly knowledgeable researchers in ethnographic and cultural studies (Macquen & Milstein, 1999).

According to Groenwald (2004) "data analysis is deliberately avoided because Hycner (1985) cautions that analysis has dangerous connotations for phenomenology" (p.17). In other words, Groenwald (2004) posited, "the term [analysis] usually means a 'breaking into parts' and therefore means a loss of the whole phenomenon…[whereas 'explication' implies an]…investigation of the constituents of a phenomenon while keeping the context of a whole" (p.17). The explication process is once again outlined in the data analysis method developed by Hycner (1985), and is as follows:

1. Bracketing and reduction.
2. Delineating units of meaning; these units include general meaning such as "words, phrases, or para-linguistic which express a unique and coherent meaning" (Hycner, 1985, p. 282).
3. Clustering units of meaning to form themes (in this case participants' responses). The interview transcripts were read to determine clusters of meaning. At this stage of the research, it was important to bracket and suspend judgment, assumptions, and presuppositions, and to present the phenomenon as openly as possible. Significant statements and descriptions were extracted and categorized (clustered units of meaning). Themes were identified as they emerged from the data. Significant statements, thematic descriptions, and verbatim quotes were organized around each theme.

4. Summarizing each interview, validating it, and where necessary, modifying it.
5. Extracting general and unique themes from all the interviews and making a composite summary. (Hycner, 1985)

This data analysis method was important in the explication of formal caregiver interviews. It also provided an opportunity to obtain rich and thick descriptions of the essence of formal caregiving to AI demented patients as well as similarities and differences in formal caregivers' responses.

Hycner's procedure for explication of data required that all interviews be transcribed and re-read for clarity to become familiar with formal caregivers' responses. In Atlas ti7©, I created hermeneutical units from the interview transcripts and gathered these units to create themes. I re-read all of the interviews to ensure the interviews emphasized the meaning, the description, as well as the understanding and totality of the experience of being a formal dementia caregiver to AI dementia patients. This process was used to create a wholeness of the essence of formal dementia caregiving to AI dementia patients, and provided me with answers to the questions, (a) "what is happening here?" and (b) "what is the experience like being a formal dementia caregiver to AI demented patients and their informal caregivers?" An analytic induction approach was used to analyze the data. This approach has been used in numerous health and cultural studies (Bendassolli, 2013; Mayring, 2000; Thomas, 2006). Figure 4 represents the model and approach that I used in the process of analytic induction.

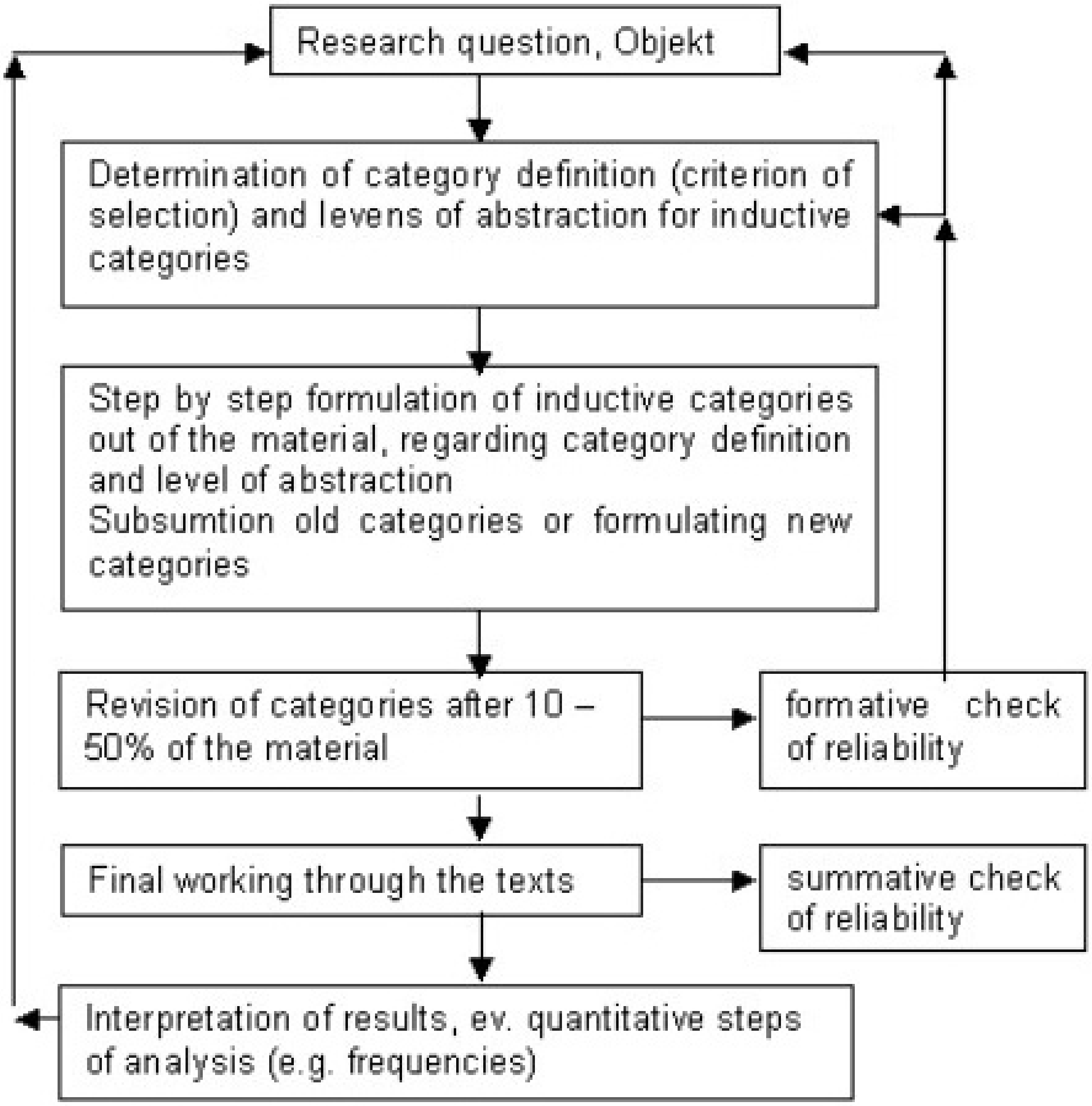

Figure 4. Step model of inductive category development.
Note. Adapted from "Qualitative Content Analysis," by P. Mayring, 2000, *Qualitative Social Research*, *1*(2), p. 11. Copyright 2000 by Forum Qualitative Sozialforschung. Permission not needed.

After completing the process of analytic induction, I utilized four steps of data analysis to ensure that I was able to generate the best possible qualitative evidence for understanding and interpreting the data, and to code, create categories, and then identify themes (Green et al., 2007). Figure 5 is a visual representation of the steps I undertook in this phase of data analysis:

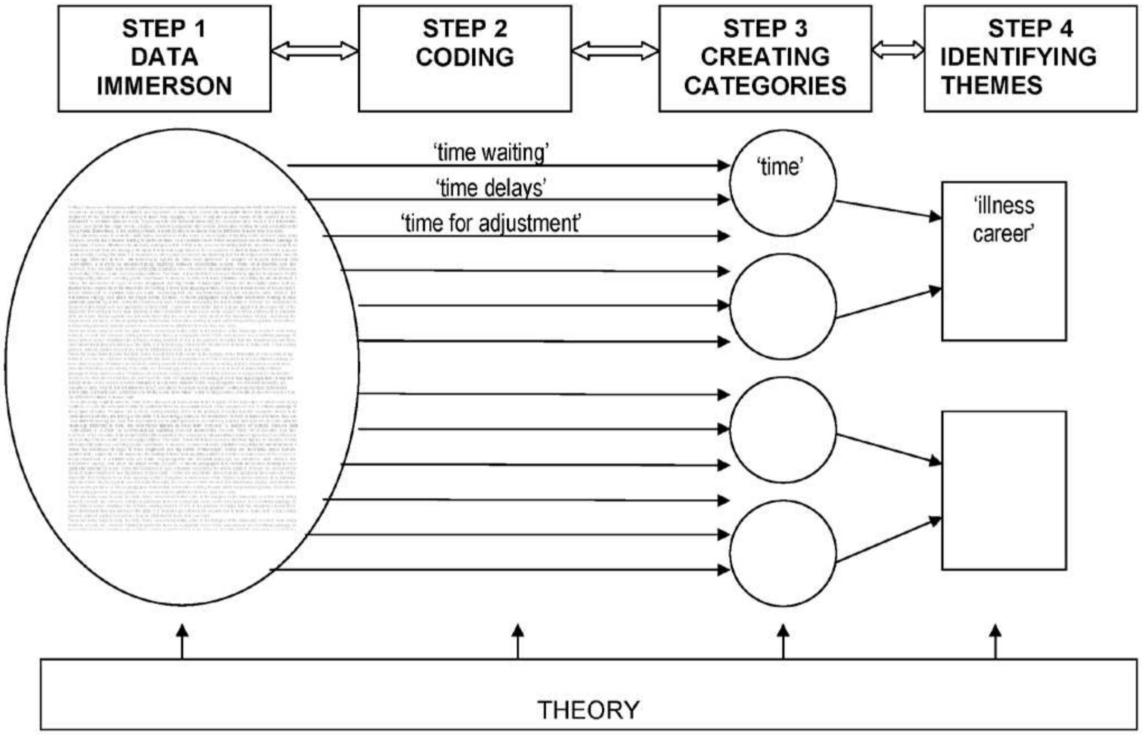

Figure 5. Four steps of data analysis to generate best qualitative evidence.
Adapted from "Generating the best evidence from qualitative research: the role of data analysis," by J. Green, K. Willis, E. Hughes, R. Small, N. Welch, L. Gibbs, & J. Daley, *Australian and New Zealand Journal of Public Health, 31,* p. 547. Copyright by Australian and New Zealand Journal of Public Health. Reprinted with Permission.

Atlasti 7©

Atlasti7© is the computer assisted qualitative data analysis software (CAQDAS) selected to organize the data for analysis. The interview transcriptions were transcribed into Microsoft Word and the imported into Atlas ti 7©. Atlas ti 7© has been used in many phenomenological, health, social science, and cultural studies (Friese, 2014, Hiratsuka, Brown, Hoeft, & Dillard, 2012; Hwang, 2008; Paulus, Woods, Atkins, & Macklin, 2013; Pope et al., 2000; Stanford University, 2012; Wallerstein & Duran, 2006).

Atlas ti7© has the capability to analyze each line of the interview response and arrange these lines into clusters of meaning (Friese, 2014; Lewis, 2004). Words, phrases, and terms are analyzed through this software (Friese, 2014; Paulus et al., 2013). All work is stored in hermeneutic units (HUs) and are easily accessed through opening of a particular document and using a drop down box (Friese, 2014). Atlasti7© is the most appropriate qualitative software, because it allowed me to code, create categories, analyze, and evaluate all of the interview transcripts (Friese, 2014; Hwang, 2008; Lewis, 2004). The memo section allowed me to keep accurate notes and to transpose notes from my reflexive journal. The codes code categories, and memos assisted me in developing the emergent themes for this study (Friese, 2014; Stuckey, 2015).

Epoche

Epoche, also known as phenomenological reduction, is the researcher's ability (a) to use bracketing to address and avoid potential bias; (b) to allow the researcher to gather and form significant and reoccurring statements, replies thus allowing the researcher to develop clusters and themes and (c) to eliminate and suspend all preconceived notions, assumptions and judgments (Moustakas 1994; van Manen, 2014, 1990). Phenomenological reduction was used within the context of this study to discover the meanings from the lived experiences of formal dementia caregivers to AI demented patients as well as the essence of cultural beliefs and experiences of formal dementia caregiving to AI patients.

Bracketing of Researcher Presuppositions and Assumptions

Throughout the data analysis stage, I took careful consideration to bracket my presuppositions, assumptions, opinions and prejudices. This was critical to the overall data analysis stage given that I am a Cree male who also was an AI informal dementia caregiver to a mother with AI ancestry. A reflexive journal and memos were kept to bracket my preconceived knowledge of the phenomenon of formal caregiving to AI dementia patients as well as their providing valuable assistance in helping me document what I actually heard, experienced, and saw throughout the research process (Miles, Huberman, & Saldana, 2014). By keeping the reflexive journal and memos, I was better equipped not to bring up my own perceptions and thoughts so that the data were revealed in its truest forms instead of bringing in prior conceptualizations of the phenomenon (Moustakas, 1994).

Bracketing was also essential in my role as a researcher. It provided an opportunity to reflect on my own perceptions of cultural beliefs of formal caregivers caring for AI demented patients, and it assisted me in my role as an insider/outsider of the phenomenon. The notes kept in the reflexive journal also assisted me with suspending my own suppositions, assumptions, and prejudices. Moreover, the reflexive journal was pivotal and kept me focused on the essence of the lived experiences of formal caregivers in this study. Bracketing ultimately assisted me to focus my attention on what I observed and heard in the interviews of the formal caregivers. This created for a dialectical dialogue between the caregiver and researcher (Bohm, 2004; 2005).

Data Coding

According to Saldana (2013), “ a code in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence capturing, an/or evocative attribute for a portion of language-based or visual data” (p. 3). Saldana (2013) discusses coding from a first and second cycle process. The first cycle coding process helps researcher to identify, observe and arrange words, themes, sentences, re-occurring words and thoughts, which can be single words, full sentences or an entire page of text (Saldana, 2013). In the second cycle coding process, initial codes from the primary coding process are reconfigured and grouped into themes, categories and or clusters of meaning (Saldana, 2013). Themes emerge from the codes based upon the researcher’s ability to re-read, reconfigure, and reflect upon the phenomenon under study (Friese, 2014; Miles, Huberman, & Saldana 2014; Saldana, 2013). There were two initial lists of codes identified by me prior to data analysis and reading of the interviews. These were cultural beliefs of Alzheimer’s disease and dementia among formal dementia caregivers and among AI dementia patients. These codes were then categorized by Traditional American Indian, Western, and bicultural beliefs of Alzheimer’s disease and dementia. A second list of initial codes looked at cultural approaches to caregiving and were then categorized by Traditional American Indian, Western, and bicultural approaches. From these two lists code categories were developed which included health, disease, approaches, beliefs, and concerns and from this list themes began to emerge.

Themes

Themes are the way in which a researcher is able to explain the essence and meaning of the phenomenon based upon the formal caregivers' responses (P. Atkinson, Coffey, & Delamont, 2003; Creswell, 2009; Desantis & Ugarriza, 2000; Seidman, 2006). In Atlas.ti 7©, they were created using the open coding and In-Vivo functions of Atlas.ti7©. The In-Vivo function allowed me to apply meaningful and useful names for a code (Freise, 2014) and also allowed me to extract directly from quotations within the interview transcript and to develop a theme from the meaningful words. Another function that assisted me in developing themes was the repetition of words, which helped create codes and themes based upon frequency and repetition of a single word (Freise, 2014).

Discrepant Cases

During this study I did not identify any differences in formal caregiver responses. There were no outliers, exceptions, or modification patterns found in the data. All data were indicative of the review of the literature. There were no extenuating differences in formal caregiver responses. While there were differences in formal caregiver responses about their experiences, there were no instances in the data analysis where the data did not support the explanations given by each formal caregiver. Further there were no patterns in the data that contradicted any of the explanations given by each formal caregiver.

Evidence of Trustworthiness

In order to achieve trustworthiness in qualitative data, it is essential that researchers establish (a) credibility; (b) transferability; (c) dependability; and (d) confirmability (Bowen, 2005; Creswell, 2009; Morrow, 2005; Morse et al., 2002; Shenton, 2004). To establish credibility, triangulation of the data collection and data analysis stages were used as well as member checks. Formal caregiver checks were done in this study on the spot and after the transcription of the interviews. Triangulation of Indigenous and Western research methods as well as utilizing an expert on AI worldviews and culture were used to insure accuracy in the data analysis and findings. The interviews provided a thick account of formal caregiver voices that described the essence of formal caregiving to AI dementia patients. Additionally, formal caregiver quotes addressed issues of transferability and added to a authentic account of the phenomenon under study. As previously mentioned in Chapter 3, dependability and confirmability have been used simultaneously in this study. This was done by using audit trails. These audit trails served two purposes: (a) to ensure the researcher has authentically captured the participants' correct words; and (b) to confirm findings. Transferability occurred in this study by delineating on methods, data collection, and data analysis so that the study could be replicated (Bowen, 2005; Shenton, 2004). Through detailed descriptions and explanations of formal caregiver experiences of the phenomenon under study, these same methods, data collection, and data analysis could be applicable in other studies that focus on AI dementia as well as other studies that also focus on formal caregivers of AI dementia patients.

Results

The results of this study are organized by major themes and then further divided by the responses of formal caregivers. This framework provides an opportunity to elicit and analyze essential themes from the data. Each theme is explored and relevant quotations from each of the research participants are provided. All four of the formal caregiver revealed that they had knowledge and experience in working with American Indian dementia population. In the following section five identified themes are discussed. The acronym FC will be used to designate the voices of the formal caregivers in the results section.

Theme: Alzheimer's disease and Dementia Is Understood Differently Among American Indians

All four of the research participants recognized that Alzheimer's disease and dementia is viewed differently in the AI culture. AI worldviews regarding disease diagnosis and prognosis are different from Western society. Therefore, Alzheimer's disease and dementia are not seen as problematic in the AI population. Alzheimer's disease and dementia in the AI population is viewed in terms of a passing over to the spirit world, and not seen as something that is broken, needs to be fixed, or out of balance. For AIs, disease is an unbalance and not in harmony with the earth. AIs with Alzheimer's disease are still seen as living human beings that are imbued with a special gift of living in the body and living in the spirit world.

One Western physician assistant expressed this difference as:

> I don't know any specific beliefs except that people in the Native American community do not feel easy with a diagnosis for dementia. Even when there are problems, they seem to feel like it more just a part of the person as they age, not a disease state. And do not want to give their elders a label of demented or

> Alzheimer’s for one reason or another, or they are just in denial themselves. (FC3)

One AI physician also expressed:

> Well, I would say that AIs not -- I would say AIs are just not as concerned with the formal diagnosis. They’re just accepting what’s happening and coping with it. I mean, you know, it’s -- it’s kind of a -- I don’t know. I’m not sure what word to use, but conventional mainstream society. Maybe we could call it CMS. But people are trained to want diagnoses and treatment plan. And they want prognosis. And they want -- they want certainty. They want to know what’s going to happen for the next X years. And the medicine tends to provide that to them, even though we can’t actually do it, even though, you know, we might -- we often make the wrong diagnosis, at least sometimes. (FC2)

And this same AI physician also related:

> I think -- I think people who keep the traditions tend to see someone with dementia as I described, as spending more time in the spirit world or, you know, talking with spirits, more interested in spirits than ordinary people. And that’s what I’ve heard from tradition-probing people and from elders, you know, that they’re spending a lot of time in the spirit world and will eventually go there entirely. (FC2)

Theme: American Indian Worldviews Regarding Alzheimer's disease and Dementia Treatment are Different

Another major theme that emerged was the way in which AI dementia patients access healthcare treatment for Alzheimer's disease or dementia. All of the formal caregivers practiced in northern rural New England, and their AI demented patients came from traditional tribal backgrounds. Therefore, traditional AI worldviews had a significant role in the way in which AI Alzheimer's disease or demented patients access healthcare for Alzheimer's disease and dementia. One Western nurse practitioner who was interviewed gave an extensive overview of the manner in which AI demented patient access healthcare in concert with Alzheimer's disease or dementia:

> No, not -- no. They generally never follow up for that. If they follow up here, it's because of an ailment, not because of that (Alzheimer's disease/dementia). And that just happens to come into play. But the ones that I have -- I'm trying to think of the -- I have -- I have four. One who's on Aricept and has been for some time does very well. He actually cares for his loved one, who's in a wheelchair. And he is the one with Alzheimer's. And he just does really well.
>
> The other one comes in on his own, which is kind of difficult. Because trying to ask him how his blood sugars have been or did he take his insulin and things like that, he's pretty good. His niece is the one who's his primary caregiver, but he comes in alone. So that one's a little bit difficult.
>
> Then the other one that I have, she doesn't come in unless she's had an ailment, which recently she had, but then generally she comes in the room alone. So I've

had to pull in a couple of her children with her permission, because they still weren't really on board with this memory loss, to come into the exam room so I can explain things to them.

And then, of course, the other one with her mom, they now do come in with her only because she's not driving anymore. So -- but it's not because of memory loss. It's never because of memory loss. It's only because of an ailment. (FC1).

A Western nurse practitioner also added:

Okay. There -- there are some folks -- and that's a very interesting question actually. I, as a provider, I was not good at asking people in the beginning if they were using any cultural medicines to treat their conditions outside of what we were giving them in Western medicine. And we have a certain group of folks here that I have now learned within the tribe who, although they will come in and get their prescription for their Lisinopril or for their hypertension or for their cholesterol, that they also use cultural medicine. (FC4)

Additionally, an illuminating example was shared with another Western nurse practitioner recounted:

And he'd been taking Aricept for a long time. He came to see me, I think probably for a diabetes clinic. And we talked about all of his medications. And he was very reluctant to tell me that he was taking Aricept. And he did tell me. He shared that with me behind closed doors. And he said I -- he was filling his medications off the reservation, but didn't have a transport, a way to go get them. They were 45 minutes away.

> So I encouraged him to fill his medications here at the clinic, which is a half a mile from his house and we deliver. And he agreed only to fill all of his medications for diabetes and blood pressure. He did not want his Aricept filled here. He did not want anybody who worked in this building of Tribal descent to know he was taking Aricept. So for a long time, that’s what we did. (FC1)

Theme: The Main Source of Support for AI Alzheimer’s disease or Dementia Patients is the Family

Throughout the four interviews, all of the formal caregivers agreed that the family is the main source of support for the patient. Two of the four of the formal caregivers also reported the importance of the family being the chief source of information of about the patient. AI’s have been historically tied to their families and tribes as the source of support, especially in times of need. AI families tend to be multigenerational, and support can come from not only immediate family members, but from cousins, in-laws, and other extended family members that live both on and off the reservation. The formal caregivers in these interviews talked about the high esteem for elders within the AI community.

Support

One Western nurse practitioner related that AIs are very tied to their families culturally. “So how they deal with Alzheimer’s and dementia is to keep that person very close to the family unit. They do not believe in nursing facilities or anything along those lines unless it is an absolute last resort.” (FC1), and another Western nurse practitioner noted:

> I think, again, I think the most remarkable difference is the family unit, is the coming together of all the generations of the family to assist with an elder. They are an elder-dominated society. And I think that the family unit, the family's means of dealing with an elder is a little different than I've seen sometimes in Western situations, where sometimes the family member is just dropped off at an emergency room and left. I don't -- I have never witnessed anything even remotely close to that within the Native American community. (FC 4)

The concept of family support was also described by a AI physician as: "I'd say that the more traditionally people, you know, the more that they live on reservation the more they keep their relative at home. And the more that they've adopted the modern American lifestyle, the less happy they are." (FC2)

Chief Source of Information

Two of the Western nurse practitioners interviewed for this study related that family members are the chief source of information as it relates to their family member's Alzheimer's disease or dementia, and at times family member may provide little information on the Alzheimer's disease/dementia patient because of issues of trust with non-AI and in some instance with AI formal caregivers. The first Western nurse practitioner related:" They keep things very close within the family unit and within their tribal community. And even the community can become a part of these things, to the point of someone who needs care during the daytime" (FC4), and this same Western nurse practitioner also spoke about patient and family trust:

> It is case by case. I have been working within this community for three years. And it's a trust-building process for them. I can tell you that my relationship today with some patients is very different than it was in the very beginning. I am not Native American. I do not speak their particular tribal language, but I have earned their respect. And now I am able to go into people's homes, and there is -- the tension that may have been there in the very beginning is no longer there. (FC4)

The second Western nurse practitioner noted:

> It's something that I find nobody has ever come to me with concerns that their family member has some memory loss. It's generally something that I've discovered or through outside family members, meaning cousins, you know, not inside the household, with concerns. And in order for me to bring it up to family members, of course, I have to have a release signed. And even when I do that, they're really cautious and they're really good about caring for that loved one or that parent and help making sure they get their medications and things like that. (FC1).

Theme: All Providers Stressed the Need for Cultural Competence and Bicultural Approaches When Working With American Indian Alzheimer's disease and Dementia Patients.

All four of the formal caregivers discussed the importance of creating culturally competent course of care plans for AI Alzheimer's disease and dementia patients, and most related that that when developing these care plans that both AI and Western beliefs were incorporated. However, central to this theme was honoring AI worldviews. The following quotations are very illuminating of the concept of cultural competence among these formal caregivers. One Western physician assistant related the need to use culturally competent labels with the AI community:

> Well, I used the word indigenous because, as you're probably aware, the world view concerning Native or Indigenous medicine is radically different from that of the Westerners, which we just played out. And there's this whole debate of whether to use American Indian, Native American, Aboriginal, or indigenous. So when I use the term indigenous, it's to honor the American Indian/Native American/Aboriginal worldview. (FC3)

> Another example though rather lengthy describes a lesson learned by one Western nurse practitioner as it relates to the necessity of cultural competence when trying to use Indigenous and Western approaches:

> It's a combination of both. I let the family lead me to what their best plan is. I -- I try both and whatever the family feels is best. But again, I only have one of them on medicine. I did try the gentleman whose niece cares for him on medication, and it did not make him feel well. He was -- he understands that he has forgetfulness and that he forgets things. And a lesson learned to me, a little side caveat or a little side story, is I knew when he came in because of his blood sugars being so erratic that something wasn't right. He was forgetting his medications. And it was really hard for me to get the niece onboard because she works. So I did a mini mental exam on him. And when I got to the one "spell the word world backwards," he was really struggling. And at that point I said," Do you know how

> to read?" And he said to me "no." And I'm thinking oh, my goodness. Why would that not be the first question you would ask a patient before you would even proceed with a mini mental exam? So that was a learning experience for me, because I've never in my previous work had a patient who I had to do a mini mental exam that couldn't read. So now before I do that, I will ask a patient. Because English is not always the primary language in these cultures, schooling wasn't always available, as well. I mean, this person in sixth grade, I think, went out and had to work and provide for his family. So he didn't get very far in the schooling. So that was a learning lesson for me, as well, that, you know, the mini mental exam is not always going to be part of the plan either. (FC1)

Theme: Formal Caregivers Expressed Frustration and the Essential Need for Early Intervention in Working with AI Alzheimer's disease and Dementia Patients.

The formal caregivers interviewed for this study stressed the importance of early intervention in the treatment of AI Alzheimer's disease and dementia patients. One Western nurse practitioner discussed her frustration with the lack of early intervention:

> Early intervention is -- is the most difficult. Early intervention in the aspect of getting families to recognize that there is a problem, realizing that their loved one hasn't been taking their medication for several weeks or months. Even though we can send over pillboxes weekly from our facility, and they come back half full, they still don't perceive that there's an issue. And not going into everybody's homes, it's hard for me to say whether they're eating or not. So I think that it's hard for me to get families to see that there really is an issue going on, you know,

> whether it’s insulin, whether it’s oral medications for something else. And appointments, they -- because they’re not -- they’re very westernized because we’ve blended our cultures. But, again, these elders didn’t grow up going to doctors to have immunizations and well checks. So many of them don’t go unless there’s an issue. So if it’s not broke, don’t fix it. So a lot of these patients we’re not seeing on a regular basis, as well. (FC1)

The AI physician interviewed for this study talked about the need for early intervention as it relates to comorbidities of heart disease and diabetes along with AD or dementia, he related that:

> We like to present people with certainty that they’ve come to expect from us. You know, I think it’s a vicious cycle. The more we pretend to have certainty, the more people want it. And the more people want it, the more we pretend to have it. And I think -- I think indigenous people, to the extent that there’s traditional learning and caring for the language, culture, values, tend to be more present oriented and more accepting of the moment and more accepting of uncertainty, able to -- not really thinking that anyone can tell them what the future will hold. (FC2)

This AI physician further elaborated on this theme of early intervention by discussing some approaches to early intervention:

> So I think that includes diet and exercise. You know, to use our bodies in the way they’re designed is called health producing. We’re not really designed to sit still for 24 hours a day, you know. And we have to -- we have to move. And we have

> to be with other people. And we have to, you know, challenge our brains to do stuff, you know -- stimulate each other to learn things. And that way we stay as healthy as we can, acknowledging that there's random forces all around us that we can't control. So it's not a guarantee that, you know, if you do everything right, you will be healthy. But it's a better plan than doing everything wrong. (FC2)

Theme: Early AI Mortality

The last theme extracted from the interviews was the early mortality rate of AIs even before the onset of AD begins. One AI physician related: "Well, sadly, sadly I think many people in Indian Country die before they have a chance to get Alzheimer's disease or dementia. You know, they die of the complications of diabetes or heart disease"(FC2) and the Western physician assistant interviewed stated, "the life expectancy of Native Americans is so much shorter, they carry such a high disease burden, that once someone starts getting sick with heart disease and diabetes" (FC3).

Research Questions

Having presented the themes, the following section addresses the research questions based on the findings. There were a total of three research questions for this study. Each research question is addressed and the formal caregivers' responses around these interview questions are presented.

Research Question 1

What are formal caregivers for American Indians' understandings of their patients' cultural beliefs about Alzheimer's disease and dementia? All four of the formal caregiver revealed they had some type of experience with AI Alzheimer's disease or dementia patients. The major themes that emerged for this research question included that Alzheimer’s disease and dementia are understood differently among AIs. This is particularly true from one tribe to another. There is variability with how one tribe addresses AI and dementia, copes with it, and in some instances the types of prevention and interventions used. Most remarkable is the fact that AI worldviews of Alzheimer’s disease and dementia treatment are different from mainstream Western culture, and the family is the main support for AIs who have either Alzheimer’s disease or dementia.

Issues related to these themes included a difference in AI understanding and perceptions of Alzheimer’s disease or dementia. The data revealed AI Alzheimer’s disease and dementia is not homogenous, but rather heterogeneous as it relates to the AI Alzheimer’s disease and demented population. This mainly hold true in the differences of how AIs care for their family members as opposed to the ways Westerners care for family members. A good example of this is that AIs do not typically use nursing homes for family members with Alzheimer’s disease and dementia. Westerners, however, use nursing homes and other adult day care programs for their family members with Alzheimer’s disease and dementia. Another difference is that Westerners tend to view Alzheimer’s disease as a disease, whereas, AI’s view Alzheimer’s disease as a natural progression of aging. The data also revealed that AI Alzheimer’s disease and demented patients are more likely to seek the support of their families and tribal communities rather than from non-AI formal caregivers. The formal caregivers related the AI family unit is the chief source of information about Alzheimer’s disease and dementia among AIs. This was especially true as it related to the worldview of AI treatment of disease, Alzheimer's disease and dementia.

Interviews with formal caregivers showed that there appears to be a lack of knowledge among non-AI formal caregivers. This lack of information, in turn, causes barriers and challenges as it relates to Alzheimer's disease and dementia prognosis, diagnosis, and intervention. This was particularly illuminating in Western one nurse practitioner's explanation: "It's very difficult sometimes for them to have a non-Native caregiver come in and even come into their home. They are -- they are very community oriented." (FC4)

Research Question 2

What are your formal caregivers for American Indians' cultural beliefs about Alzheimer's disease and dementia? All four of the formal caregivers interviewed had varying beliefs regarding their own cultural beliefs regarding Alzheimer's disease and dementia. This particularly held true for the three non-AI caregivers, who experienced challenges in applying cultural competence, a theme that emerged within the context of this research question. One Western nurse practitioner expressed her trying to balance Indigenous cultural beliefs with her own Western cultural beliefs regarding AI and dementia, and expressed it as:

> No, they've not changed. I think what I try to bring to the table is my experience in helping the families, keeping the person safe. I don't feel that a person has to be in a nursing home to be safe. What I've tried to do, though, is really early on

> promote safety, you know, with the cooking and the driving and things like that that are going to come up. (FC 1)

The one AI physician interviewed talked a lot about his formal medical education in a Western medical school where he was trained and expressed the following:

> Well, I was trained in a time when people thought it was unalterable, irreversible, progressive, and too bad. So the idea that people can get better or can slow the rate of decline, which is now becoming more accepted in the mainstream, but that would be unheard of when I was in training (FC2).

After 40 years of practicing medicine in both Western and Indigenous cultures, this physician related how he has tried to incorporate his Indigenous world view of medicine, he explained as follows:" I think it's been demonstrated, you know, in studies that the more meaning and purpose you have, the healthier you are. And so I think that, you know, being a part of a storytelling process is absolutely conducive to wellness". (F2) This AI physician related that stories and storytelling are a part of the Indigenous worldview of medicine, and are essential in Indigenous healing and treatment.

Research Question 3

How do formal caregivers for American Indians use their cultural beliefs about Alzheimer's disease and dementia to develop courses of care for their patients? This research question included all of the themes that emerged from the data. Cultural beliefs and issues encountered in formal caregiver experiences with the AI Alzheimer's disease and dementia. Central to this research question was the unpacking of AI understanding of Alzheimer's disease and dementia, formal caregiver beliefs about Alzheimer's disease and dementia in the AI population, and how formal caregivers use their understanding and beliefs to develop a course of care. While each of the formal caregivers interviewed had varying ways of expressing their cultural beliefs in their care plans, all agreed that cultural competence and bicultural approaches were essential in treating AI Alzheimer's disease and dementia. The AI physician interviewed expressed this as: "And I think that relates to the culture's perception of aging. You know, old people are honored more in both Native American and Asian cultures than they are in the contemporary Western society". (FC2), and this same sentiment was expressed by a Western physician assistant interviewed as: "And I think the Native American community is much better at seeing that the Alzheimer's is just one part of what's happening to the person. And they -- they seem to be very calm about it. It's like it doesn't change who that person is to them." (FC3)

This last research question unpacked and interconnected all of the themes that emerged in the data.

Research Questions Summary

At the time of the interviews, it was identified that all four of the formal caregivers had some experience of caring for AI Alzheimer's disease and dementia patients. All found their experience to be a positive and educational one. Each formal caregiver varied in the amount of time of working with AI Alzheimer's disease and dementia patients, but the findings showed their experiences to be similar. Despite the years of being exposed to the AI community and AI Alzheimer's disease and dementia patients, the findings showed similarities in incorporating bicultural beliefs in the development of course of care plans with AI Alzheimer’s disease and dementia patients. These findings must be considered in the development of efficacious, culturally competent, and culturally sensitive course of care plans with AI Alzheimer’s disease and demented patients. Additionally, the interviews revealed the critical importance developing sustainable relationships with non-AI formal caregivers who work with AI Alzheimer’s disease and dementia patients.

Table 1

Paired Research Questions and Themes

Research question	Theme(s)
RQ1 What are formal caregivers for American Indians’ understandings of their patients’ cultural beliefs about Alzheimer’s disease and dementia?	•Alzheimer’s disease and dementia is understood differently among American Indians •American Indian worldviews regarding Alzheimer’s disease and dementia treatment are different from Western worldviews. •The main source of support for AI Alzheimer’s disease and dementia patients is the family
RQ2: What are formal caregivers for American Indians’ cultural beliefs about Alzheimer’s disease and dementia?	•Bicultural
RQ3: How formal caregivers for American Indians use their cultural beliefs about Alzheimer’s disease and dementia to develop courses of care?	•Cultural competence when working with American Indian Alzheimer’s disease and dementia patients •Early intervention •Early mortality in the AI population, do not live long enough to develop Alzheimer’s disease or dementia

Summary

This chapter discussed the research questions of the study and presented how each theme related to the research questions. This chapter also presented in detail the data analysis and subsequent findings extracted from the four semistructured interviews. The data analysis and findings provided insight to the phenomenon of the cultural beliefs and experiences of formal caregivers providing dementia care to AI patients. The findings were essential in discussing formal caregiver and AI cultural beliefs around Alzheimer's disease and dementia.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was to explore the cultural beliefs and experiences of formal caregivers who provide dementia care to AI patients. This study specifically sought to understand formal caregiver beliefs about Alzheimer's disease and dementia, and how these beliefs define the course of care developed by formal caregivers for AI dementia patients. I used a phenomenological approach to identify differences specific to the AI population, including whether these formal caregivers chose traditional medicine, Western medicine, or a combination. I collected data from telephone interviews with four formal dementia caregivers in northern rural New England to elicit their experiences in working with the AI demented community in this region.

Research on this topic is critical in advancing cultural, public health, and evidence-based health practices regarding AI dementia patients. The potential implications for social change include cross cultural provider-patient interactions, and advancing public health policy and practice for this underserved population. Many of the issues and challenges explored may have implications for other ethnocultural minority groups.

The findings were answered by the following research questions:

1. What are the understandings of formal caregivers for American Indians about their patients' about their patients' cultural beliefs about Alzheimer's disease and dementia?

2. What are the cultural beliefs about Alzheimer's disease and dementia of formal caregivers for American Indians?
3. How do formal caregivers for American Indians use their cultural beliefs about Alzheimer's disease and dementia, to develop a course of care for their patients?

Interpretation of the Findings

This study utilized a combined phenomenological and Indigenous research method approach to understand formal caregiver and AI cultural beliefs and experiences of AI and dementia. The findings of this study aligned with the literature review's findings on heterogeneity in AI Alzheimer's disease and dementia within this specific AI group. Further, the literature revealed that Alzheimer's disease and dementia as well as the concept of disease differs among AIs from that of their Western counterparts. Additionally, the study findings validated the selection of a conceptual framework honoring AI worldviews concerning disease and utilizing a bicultural approach to understand the cultural beliefs of formal caregiver and AI dementia groups. One of the most important findings derived from the data was the notion that Westerners need to develop an empathetic understanding of AI worldviews concerning not just Alzheimer's disease and dementia, but also with the concept of disease and understanding of disease as a whole.

One of the most important findings of this study was how formal caregivers and AI dementia patients view Alzheimer's disease and dementia. The formal caregivers in this study ranged in age from mid-30s to the mid-60s. All had obtained a graduate or post graduate in their field of training. The findings indicated that AI patients view Alzheimer's disease and dementia differently than their Western counterparts. According to Goins et al. (2011), a common coping strategy for AIs dealing with any type of disease is *passive forbearance.* Passive forbearance is "defined as accepting and adapting to the caregiving role rather than trying to control it" (Goins et al., 2011, p. 311). The review of the literature and interview data analysis also supported that this is the same way in which the AI population deals with disease in total. Common examples of *passive forbearance* include the way in which AI families gather together to help one another during a time of need and sickness. AIs have also used *passive forbearance* to effectively deal with the mental health aspects of the historical and cultural traumas faced by AIs in the United States over the past five centuries. AIs rely mainly on one another for support Goins et al., 2011). According to Goins, Spencer, Goli, and Rogers (2010), AIs faced with any disease or disability "value autonomy and not imposing needs on others" (p. 2190). In other words, AIs are more adept at finding solutions than their Western counterparts, rather than relying and being an imposition on others.

In the current study, regional, tribal, and cultural beliefs were found to be a major factor in the ways that AIs and their formal caregivers addressed Alzheimer's disease and dementia. While Westerners generally believe in diagnosis, prognosis, and a linear course of care, AIs generally believe in the notion that all things are in nature are imbued with nature (Deloria, 2003; Lowe, 2002), and that disease is a symptom of disharmony and imbalance in one's life. The data analysis of the formal caregivers' experiences with AI dementia patients also indicated that any studies and treatment of disease including

Alzheimer's disease and dementia need to focus on the social determinants that prohibit unequal access to health care, stress of life, and poverty. These appear to be indicative of the larger picture of morbidity and mortality among these groups of AI Alzheimer's disease and dementia patients. This was discussed by several of the formal caregivers who mentioned that the life expectancy of AIs is less than that of their Western counterparts. This is consistent with Solomon and Randall (2014) statement that "Native people suffer from not only one disease state but often from multiple co-morbidities" (p. 29).

Results from this study also suggest that formal caregivers and AI dementia patients did operate with the same definition of Alzheimer's disease and dementia. Both the formal caregivers and AI dementia patients were far less concerned than their Western counterparts with prognosis and diagnosis, and more centered on quality of life. Western formal caregiver understanding of cultural competence and cultural sensitivity as well as a basic understanding of a particular tribe's cultural beliefs and worldviews were cited as essential in working with their respective tribes. The AI formal caregivers also discussed the need for cultural competence and sensitivity as it related to using bicultural approaches with AI dementia patients. This AI physician in this study advocated for a balance between AI worldviews and Western approaches particularly as it related to the use of Western medications, which is consistent with Joe's (2014) finding that "cultural awareness about a problem in a special population includes not only knowledge about the population but also about the populations ongoing interventions in addressing the problem" (p. 87). Among all four of the formal caregivers there appeared to be a cultural humility, in keeping with Joe's (2014) definition of this as "a process by which one attempts to evaluate his or her own perceptions based on experience in order to expand one's knowledge and improve his or her ability to function more effectively in a different culture" (p. 91).

One area where the literature and data analysis differed was in the fact that US Census data has made a claim that AIs are the fastest-growing aged population in the United States (U.S. Department of Commerce, Economics and Statistics Administration, 2010). However, within the context of the interviews, and further discussion of morbidity and mortality amongst AIs, the literature indicated that most AIs do not have long life spans. In fact, in two of the interviews with the AI physician and one Western physician assistant, both discussed that AIs tend to die long before any indication of AD or dementia. The literature review and interviews discussed the fact that due to co-comorbidities, many AIs die before reaching the age of 70. In fact, it was found that AIs have the highest rates of diabetes, cardiovascular disease, and cancer than their Western counterparts.

Limitations of the Study

The major limitation of this study was the difficulty of recruiting formal caregivers for inclusion into the study. Two of the major reasons for this were that most formal caregivers that I contacted had little experience with AI Alzheimer's disease and dementia patients and that Alzheimer's disease and dementia are not common among the AI population. This resulted in a low participation rate for the current study. I found the recruitment of Western and AI formal caregivers to be an arduous task because of my lack of experience with AI Alzheimer’s disease and dementia patients and my lack of knowledge of AI worldviews, culture, and tribes. The reticence of AI formal caregivers also played a role in low recruitment rate, and mainly occurred because of the stigmas, inaccuracies, and traumas placed upon the AI population by Western researchers.

I attempted to address this limitation by contacting individual formal caregivers who may have had experience with AI Alzheimer’s disease or dementia, but often received no response from these caregivers. As a result, I was only able to obtain a small sample. Because of the small sample size, the current results can in no way be generalizable to the AI Alzheimer’s disease and dementia patients, or even for all formal caregivers who care for AI Alzheimer’s disease or dementia patients. This study was, instead, reflective of limited insights into a larger population that needs further research.

Recommendations

Based on the results of this study, I recommend several actions for further study of the phenomenon of cultural beliefs and improving understanding of Alzheimer’s disease and dementia among formal caregivers. These are:

1. Research needs to be conducted by AI researchers interested in this timely topic. Further studies may be able to replicate similar findings such as those presented in this study.
2. Cultural competence and cultural sensitivity trainings need to occur in medical and public health based educational programs.
3. Relationships with AI tribes and communities need to be established with Western researchers prior to any AI centered research topic is executed.

4. Community based research and evidence based programs need to be established with individual tribes that focus on “interventions that would reduce morbidity and mortality” (Solomon & Randall, 2014, p. 24).
5. Epidemiological studies that look at risk behavior, disease status, and healthcare need to be conducted (Solomon & Randall, 2014).
6. Research needs to be conducted on specifically Alzheimer’s disease and dementia within rural, tribal, and urban communities, both qualitatively and quantitatively.
7. Cultural competence and cultural sensitivity trainings need to occur on reservations staffed by Western healthcare professionals.
8. Screenings for Alzheimer’s disease and dementia in the AI population need to be established that take into account areas of cultural competence and cultural sensitivity.
9. Alzheimer’s disease and dementia information sessions need to occur with AI rural and urban populations as well as their formal caregivers that specifically focus on Alzheimer’s disease and dementia.
10. Education of AI Alzheimer’s disease and dementia patients’ needs to explore alternative medications along with lifestyle changes and risk behaviors.

Implications

Alzheimer’s disease and dementia affect every racial group in the United States. Because the AI population is so small and diverse, attempts must be made to produce further research that will enhance understanding for AI formal caregivers and AI

Alzheimer’s disease and dementia patients. There has been very little research in the area of AI Alzheimer’s disease and dementia and the experiences of formal caregivers caring for AI dementia patients. Extending the literature and research within this area is of marked importance because of the high comorbidity patterns that exist in this population, which in turn may have an impact on the level of AI Alzheimer’s disease and dementia. Future qualitative studies that build upon this current study may enhance understanding of AI Alzheimer’s disease and dementia as well as the cultural beliefs and experiences of formal caregivers caring for AI Alzheimer’s disease and dementia patients. These types of ethnocultural studies are needed to assist researchers in developing feasible community based research, tribal based research, evidence-based research as well as appropriate public health and public health policy research that addresses this special population. Moreover as Solomon and Randall (2014) state: “All research should be consistent with the values of the population study. Core values of Native communities such as family, respect, honesty, kindness, caring, and sharing should be honored” (p. xv). The implications for positive social change within this study include considering Alzheimer’s disease and dementia from a bicultural approach rather than from a Western approach, which may advance formal caregiver knowledge of how to address AI Alzheimer’s disease and dementia.

Conclusion

Rather than considering Alzheimer’s disease and dementia from a Western perspective, formal caregivers and other healthcare professionals need to adopt a bicultural approach in addressing AI Alzheimer’s disease and dementia. Future research on AI Alzheimer’s disease and dementia patient care is of marked importance needs to be balanced. It should include Western and traditional AI approaches to disease and more specifically to Alzheimer’s disease and dementia. Different attitudes about AI health, and a clearer understanding of AI beliefs, hopes, fears, and perception as it relates to research and disease are needed. Moreover, Western and traditional approaches to Alzheimer’s disease and dementia require a mutual acknowledgement of cultural beliefs with the overall goal for improving social, cultural, and public health. Solomon (2014) best sums this up by writing, “scientific discovery in its purest state is the understanding that we do not have answers; thus, researchers have a healthy respect for what is unknown” (p. 212).

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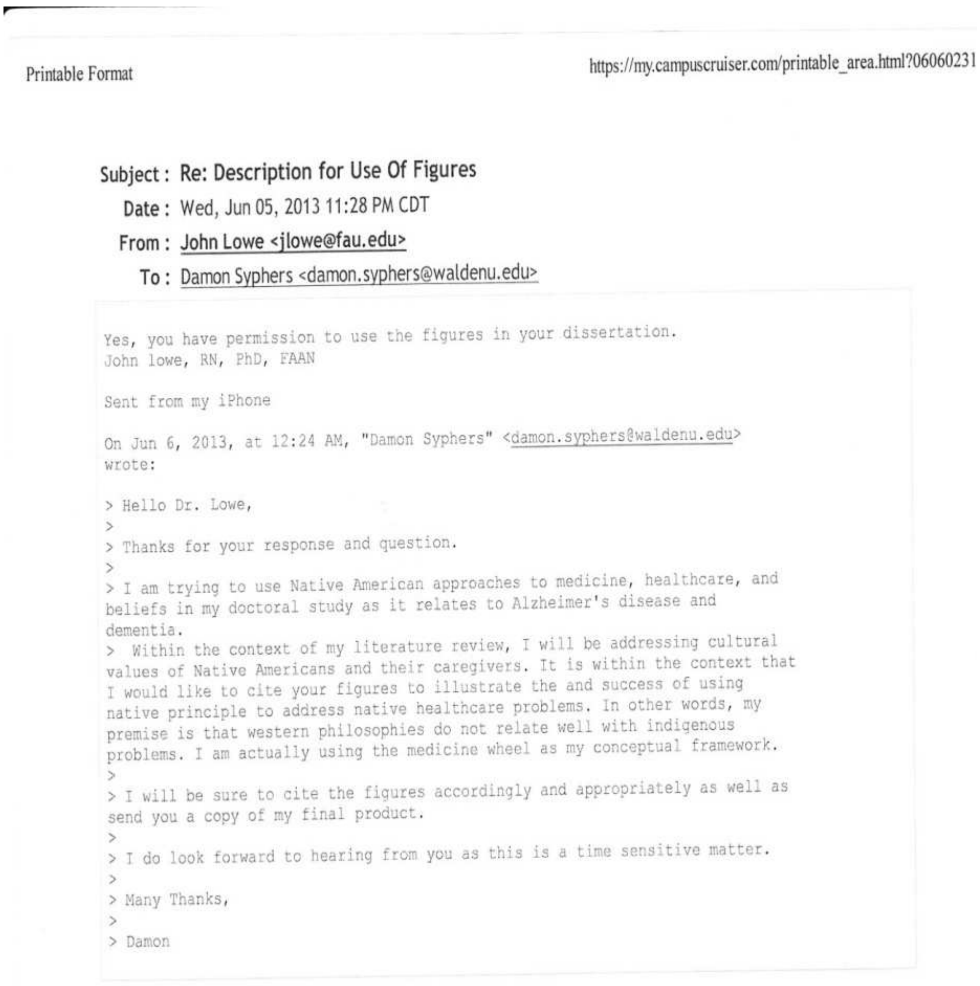
Appendix A: Permission to Use Figure 1



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Subject : Re: Description for Use Of Figures
Date : Wed, Jun 05, 2013 11:28 PM CDT
From : John Lowe <jlowe@fau.edu>
To : Damon Syphers <damon.syphers@waldenu.edu>

Yes, you have permission to use the figures in your dissertation.
John lowe, RN, PhD, FAAN

Sent from my iPhone

On Jun 6, 2013, at 12:24 AM, "Damon Syphers" <damon.syphers@waldenu.edu> wrote:

> Hello Dr. Lowe,
>
> Thanks for your response and question.
>
> I am trying to use Native American approaches to medicine, healthcare, and beliefs in my doctoral study as it relates to Alzheimer's disease and dementia.
> Within the context of my literature review, I will be addressing cultural values of Native Americans and their caregivers. It is within the context that I would like to cite your figures to illustrate the and success of using native principle to address native healthcare problems. In other words, my premise is that western philosophies do not relate well with indigenous problems. I am actually using the medicine wheel as my conceptual framework.
>
> I will be sure to cite the figures accordingly and appropriately as well as send you a copy of my final product.
>
> I do look forward to hearing from you as this is a time sensitive matter.
>
> Many Thanks,
>
> Damon

Appendix B: Permission to Use Figures 2 and 3

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November 18, 2014

Damon Syphers
Walden University
DAMON.SYPHERS@comcast.net

INVOICE #078013

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Appendix C: Recruitment Letter Key Informants

Date

Dear (Informant's Name),

Thank you for participating in the cultural beliefs and experiences of American Indian Alzheimer's disease (AD) and dementia. As mentioned during the interview this study is designed to identify ways in which cultural beliefs and experiences of American Indians and their formal caregivers can be used to address AD and dementia within the American Indian community. The study is designed to address American Indian and Western cultural beliefs about AD and dementia and how course of care plans developed can be taken to facilitate culturally competent and culturally sensitive health care to American Indian demented patients and their informal caregivers. This study offers the potential for future explanatory models of American Indian AD and dementia, as well as the potential of how to best serve the American Indian AD and dementia communities where little is currently known. I thank you for your willingness to share your professional perspectives and experiences.

If you should have any questions or comments please feel free to contact me. Thank you once again for your participation in this study.

Sincerely,

Damon Syphers

Appendix D: Informed Consent

You are invited to be in a research study aimed to describe the cultural beliefs and everyday life experience of being a formal dementia caregiver of American Indians. You are invited to participate because you are a formal dementia caregiver for an American Indian dementia patient and his or her informal caregiver.

This study is being conducted by Damon Grew Peter Syphers. I am a graduate public health student at Walden University located in Minneapolis, Minnesota.

Background Information

The purpose of this study is to describe the meaning and essence of what it is like to be a formal caregiver caring for American Indian dementia patients and their informal caregivers. You will be asked to tell your experiences of caring for American Indian dementia patients and their informal caregivers.

Procedures

If you agree to be in the study, I will ask you to do the following things:

- Participate in one interview lasting one hour that describes the experience of being a formal dementia caregiver to American Indian dementia patients and their informal caregivers. These interviews will be conducted by telephone. The interview will be taped.
- Review a copy of the typed transcript of your interview that will be given to you to check for accuracy and identify if corrections need to be made. If there are changes to your interviews, you will be provided with another typed transcript and we will again clarify and or verify accuracy of your interviews.

Risks and Benefits of being in the study

This study can play an important role in developing much-needed AD and dementia resources and programs for American Indian demented patients and their informal caregivers

There are minimal risks of being in the study.

Confidentiality

The records of this study will be kept private. In any report I publish, I will not include any information that will make it possible to identify you. Research records will be kept in a locked file. The only person who will have access to those records are me, the researcher. The taped recordings and typed transcriptions will also be locked up. The tape interviews will be erased and transcriptions will be shredded and disposed of properly after seven years time.

Voluntary Nature of the Study

Your decision whether or not to participate will not affect is strictly voluntary. If you decide to participate, you are free to withdraw at any time and you are free to decline answering any specific questions.

Contacts and Questions

The researcher conducting this study is Damon Grew Peter Syphers. You may ask questions you have now or contact me at. You may also contact my advisor, Dr. C. J. Schumaker. If you have any questions or concerns, and would like to talk to someone other than the researcher or the advisor, you may contact the Research Participant Advocate Dr. Leilani Endicott, 100 Washington Avenue South #900, Minneapolis, Minnesota 55401, telephone 800-925-3368 extension 3121210. Walden University's approval number for this study is 03-17-14-0106750 and it expires on March 16, 2015.

You will be given a copy of this form for your records.

Statement of Consent:

I have read the above information. I have asked questions and received answers. I consent to participate in this study.

Signature____
Date____________

Signature of Investigator___________________________________
Date____________

Appendix E: Provider Demographics Sheet

1. What is your gender:____________________
2. How many years have you been practicing medicine?_________________
3. What is your specialty?________________________
4. What is your racial background?

   ☐Western

   ☐American Indian

   ☐Other____________
5. What is your age range?

   ( ) 18-30 ( ) 31-45 ( ) 46-61 ( ) 61+

Appendix F: Interview Protocol

Interview Question 1: Tell me about American Indian cultural beliefs regarding Alzheimer's disease and dementia?

1. How do American Indian demented patients and their American Indian informal caregivers communicate their understanding of Alzheimer's disease and dementia to you?
2. Tell me about how their understanding is different from that of Westerners?
3. How do beliefs about Alzheimer's disease and dementia vary from tribe to tribe?
4. How have tribal legends, stories or other forms of folklore shaped American Indians cultural beliefs about Alzheimer's disease and dementia?
5. How are American Indians informal dementia caregiver beliefs different from that of Western informal caregivers?

Interview Question 2: Tell me about your cultural beliefs about Alzheimer's disease and dementia as a formal caregiver?

1. How do you understand illness and disease within the American Indian culture?
2. How has your cultural background played a part in shaping your own beliefs about Alzheimer's disease and dementia in among American Indians?
3. What are some of your early memories of your cultural beliefs and influence about Alzheimer's disease and dementia?
4. How has your cultural background played a part in your past or present life? If you grew up as a Westerner have your beliefs changed about Alzheimer's disease and dementia among American Indians? If you grew up as an American Indian, have your traditional beliefs about Alzheimer's disease and dementia among American Indians changed?

Interview Question 3: Tell me about how you use your own cultural beliefs to develop a course of care with your American Indian dementia patients and their American Indian informal caregivers?

1. How do you develop a course of care plan for your American Indian dementia patients and their informal caregivers?
2. How do you use a Western course of care?
3. How do you use an Indigenous course of care?
4. How do you use a combination of Western and Indigenous course of care?
5. From your past and present experiences, how has the choice of care you chose benefited the American Indian demented patient and their American Indian informal caregiver? How have these benefited American Indian demented patients and American Indian informal caregivers?

6. In developing your course of care, what has been the least successful in your work with American Indian dementia patients and their American Indian informal caregivers?
7. Why do you think that the chosen course of care was least successful?
8. What improvements to the course of care could have been modified to make it more successful?

Appendix G: Confidentiality Agreement

Appendix H: Emails for Transcript Accuracy

Dear (Informant's Name),

Thank you again for your participation in the Cultural Beliefs and Experiences of Formal Caregivers Providing Dementia Care to American Indians.Your contributions, input, and experiences assisted greatly in this study.

Please review the attached transcript from the interview for accuracy. If there is anything that you feel is not accurate or would like to omit anything from this transcript please use the strikethrough feature on Microsoft Word. If you would like to add anything to this transcript please use the track changes feature on Microsoft Word. If you make any changes to the document please email the entire transcript back to me by XX, XX, 2011. If the transcript needs no editing please reply to this email stating no changes need to be made.

All transcripts will be analyzed once all identifying factors, such as name, organization, address, etc. have been removed. No details will be included that can reveal the identity of any research participant.

If you have any questions, please feel free to contact me at. Thank you for your time and consideration.

Very Respectfully,

Damon G. Syphers

Appendix I: Thank You Letters to Key Informants

Date

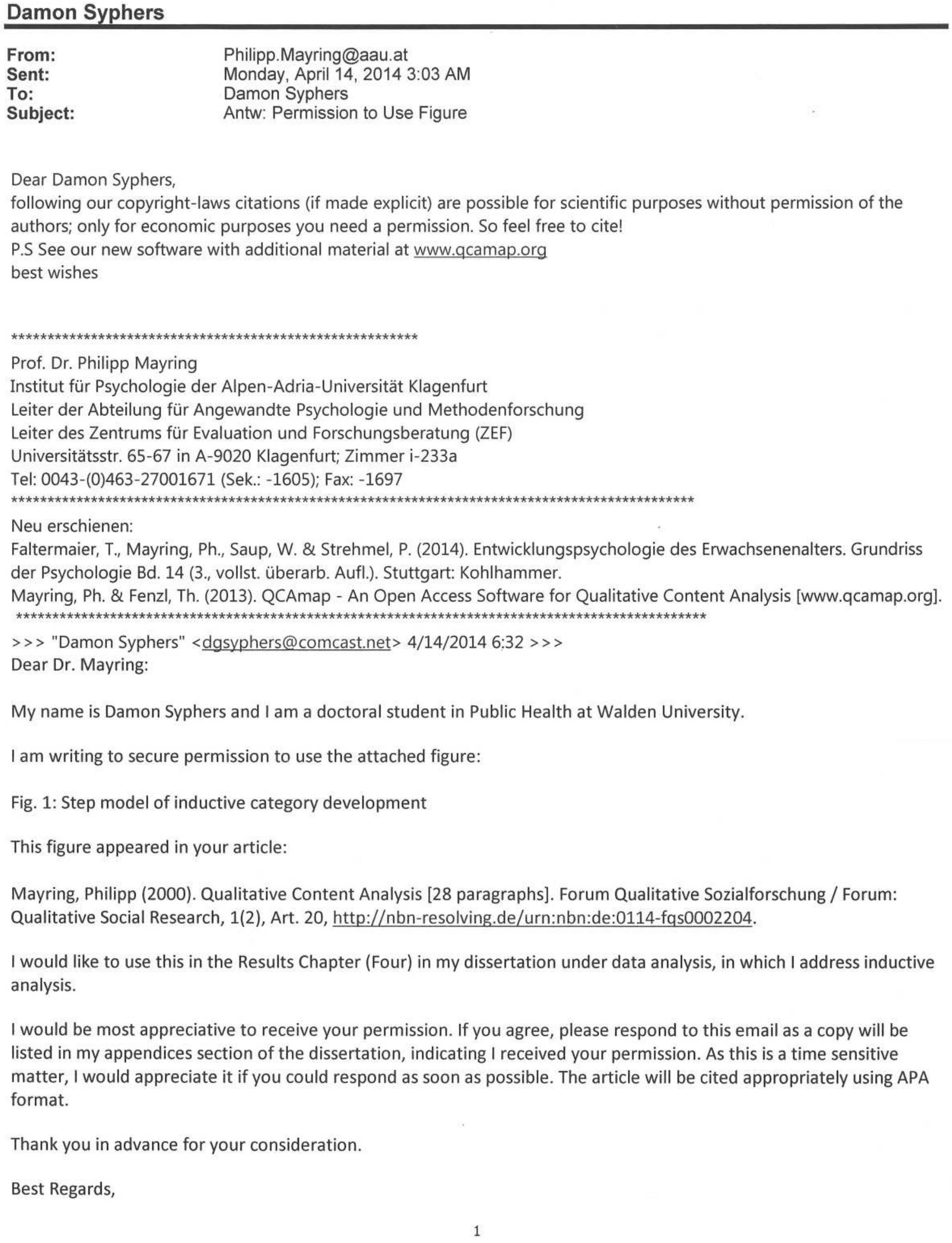
Dear (Informant's Name),

Thank you for participating in the cultural beliefs and experiences of American Indian AD and dementia. As mentioned during the interview this study is designed to identify ways in which cultural beliefs and experiences of American Indians and their formal caregivers can be used to address AD and dementia within the American Indian community. The study is designed to address American Indian and Western cultural beliefs about AD and dementia and how course of care plans can be taken to facilitate culturally competent and culturally sensitive health care to American Indian demented patients and their informal caregivers. The potential this study holds for the future possible explanatory models of American Indian AD and dementia and how to best serve the American Indian AD and dementia communities where little is currently known. I thank you for your willingness to share your professional perspectives and experiences. If you should have any questions or comments please feel free to contact me. Thank you once again for your participation in this study.

Sincerely,

Damon Syphers

Appendix J: Permission not Needed to Use Figure 4



Damon Syphers

From: Philipp.Mayring@aau.at
Sent: Monday, April 14, 2014 3:03 AM
To: Damon Syphers
Subject: Antw: Permission to Use Figure

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best wishes

****
Prof. Dr. Philipp Mayring
Institut für Psychologie der Alpen-Adria-Universität Klagenfurt
Leiter der Abteilung für Angewandte Psychologie und Methodenforschung
Leiter des Zentrums für Evaluation und Forschungsberatung (ZEF)
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Mayring, Ph. & Fenzl, Th. (2013). QCAmap - An Open Access Software for Qualitative Content Analysis [www.qcamap.org].
****

>>> "Damon Syphers" <dgsyphers@comcast.net> 4/14/2014 6:32 >>>
Dear Dr. Mayring:

My name is Damon Syphers and I am a doctoral student in Public Health at Walden University.

I am writing to secure permission to use the attached figure:

Fig. 1: Step model of inductive category development

This figure appeared in your article:

Mayring, Philipp (2000). Qualitative Content Analysis [28 paragraphs]. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 1(2), Art. 20, http://nbn-resolving.de/urn:nbn:de:0114-fqs0002204.

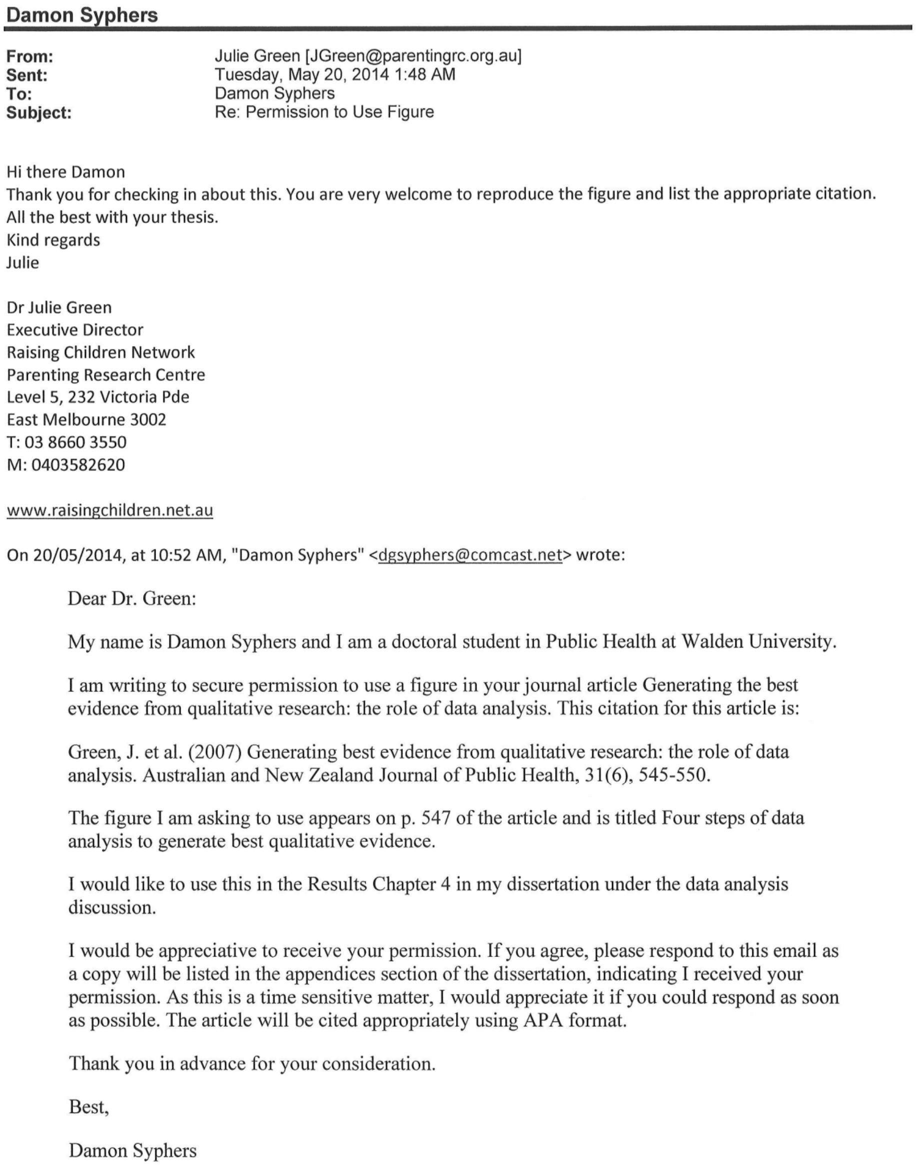
I would like to use this in the Results Chapter (Four) in my dissertation under data analysis, in which I address inductive analysis.

I would be most appreciative to receive your permission. If you agree, please respond to this email as a copy will be listed in my appendices section of the dissertation, indicating I received your permission. As this is a time sensitive matter, I would appreciate it if you could respond as soon as possible. The article will be cited appropriately using APA format.

Thank you in advance for your consideration.

Best Regards,

Appendix K: Permission to Use Figure 5



Damon Syphers

From: Julie Green [JGreen@parentingrc.org.au]
Sent: Tuesday, May 20, 2014 1:48 AM
To: Damon Syphers
Subject: Re: Permission to Use Figure

Hi there Damon
Thank you for checking in about this. You are very welcome to reproduce the figure and list the appropriate citation.
All the best with your thesis.
Kind regards
Julie

Dr Julie Green
Executive Director
Raising Children Network
Parenting Research Centre
Level 5, 232 Victoria Pde
East Melbourne 3002
T: 03 8660 3550
M: 0403582620

www.raisingchildren.net.au

On 20/05/2014, at 10:52 AM, "Damon Syphers" <dgsyphers@comcast.net> wrote:

> Dear Dr. Green:
>
> My name is Damon Syphers and I am a doctoral student in Public Health at Walden University.
>
> I am writing to secure permission to use a figure in your journal article Generating the best evidence from qualitative research: the role of data analysis. This citation for this article is:
>
> Green, J. et al. (2007) Generating best evidence from qualitative research: the role of data analysis. Australian and New Zealand Journal of Public Health, 31(6), 545-550.
>
> The figure I am asking to use appears on p. 547 of the article and is titled Four steps of data analysis to generate best qualitative evidence.
>
> I would like to use this in the Results Chapter 4 in my dissertation under the data analysis discussion.
>
> I would be appreciative to receive your permission. If you agree, please respond to this email as a copy will be listed in the appendices section of the dissertation, indicating I received your permission. As this is a time sensitive matter, I would appreciate it if you could respond as soon as possible. The article will be cited appropriately using APA format.
>
> Thank you in advance for your consideration.
>
> Best,
>
> Damon Syphers