

WHAT METHODS DO RURAL PROVIDERS EMPLOY TO EDUCATE PATIENTS AND
PROVIDE CARE TO PATIENTS WITH SUSPECTED LOW HEALTH LITERACY: A
PHENOMENOLOGICAL APPROACH

by

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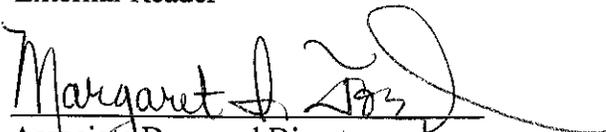
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Abstract

This phenomenological approach aims to learn from the experiences of rural Licensed Independent Providers as they deliver chronic disease education and support to patients with suspected low health literacy. The study asks the question: How do rural providers who have fewer resources available to them typically aid patients with low health literacy in chronic disease self-management through authentic relationships, problem-solving and transpersonal practices? This study interviewed six rural New England Providers (4 physicians, a nurse practitioner and a physician assistant) to learn their lived experiences in caring for these patients. The providers were interviewed and transcripts were analyzed to identify significant statements relevant to their interactions with patients having chronic disease and suspected low health literacy. The significant statements were reduced to five themes and three major findings. The findings indicated that despite a lack or minimal training in health literacy, providers assessed patient needs and provided appropriate education and support; the relationship between the provider and the patient was a catalyst to improve the health of the patient; and Watson's Theory of Caring was interwoven in the interactions between the patient and provider. The providers described the unique challenges present in rural healthcare, the trust relationship that builds over time between patient and providers and the techniques they utilize to mitigate the effects of low health literacy.

Keywords: health literacy, chronic disease, chronic disease self-management, rural

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“For I know the plans I have for you, declares the Lord. Plans to prosper you and not to harm you, plans to give you hope and a future.” Jeremiah 29:11

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Chapter 1

Introduction to the Research

Summary of Chapter

This study intends to understand the experiences of rural Licensed Independent Providers (LIPs, from here on called “providers”) as they support their patient’s comprehension of chronic disease self-management when the patient is at risk of having low health literacy. Providers are physicians, physician assistants and nurse practitioners that can independently examine and diagnose patients within a medical practice. The purpose of this phenomenological approach is to explore with a group of rural providers how they support their patient’s chronic disease self-management. It is believed that this study can provide the body of healthcare providers’ insights on how to support patient’s ability to understand and manage their chronic disease.

This research utilized a qualitative phenomenological methodology to investigate the provider's experience. Participants of this study included six providers who work in a rural community who cared for patients at risk for low health literacy. They were asked to talk about their knowledge of health literacy, as well as the techniques they used to determine patients’ needs and to support their disease management.

This chapter begins with an overview of the context and background that frames the study. It will describe why the research is of value in the problem statement, the purpose of the research and the research questions that will be answered. This chapter will also discuss the rationale for the research approach, the researcher’s perspectives and philosophical assumptions as they relate to the providers’ experiences in caring for their rural patients that may have low health literacy. The chapter will conclude with the significance of the research and definitions of

key terminology used in the study.

Background and Context

Since the turn of the twentieth century, healthcare has gone through a great number of changes that affect rural citizen, hospitals and healthcare providers. As of the mid 1980s, a shift in health indicators has intimated that those living in rural areas are sicker to now compared to populations in metropolitan areas (James, 2014). Nearly 25% of the US population is considered rural and rural communities have a 17% higher prevalence rate of diabetes than in their urban counterparts (Ross, Benavides-Vaello, Schumann & Haberman, 2015). Anderson, Saman, Lipsky & Lutfiyya (2015) report rural residents have a higher incidence of smoking in adults and adolescents, are more likely to be obese, consume fewer fruits and vegetables but consume more alcohol than those living in urban areas. They also note more dental problems, and a higher percentage of preventable hospital stays for acute and chronic conditions and more co-morbid (multiple diseases/conditions occurring simultaneously within one patient) conditions and diseases.

The U.S. Department of Agriculture classifies counties as metro, and non-metro counties in a scale from 1-9 on the rural-urban continuum (RUC) codes. Rural code one is the most populous with 9 being the most remote. The determination of the codes also considers if the county is adjacent to a metro county. According to James (2014), counties in RUC 6 have the highest disparity in health issues as compared to the other 8 county groups which James calls a rural mortality penalty. RUC 6 is defined as a nonmetro or urban population of 2,500 to 19,999 people and is adjacent to a metro area.

In New England, there are 30 counties considered rural and of these 8 counties are within the RUC 6 group that exhibits the highest rural mortality penalty (U.S. Department of Health and

Human Services, 2010). Contributing factors to the transition from higher mortality in urban areas to a rural mortality penalty are the decrease in pollution, crime, overcrowding and infectious diseases in urban areas contrasting with rural communities seeing an increase in stroke, diabetes and heart disease due to smoking, sedentary lifestyle and obesity (Anderson et al., 2015). Anderson et al., also find that those living in rural areas are more likely living in poverty, were less likely to have health insurance (prior to Affordable Care Act), have less access to healthcare due to distance and shortages of healthcare providers and specialty services in the geographic area. Even death from motor vehicle accidents is higher, not due to the severity of injury, but due to the length of response time by (usually volunteer) emergency management services and travel time to a trauma center (Garcia et al., 2017; Anderson et al., 2015; Hsai & Shen, 2011). These rural areas are often medically underserved, a specific designation that when achieved, affords eligibility of specific federal funds and compensation structures. Many, if not most, rural communities in northern New England are considered medically underserved based on calculations that include the population to provider ratio, the percent of the population below the federal poverty level, the percent of the population over age 65, and the infant mortality rate.

The role of health literacy with current healthcare consumers is becoming a more important consideration. With the trend in the healthcare system to shorter appointments with providers, more complicated chronic disease management on the part of the patient and their family or caregivers, more active learning and participation by the patient; there is more of an onus on the patient to understand what they are being told by the provider (Osborne, 2013). A simple definition of health literacy is the patient's ability to take health information and apply that information in their decision making on health matters. The U.S. Department of Health and

Human Services [HHS] defines health literacy as “the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions and services needed to prevent or treat illness” (Selden, Zorn, Ratzan & Parker, 2000). The application of health literacy does not exclusively mean the understanding reading materials as the word *literacy* implies. Health literacy includes all methods of receiving health information including written texts, diagrams, verbal instructions, websites, videos, classes, etc. (Osborne, 2013). From a practical point of view, how does health literacy play out when a patient has a chronic disease? The patient first should understand the definition of their chronic disease and how the chronic disease manifests and progresses. What are the signs of an emergency and when should the provider be called? What numbers does the patient need to keep track of; peak flow, blood pressure, blood glucose? What do these numbers mean and what has to be done when the number reaches a certain point? How and when are medications taken? Are medications taken in different amounts on different days or for different numeracy results? Health literacy takes into account the ability to not only comprehend instructions but numeracy skills as well. The role of numeracy can be demonstrated by looking at food labels to adjust caloric or fat intake, or adjust the time of medications or days of medications. When will the medication need a refill? When given instructions to “take on an empty stomach”, a common instruction, does the patient know that they should not have eaten for 2 hours prior to taking and should not eat for 2 hours after taking the medication? The ability of the provider to assess the patient’s skills in these various tasks can enable the provider to provide education and support therefore the patient can better self-manage their chronic disease through proper diet, medication compliance and identification of warning signs or emergency situations (Osborne, 2013).

In order for a provider to provide education to the patient, the provider should be aware

that rural patients are at higher risk for low health literacy (Zahnd, Scaife, & Francis, 2009; Lutfiyya et al., 2012) and assess the patient's cognitive ability in relation to the revised Bloom's Taxonomy described by Anderson & Krathwohl (2001) and their ability to be motivated to make lifestyle/health changes as indicated by Maslow's Hierarchy of needs (1943). A provider should not assume all rural patients have low health literacy but that they have a higher risk of low health literacy due to characteristics of rural populations. Patients with low health literacy may have difficulty with tasks that require higher cognitive abilities such as calculating carbohydrates based on reading the food label or distinguishing between a controller medication or rescue medication and using each medication appropriately. These higher-level tasks place them at the apex of the updated Bloom's six major categories of educational goals: remember, understand, apply analyze, evaluate, and create (Anderson & Krathwohl, 2001). In contrast, a patient with low health literacy may exhibit skills in the knowledge and comprehension level but be unable to apply that information to changing conditions.

Maslow (1943) describes the ability to fulfill personal needs based on a hierarchical approach that begins with the most basic of human needs, physiological (food, water, clothing, health, etc.). The basic physiologic needs at the lower point of Maslow's pyramid needs to be met before higher level needs. Vulnerable patients may not have the needs of physiological, safety, and love/belonging. When these needs are unmet due to food insecurity, health issues, relational problems within friend and family groups, the patient may not achieve self-esteem or self-actualization. From a healthcare point of view, the patient may not consider their chronic disease management a priority if they need money to pay for prescriptions, to place food on the table, or pay for rent and/or utilities.

This research theorizes that how the provider assisted the patient in bridging these gaps

which had an impact on the patient's ability to self-manage their chronic disease and improve quality of life. Watson's Human Caring Theory (Watson, 2006) may be a conduit that spans the gap between where the patient was initially functioning and where they need to advance to manage their chronic disease. Watson's theory can provide the provider the means to impact outcomes and quality of life through authentic relationships, problem-solving and transpersonal practices (Sitzman & Watson, 2014). Caring theory in healthcare can be utilized as a premise in which to focus on the patient-provider interactions. Caring theory indicates that interactions between the parties are based on a spirit of caring. The feeling of being/feeling cared for allows the patient to feel valued and establishes trust. A caring and trusting relationship could be a catalyst to help the patient desire to seek healthier behaviors and make more positive life decisions.

The 10 Caritas Processes are described by Sitzman & Watson as:

1. Sustaining humanistic-altruistic values by practicing loving kindness, compassion, and equanimity with self/others
2. Being authentically present, enabling faith/hope/belief system; honoring subjective inner, life-world of self/others
3. Being sensitive to self and others by cultivating own spiritual practices; beyond ego-self to transpersonal presence
4. Developing and sustaining loving trusting-caring relationships
5. Allowing for expression of positive and negative feelings -authentically listening to another person's story
6. Creatively problem-solving-"solution-seeking" through caring process; full use of self and artistry of caring-healing practices via use of all ways of

knowing/being/doing/becoming

7. Engaging in transpersonal teaching and learning within context of caring relationships; staying within other's frame of reference-shift toward coaching model for expanded health and wellness

8. Creating a healing environment at all levels; subtle environment for energetic authentic caring presence

9. Reverentially assisting with basic human needs as sacred acts, touching mindbodyspirit of other; sustaining human dignity

10. Opening to spiritual, mystery, unknowns-allowing for miracles (Sitzman & Watson, 2014).

Watson's Caring Theory was designed to be practiced in nursing interactions. Caring is not specific only to nursing though and this research was designed to learn if this nursing theory applies also to providers. The themes that emerged from the interviews of providers were correlated with the 10 Caritas of Watson's Theory to confirm or deny the connection between how the provider perceived their relationship with patients. The 10 Caritas were also assessed as being a bridge between the provider and patient and how this was accomplished in the limited time the patient and provider had to spend together in the visit.

Problem Statement

Patients with low health literacy are more likely to have adverse health outcomes and lower quality of life that may be related to medication errors, inability to follow instructions provided by the healthcare personnel, and decreased ability to manage chronic illnesses (Dickens & Piano, 2013). Patients living in rural communities are at higher risk for low health literacy due to a higher prevalence of older population, low socioeconomic status, minority populations and medically

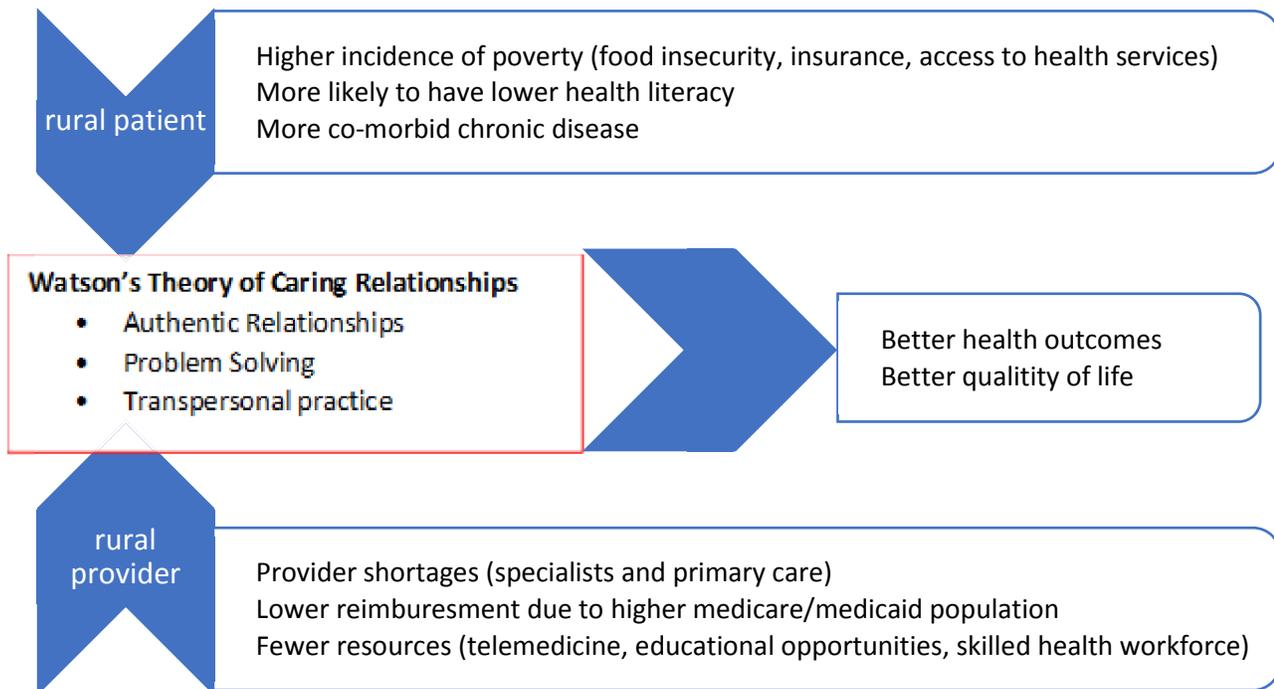
underserved communities according to the U.S. Department of Health and Human Services (HHS, 2014; James, 2014; Osborne, 2013). Low health literacy and lack of medical resources available not only impacts the health of the individual patient it also increases costs to the healthcare system as a whole through inefficient resource utilization, poor chronic illness management and higher utilization of emergency services (Dickens & Piano, 2013). Providers play a crucial role in the education of patients who have chronic disease. In order for patients to be able to manage their chronic disease they must understand the medications they take, what numbers do they need to monitor (blood pressure, blood glucose, peak flow, etc.), when to call the provider or go to emergency room, and what is the expected disease progression. Good disease management improves health outcomes and quality of life for the patient (Zahnd, Scaife, & Francis, 2009). In rural communities where patients have less access to specialty services than their urban counterparts, the primary provider is the gatekeeper of the patient's care and chronic disease management. The primary provider is a generalist who walks the patient through all of their healthcare needs, often without help from other healthcare practitioners. The provider may be solely responsible for assessing the patient's ability to self-manage complicated aspects of their chronic disease. Chronic disease management can include proper use of medications, understanding signs and symptoms of chronic disease progression, diet control, monitoring of key numbers and making adjustments to medications or diet based on those numbers. When patients have low health literacy, the provider and the healthcare team are responsible to provide the patient information in a way s/he can understand so outcomes and quality of life are impacted in a positive way (Bushey, 2000).

Purpose

The purpose of this study was to investigate how rural providers experience assessing the educational needs of their patients with chronic disease and suspected low health literacy and how

they support their patients' ability to self-manage their chronic disease resulting in improved health outcomes and quality of life (Figure 1) through authentic and caring relationships. A phenomenological approach was utilized to gain an understanding of how the rural providers, who have fewer resources than their urban counterparts, impact their patient's outcomes. This research could inform other healthcare practitioners on the importance of instructing and supporting the patient at the level s/he understands to improve health outcomes and quality of life through authentic and caring relationships and problem-solving. Watson's Caring Theory has been used in nursing care and education since it was first published and is still used in the literature today. For over 30 years, the U.S Department of Health and Human Services has identified a set of health priorities to strive to attain in the following 10-year increment. The most recent goals, entitled Healthy People 2020, have added three measures addressing health literacy: 1) giving instructions about health topics that are easy to understand; 2) asking patients how they will follow the instructions given; 3) providing help filling out forms (U.S. Department of Health and Human Services, 2017).

Figure 1. Theoretic Framework Using Watson's Caring Theory



Research Questions

Main Question:

How do rural providers who have fewer resources available to them typically aid patients with low health literacy in chronic disease self-management through authentic relationships, problem-solving and transpersonal practices?

Sub-questions:

1. What information do providers look for to assess if a patient has adequate health literacy to manage their chronic disease?
2. How do rural providers creatively problem solve and coach their patients in chronic disease management?

3. What are the unique healthcare needs and limitations of patients living in rural communities and how do their providers address these needs and limitations?
4. How do rural providers impact chronic disease outcomes and quality of life through teaching patients how to manage their chronic disease?
5. How does the provider adjust their method(s) of education through informal assessments applying Bloom's Taxonomy and Maslow's Hierarchy of Needs?
6. In what circumstances have providers been taught about health literacy needs and risk factors associated with low health literacy?
7. In what ways do providers apply the 10 Caritas of Watson's Caring Theory as the bridge between their understanding and that of their patients?

Theoretic Framework

This study is informed by the literature and theories related to the understanding and application of patient cognitive abilities. Anderson and Krathwohl (2001) described six major categories of educational goals: remember, understand, apply, analyze, evaluate, and create. It may be theorized that many rural patients are in need of more educational support as a result of the sequelae from their illness (physiological and psychosocial impacts of chronic disease), higher incidence of poverty, lower educational levels, and age (HHS, 2014; James, 2014; Osborne, 2013). Watson's Theory of Caring Relationships (Watson, 2006) describes 10 Caritas that may be the method of support that providers use to assess patient's physical, psychological, and spiritual needs and then be able to utilize these relationships to impact outcomes and quality of life through authentic relationships, problem-solving and transpersonal practices.

Research Design Overview

The research approach in this study will be a qualitative analysis using phenomenological methodology. Phenomenology allows the researcher to get an in-depth look at how providers assessed their patients' ability to manage their chronic disease and provide the education and support to encourage behaviors. In-depth interviews were done with six providers who practice in rural communities. The interviews informed the researcher of common themes from providers in their experience of treating and supporting their patient's chronic disease management. The interviewed providers are identified as "a/the provider" when describing the interactions with their patients. Each interview was digitally recorded and transcribed verbatim. Coding categories were developed from the provider experiences to discover common themes that the providers identify as being meaningful. These meaningful experiences were the descriptors to fully describe how the provider's approach to the patient impacted outcomes. The provider's words were correlated with the intent behind the 10 Caritas to investigate if the providers practice the 10 Caritas. The research also intended to learn if/how the interactions between patient and provider encouraged the patient to make healthy life choices that could impact their chronic disease.

Assumptions

Based on my experience in a healthcare and academic settings, there are three assumptions that were made during this study. First, providers do not necessarily have the training to identify patients with low health literacy or to assess the cognitive ability of the patient to be able to customize the message to deliver. The patient may have difficulty at the remember level due to physiological changes to the brain from illness or age, the effects of medications on cognition or the effects from depression as is common with chronic disease. Further communication breakdowns can occur if the patient is purely focused on obtaining basic human needs that are

unmet. When basic physiologic needs are not met, according to Maslow (1943), an individual is very unlikely to be motivated to pursue needs that do not meet their physiologic or safety needs in search of love, esteem or self-actualization.

A second assumption is that vulnerable patient populations do not want to ask questions or question the orders of the provider. Do they feel as though they do not have the right to question due to social expectations or cultural norms? Do they not want to feel “stupid” by asking questions they “should know” the answer to? Or do they feel they don’t have options and the provider is providing them with their only choice? Do they rely on friends and family members to "translate" the information provided in their appointment?

The third assumption is that through a provider’s personalized approach to chronic disease management, a provider can help the patient have improved health outcomes and quality of life. Building relationships based on trust and communication can result in a patient who will provide the provider with all the information needed and will trust the care plan suggested by the provider.

Rationale and Significance

I have had the opportunity to observe providers communicating with patients who have low health literacy in a way that promotes chronic disease management without shaming them for their lack of ability to cognitively process complex data. The results are a patient who is empowered to believe they can manage their chronic disease and make the best decisions possible for their situation. I have a strong desire to identify and describe those elements that make these rural providers champions for their patients. These rural providers are the providers who care for the whole community with many fewer resources than within urban communities and yet have every bit of respect and “living room language”, return demonstrations, chunk and check, etc.

(Doak, Doak & Root, 1996; Coleman et al., 2016; DeWalt et al., 2011; Dicken & Piano, 2013). The methods that these providers may employ are not the result of technological advances or specialty education and training. In that, any provider can use these techniques with low health literacy patients to improve their health outcomes and quality of life through a caring relationship. Use of Watson's Theory of Caring can describe how the provider can bridge the gap between themselves and the patient. The gap manifests in both Bloom's Taxonomy and Maslow's Hierarchy of Needs as evidenced through the patient's need for educational support in disease management and the patient's complicated socioeconomic situations that occur.

Summary of Chapter

This chapter provided information on the scope of the issues related to low health literacy and the health risks of living in a rural area. The method of a phenomenological approach to investigate how providers use authentic and caring relationships to help patients' problem solve their chronic disease and improve outcomes and quality of life was outlined. The use of Bloom's Taxonomy and Maslow's Hierarchy of Needs addresses the provider's knowledge in assessing the patient's educational needs. Finally, the theoretic framework of applying Watson's Theory of Caring Relationships to the rural provider's method of teaching and supporting the patient with suspected low health literacy was presented.

Key Terms

Health Literacy: a person's ability to take health information (verbal, written, charts, graphs, video, classroom, diagrams, models, etc.) and apply the information to make informed health decision

Chronic Disease: an illness lasting 3 months or longer, cannot be prevented by vaccinations and

cannot be cured but can be managed. Commonly seen examples are diabetes, heart failure, chronic obstructive pulmonary disease (COPD), cancer and arthritis.

Chronic disease self-management: the ability to understand one's chronic disease and make informed decisions to prevent exacerbations and slower disease progression through: proper use of medications, diet and exercise, emotional support and depression screening, pain/fatigue control, therapies that may decrease symptoms, decision making, family support, and communicating with healthcare providers.

Rural: The U.S Census Bureau defines urbanized areas as areas with 50,000 or more people and urban clusters are areas with at least 2,500 but fewer than 50,000 people. By default, if an area is not urban, it is rural.

Chapter 2

Review of the Literature

Introduction to the Chapter

This chapter will review the current literature pertinent to the study. This literature review focused on the healthcare system in the United States and the specific characteristics of rural healthcare. The chapter also reviews health literacy and its effects on the disease processes. Finally, the chapter reviews the concepts of Watson's Caring Theory, Bloom's Taxonomy and Maslow's Hierarchy of Needs and how they apply to the patient's experience of disease management.

Access to healthcare in the United States

The healthcare system has undergone the most significant changes since the passage of Medicare and Medicaid in 1965 with the enactment of the Affordable Care (ACA) in 2010. The legislation was proposed to increase quality and affordability of health insurance, decrease uninsured rates, and lower the costs of healthcare through mandates, subsidies and insurance exchanges while protecting patients from arbitrary actions by insurance companies. The ACA provided access to health insurance for many Americans that were previously uninsured or underinsured with the addition of subsidies to offset costs for those with low income and mandating the purchase of insurance for all to offset the costs of higher risk utilizers (Smith et al., 2016). In a 2016 report created by the Henry J. Kaiser Family Foundation, 13 million people were added to the number of insured after the implementation of the Affordable Care Act (Smith et al., 2016). Since these previously uninsured are more likely to be within vulnerable populations, it may be assumed that a large proportion of the newly insured are a higher risk population in regards to healthcare needs, chronic disease and service utilization.

Another landmark change in the healthcare system released in 2010 is Healthy People 2010 and now Healthy People 2020 (HHS, 2010). This program was developed to improve health outcomes with the goals of increasing quality and years of healthy life and eliminating health disparities through disease prevention and reducing controllable health risks. Two of the 28 focus areas are in education and health communication. These two focus areas brought about a heightened awareness of the need for improved health literacy for vulnerable populations.

The Institute of Medicine published a report on health literacy in 2004 that has four objectives: to define the scope of the health literacy problem, identify obstacles to creating a health-literate population, identify what has already been done to promote health literacy, and identify the health literacy goals for the future as well as the barriers to accomplishing the goals (Nielsen-Bohlman, Panzer, & Kindig, 2004). This report highlights the importance of health literacy as a public health priority.

Rural Health in the United States

Rural healthcare in the United States has gone through great transition since the very foundations of the nation. Healthcare needs were initially provided primarily by the family. Angeline Bushy (2000) describes the use of relatively untrained women in the frontier providing midwifery services, crude treatments, and herbal medicine. At this time, little was known of the role of microbes so infections were a common occurrence which could be deadly even in initially minor injuries and illnesses and childbirth. Areas that were fortunate enough to have a provider may have to wait days or weeks for the arrival of the provider due to the great geographical area covered, the difficulties of traveling through inclement weather, and the poor traveling conditions in general in the rural areas.

Prior to the 20th century, people living in rural areas were healthier than their urban counterparts (James, 2014). In 1900 the average lifespan for a male living in a rural area was ten years longer than his urban counterpart, and a woman's life span was seven and a half years longer than a woman living in a city. Due to disease, pollution, crime, city dwellers had a shorter life span and greater health needs than those who live in rural areas. A reversal of this formed between 1900 and 1939 where the average lifespan increases forty percent in city dwelling men and only by nineteen percent for those living in the country.

After the stock market crash of 1929, health status for all Americans decreased but rural areas were hardest hit. Farmers could not afford to sell crops at rock bottom prices and over twenty percent of children were suffering from malnutrition, greater than those living in cities who had access to soup lines and other social supports. In the Midwest, the problems were worse due to the drought. Many families needed to keep moving to look for food and work, this prevented children from attending school. At times, the schools were closed due to lack of funding. The death rate for children increased during this time due to the physical stressors of disease, malnutrition, poor diet and the inability to recover from otherwise non-life-threatening illnesses (McElvaine, 1993). It wasn't until after World War II when the government started providing a significant proportion of funding to community hospitals with the Hill-Burton Act in 1945 (Meit, 2009). This act provided funding for hospitals to be built in underserved areas, particularly in rural areas.

Due to wage freezes as a result of World War II, companies started offering fringe benefits that were not included as wages to help attract employees. These included sick leave and paid health insurance (Buchmueller & Monheit, 2009). These benefits would not have extended as much to rural areas due to few large manufacturers as they were concentrated in

urban areas that provided resources such as raw materials, access to transportation services and a large workforce in close proximity or with access to public transportation.

The Migrant Health Act of 1962 was created to aid migrant and seasonal farmworkers (MSFW) with their health needs (Anthony, Williams & Avery, 2008). These workers and their families move throughout the U.S. planting, harvesting and processing crops. Poor living conditions, chemical exposures, lack of education, workplace injuries, no health insurance, transient lifestyle (for individuals and families), and lack of English speaking skills marginalizes this population. The Migrant Health Act provided grants to non-profit organization in order to provide healthcare services to this population.

Medicare was enacted in 1965 as insurance for the elderly who were no longer in the employment pool. This program is funded primarily by those currently in the workforce to support the (basic) health needs of the elderly no longer in the workforce. Employers and employees pay mandatory contributions into the system and a small amount of funding comes from the payment of premiums, co-pays, and deductibles paid by beneficiaries (Inglehart, 1999). This program has aided the rural elderly afford healthcare services that prior to Medicare they may not have been able to afford.

The 1980s and 90s were times of great change in the landscape of rural hospitals. Due to higher percentages of Medicare and Medicaid in the payor mix, many rural hospitals closed, merged, or were converted to a different care model (Ricketts & Heaphy, 2000). Rural hospitals tended to be the largest or second largest employer in the community. When these closed, the impact was not only to the patients but to the financial health of the community. To mitigate the damage to the hospital and to the communities reliant on these small hospitals, the Balanced

Budget Act of 1997 created the critical access hospital program. Due to the high percentage of Medicare and Medicaid patients, Critical Access Hospitals (CAH) also have a different reimbursement structure than non-CAH to help them survive despite lower reimbursement opportunities. Legislation has continued to develop to support these rural entities and encourage their survival.

Rural Healthcare 2000-Present

Since the turn of the century, healthcare has once again gone through a great number of changes that affect rural citizen, hospitals, and healthcare providers. There has been a shift in the balance in the healthcare system as a transition from those living in urban areas being sicker to now the rural population is in poorer health than those in metropolitan areas (Beck, 2012). Contributing factors are the decrease in pollution, crime, overcrowding and infectious diseases in urban areas contrasting with rural communities seeing an increase in stroke, diabetes and heart disease due to smoking, sedentary lifestyle and obesity. Those living in rural areas are more likely living in poverty, were less likely to have health insurance (prior to Affordable Care Act), have less access to healthcare due to distance and shortages of healthcare providers and specialty services. Even death from motor vehicle accidents is higher, not due to the severity of injury, but due to the length of response time by (usually volunteer) emergency management services and travel time to a trauma center (Beck, 2012).

Possibly one of the most impactful changes to healthcare for rural citizens is the passage of the Affordable Care Act (ACA) in 2010. Since rural areas had greater rates of being uninsured the ACA now gives access to insurance to the rural population that may not have previously had insurance. The real impact of the ACA will need to be determined in the future. Many rural businesses fall below the number of employee threshold of fifty employees. These

small employers are not obligated to ensure employees driving people to the government exchanges to obtain their coverage. These are often high deductible plans that are still outside of the financial means for rural families in poverty. Many may risk the penalty rather than the expense of the insurance.

Even in the writing of this research, the future of the healthcare system in the United States is in question. Legislations is being proposed and voted on to repeal and amend the ACA. Many questions will arise as to the effect these changes will have on rural populations.

Definition and Origin of Health Literacy

Health literacy has a variety of definitions used in the literature. The Institute of Medicine defines health literacy as, “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman, Panzer & Kindig, 2004). Helen Osborne (2013) describes health literacy a little more simplistically as, “communicating health information clearly and understanding it correctly”. She goes on to describe health literacy is not to be confused with only written words as *literacy* suggests. This breakdown in communication of health information can be the result of age, literacy, disability, emotional state, language, culture, and numeracy (Osborne, 2013). Health literacy also includes numeracy. Numeracy in health literacy is the understanding and application of numbers, graphs, statistics in health management (Golbeck, Ahlers-Schmidt, Paschal & Dismuke, 2005; Smith, Wolf & von Wagner, 2010).

The field of health literacy began in the early 1970s with married couple Leonard and Cecilia Doak. As a literacy tutor and health educator, they realized that people who can't read or write may have difficulty understanding the health information they receive from their doctor.

The Cecilia and Leonard Doak Health Literacy Champion Award is given to pioneers in the health literacy field (Newswire, 2015). The Doaks published books and articles on how to identify those with low health literacy and how to provide educational materials to patients. They promote that healthcare practitioners do not need to “dumb down” materials and information, but provide the subject in a way that uses common vocabulary, not medical jargon, simple sentence structure, and avoid extraneous information that will confuse instead of contribute (Doak & Doak, 2010; Doak, Doak, Friedell, & Meade, 1998). Since the importance of health literacy has been brought forth, many health literacy assessment tools have been created. Altin, Finke, Kautz-Freimuth, & Stock (2014) performed a systematic review of health literacy assessment tools. At that time, they identified 17 assessment tools that had been validated and found that approximately one-third of the assessment tools were based on the Rapid Estimate of Adult Literacy in Medicine (*REALM*) or the Test of Functional Health Literacy in Adults (*TOFHLA*) (Griffin et al., 2010). Boston University lists 129 different health literacy assessment tools in their “Health Literacy Tool Shed” including common assessments as the REALM, Newest Vital Sign (NVS), & TOFHLA. There is debate in the field whether or not to use literacy assessment tools. One proposal is a form of “universal precautions” that assumes all patients will have difficulty understanding medical information provided for any number of reasons including stressors that can impede comprehension, illness that impacts cognition, effects of medications and literacy level (DeWalt et al., 2010, Dickens & Piano, 2013).

Health Factors Associated with Health Literacy

In reviewing the literature related to health outcomes associated with low health literacy, most research has been disease specific or related to lifestyle choices. Among the general health risk outcomes associated with a low health literacy include a decrease in patient safety,

medication errors, noncompliance with treatment plans, poor self-care, increased hospital admissions and readmissions, lower rate of preventive screening tests, lower rates of vaccinations, higher emergency room use versus primary care, and misunderstanding of risk factors (Berkman, Sheridan, Donahue, Halpern & Crotty, 2011; Nielsen-Bohlman, Panzer, & Kindig, 2004).

More research has been devoted to the outcomes associated with low health literacy in specific disease states or lifestyle choices. A Review of Medline and CINAHL databases produced 47 studies in the United States which described the health impact of low health literacy on patients suffering from a specific disease or who has made specific lifestyle choices impacting their health. These studies include low health literacy as one confounding issue in their health as well as poverty, access to providers and insurance, and educational attainment.

The greatest amount of research has been in the area of diabetes and renal disease, 12 articles in this literature review discussed the impact health literacy has on diabetes self-management, often related to obesity. All 12 articles describe the difficulties patients have understanding and managing a complex array of tests, expectations, and dietary parameters that have a direct impact on the course of the disease and quality of life (Moffet, Parker, Sarkar, Schillinger, Fernandez, et al., 2011; Rubin, Donnell-Jackson, Jhingan, Golden & Paranjape, 2014).

The second largest focus has been in the area of heart disease and associated conditions. Patients with low health literacy are more likely to be admitted and readmitted to the hospital as a result of heart disease. This may be the result of patients not following recommended lifestyle changes that may help mitigate the seriousness of the disease. Patients are also likely to die

earlier due to the progression of the heart disease, mismanagement of medications, and have more complications related to their heart disease (Moser et al., 2015; Evangelista et al., 2010).

Diabetic and cardiovascular patients with low health literacy have to manage a complex array of numbers, medications, and dietary limitations (Dunn, Margaritis & Anderson, 2017). There are a myriad of skills, knowledge, and attitudes that must be juggled and balanced in living with these diseases. Dunn, Margaritis & Anderson (2017) describe the need of the patient with diabetes and/or heart disease to have, “understanding of the condition, the ability to manage and manipulate numbers, navigation of the healthcare system, communication with healthcare professionals and the ability to make decisions regarding medical and behavioral strategies” (p. 44).

Socioeconomic Factors that Affect Health Literacy

A review of the literature published since 2010 in the United States indicates socioeconomic factors have an impact on one’s health literacy. A multi-search was performed to include not only medical databases but education, social and business publications. The date was limited to 2010 to capture data from the passage of the Affordable Care Act which provided access to medical insurance to the previously uninsured and underinsured. There were 65 journal articles identified that studied the socioeconomic factor related to health literacy. Of those, 46 studies included data demonstrating an increased likelihood that socioeconomic disparity resulted in higher incidence of low health literacy compared their counterparts. The studies ranged from disease-specific reviews of HIV (Dawson-Rose et al., 2016), diabetes (Yamashita and Kart, 2011), heart disease (Wu et al., 2013; Lee et al., 2017) oral health (Bersell, 2017), COPD and smoking (Omachi et al., 2013), and infectious diseases and parasites (Joseph et al., 2016). Some studies focused on the effect of parenting and child disease management

(Van Wagenen, Magnusson, & Neiger, 2015) or on tools for educating those at risk for socioeconomic disadvantages (Paasche-Orlow & Wolf 2010; Smith, Wolf, & von Wagner, 2010; Feinberg et al., 2016).

Studies were also done on specific races: African American (Rowe, Denmark, Harden, & Stapleton 2016) Latino (Calvo, Rocio, 2016; Fitzgerald, 2010), and South Asian populations (Mukherjea et al., 2012). Each study demonstrates non-whites were at risk for low health literacy and the health sequelae as a result of the low health literacy.

Consistently, regardless of the reason for the socioeconomic disparity, those in an at-risk group were more likely to suffer consequences of low health literacy. These could be attributed to language barriers, cultural differences, lack of resources, lack of trust in the healthcare system or health provider, understanding of the information provided or patient engagement in their own disease process or self-management.

Health Literacy Education for Providers

In order to begin to appreciate the level of understanding providers may have in assessing and supporting patients with low health literacy, the researcher reviewed the literature on the education providers receive specific to health literacy and provider education in their initial training or as Continuing Medical Education (CME) offerings. The literature demonstrates the lack of formal education that providers receive in their training. The training they do receive is often early in their medical school curriculum and is not embedded in their clinical experiences in most cases.

Of the research identified, Dr. Clifford Coleman and colleagues have published five articles specific to health literacy training for health professionals (Coleman & Appy, 2012;

Coleman & Fromer, 2015; Coleman, 2010; Coleman, Hudson & Maine, 2013; Coleman, Peterson-Perry & Bumsted, 2016; Coleman et al., 2016). In each study and literature review completed by Dr. Coleman and colleagues, the evidence demonstrates a lack of training for health professionals on health literacy.

The first article written by Dr. Coleman (2011) is a literature review of the education being provided to healthcare practitioners on the subject of health literacy. Coleman states the importance and scope of health literacy knowledge, “Because health literacy is a cross-cutting issue that affects virtually every aspect of healthcare delivery, anyone who interacts with patients, their families, communities or populations via oral or written communication should possess basic competency in health literacy principles” (p. 71). The literature review that follows this statement confirms that health literacy is not adequately addressed in health education programs including medical schools, nursing programs, and allied health schools.

Since Dr. Coleman found few studies done on the outcomes of health literacy education programs in medical education schools, he began doing his own research in this area. The first study performed by Coleman and Appy (2012) was a survey sent to deans of medical schools inquiring how health literacy was taught in their curriculum. With a 47% response rate of the 133 surveys sent to medical school, Coleman and Appy report 72% of the schools reporting teach specifically about health literacy as part of the required curriculum whereas two schools of the forty-four have health literacy as an elective. The schools that teach health literacy as a requirement taught an average of three hours on the topic, mostly in the first year of the program.

A study conducted by Coleman, Hudson, and Maine (2013) attempted to identify a list of health literacy competencies that could be used in health professional schools to promote health

literacy education. The list of competencies identified through a literature review was categorized into educational domains of knowledge, skills, and attitudes following Bloom's Taxonomy. A modified Delphi method was used to gain consensus from 23 experts in health education. Four rounds of rating and modifications resulted in consensus on 62 potential educational competencies. Coleman, Hudson, and Maine (2013) recommend that these competencies be used as a foundation for health literacy education in health education programs, residencies, and continuing education formats.

Coleman and Fromer (2015) conducted a study using a pre/post intervention design. Participants (58) were given a pre- and post-assessment on their self-perceived health literacy knowledge before and after training was provided by Dr. Coleman on health literacy principles. The results demonstrated a significant positive change in the self-perceived health literacy knowledge after the training as compared to knowledge pre-training. Coleman and Fromer (2015) suggest that training for medical professionals can improve their knowledge of health literacy and improve communication behaviors by providing information on the following topics related to low health literacy: prevalence, the health and care-related outcomes, the use of "Universal Precautions", best practices for assessing, knowledge of learning style preferences and use of readability tools.

Coleman, Peterson-Perry, and Bumsted (2016) followed the above study with research on the long-term effects of health literacy curriculum for medical students. In this study, 110 medical students were given a pre- and post-assessment on health literacy knowledge. Forty-eight of these students were asked to read an article on health literacy. One year later they were given the pre-assessment survey and additional health literacy training and a post-training survey. The combination of the assessments demonstrated an improvement in self-perceived

knowledge after 1 year but the knowledge diminished prior to the second year indicating the need for ongoing education in health literacy. Coleman, Peterson-Perry and Bumsted (2016) suggest that health literacy education should be on-going throughout the educational process as well as throughout medical practice. The skills needed in assisting patients with low health literacy can be diminished if they are not on the forefront of practice on a daily basis.

Coleman, Nguyen, Garvin, Sou, and Carney (2016) performed a follow up to the Coleman and Appy (2010) study of medical school deans. An adapted version of the 2010 survey was sent to program directors of 444 family medicine residency programs. The survey reported on the 138 respondents revealed that less than half (42%) of the residency programs require health literacy curriculum during the three years of the program. Approximately two-thirds of the residents who received health literacy education did not feel they received adequate health literacy training. The average amount of time spent in health literacy training was between two and five hours per year in each of the three years of residency education. This research demonstrates the need for medical school curriculums to include health literacy education throughout the continuum of the programs. Students themselves feel they are not adequately training in this area.

An article published by Harper, Cook, and Makoul (2007) describe two medical school programs in Chicago that teach health literacy. The programs both promoted the use of limiting medical jargon and using a “teach-back” approach to checking patient understanding. Teach-back asks the patient to explain to the provider what they were just taught using their own words. The first school experienced a 10% increase in the use of teach-back in the clinical setting after including the teach-back techniques within the curriculum. The second program in Chicago indicated it would be looking at student and faculty evaluations to determine future

enhancements to the program.

A study by Deuster, Christopher, Donovan, and Farrell (2008) measured the number of jargon words that were used by medical residents when providing information to patients. In this study, transcripts of conversations between resident and patients were reviewed for the number of jargon words used in the interactions and if the jargon was explained to the patient. The transcripts revealed that 350 jargon words were used in the 86 transcripts and 85% of the jargon was not explained or the explanation occurred at least two statements after the jargon word. The study indicated that patients are not often provided explanations of the jargon words that residents need more education on effective communication and the use of jargon in their conversations with patients.

Watson's Theory of Human Caring

In 1979 Jean Watson published a book for nursing practice surrounding the science of caring (Watson, 2008). Watson describes the Caring Science as:

informed by an ethical-moral-spiritual stance that encompasses a humanitarian, human science orientation to human caring processes, phenomena, and experiences. It is located within a worldview that is non-dualistic, relational, and unified, wherein there is a connectedness to all (Chapter 1, Working Definition section, para. 1)

This definition then evolves into 10 Carative factors (2008) and finally to the 10 Caritas Process (Sitzman & Watson, 2014). The 10 Caritas Processes are described by Sitzman & Watson as:

1. Sustaining humanistic-altruistic values by practicing loving kindness, compassion, and equanimity with self/others
2. Being authentically present, enabling faith/hope/belief system; honoring

subjective inner, life-world of self/others

3. Being sensitive to self and others by cultivating own spiritual practices;
beyond ego-self to transpersonal presence
4. Developing and sustaining loving trusting-caring relationships
5. Allowing for expression of positive and negative feelings -authentically
listening to another person's story
6. Creatively problem-solving-"solution-seeking" through caring process;
full use of self and artistry of caring-healing practices via use of all ways of
knowing/being/doing/becoming
7. Engaging in transpersonal teaching and learning within context of caring
relationships; staying within other's frame of reference-shift toward coaching model
for expanded health and wellness
8. Creating a healing environment at all levels; subtle environment for
energetic authentic caring presence
9. Reverentially assisting with basic human needs as sacred acts, touching
mindbodyspirit of other; sustaining human dignity
10. Opening to spiritual, mystery, unknowns-allowing for miracles

Watson's Caring Theory has been used in nursing care and education since it was first published and is still used in the literature today. Since Jean Watson published her caring theory in 1988, over 650 peer-reviewed articles have been presented. All of the articles and studies were found in nursing journals or focused on nursing practice. There were no articles applying Watson's theory to medical practice by physicians or physician assistants. Since the nurse practitioners begin their training in nursing schools, they would have a greater likelihood of learning about

Watson's Caring Theory in the undergraduate portion of their training. In the last few years, Watson's work has been used to promote better patient care in specific diseases and conditions (Ozan, Okumus, & Lash, 2015) or as a central tenant of nursing education (Carey, 2016).

Though there does not appear to be evidence of Watson's Theory in relation to provider education or practice at this time, it is used in this study as a portion of the theoretic framework. Providers are intimately involved in direct patient care in outpatient and primary care settings and caring theory could apply to their practice as it does in nursing practice. Especially in rural practices, there may not be a nurse in the practice or they may be providing other roles rather than direct patient care. It is then up to the provider to engage in the caring relationship.

The Patient Experience

How the patient experiences their healthcare is a component of this study's theoretic framework. The patient should be able to take the instructions given to them by the provider and apply them to their disease or condition(s). The way the patient experiences these interactions can have an impact on their ability to follow the provider's instructions to them. There may be situational and cognitive factors that have a particular impact on rural patients. How the patient's experience is affected by their rurality is discussed in Chapter 3. The demonstration of the provider's acknowledgment of the effects of rurality will be discussed in Chapter 4.

To understand the condition and characteristics the patient presents to the provider with, two theories of education and motivation have been reviewed. The first is that of Bloom's Taxonomy. It is important to take into consideration for a patient with suspected low health literacy that they may have diminished cognitive performance due to disease, medications, age, educational attainment or another sociocultural variable. Providers are expected to be able to get

the patient to the point that they can self-manage their disease which can include taking medications, making and keeping appointments, dietary restrictions, monitoring and trending biometric results (blood sugar, blood pressure, weight, etc.), and identifying emergency situations to name just a few.

The second consideration for providers is to understand where the patient falls on Maslow's Hierarchy of needs. A patient that has food insecurity or is having chronic breathing difficulties may not have the motivation to make lifestyle changes or have the financial means for medications/treatments/therapies.

Bloom

In 1956 Benjamin Bloom and colleagues created a taxonomy to promote higher forms of thinking (Bloom, et al. 1956). This committee identified 3 domains of learning: cognitive (knowledge), affective (attitude), and psychomotor (skills). The cognitive domain contains six categories of processes that transition from the simplest to the most complex. Bloom (1956) originally described these as knowledge →comprehension→application→analysis→synthesis→evaluation. This was updated by Anderson and Krathwohl (2001) to reflect creating being at the highest level of cognitive ability and rewording the categories as: remembering→understanding→applying→analyzing→evaluating→creating. These cognitive abilities are described in the body of literature as the functions of health literacy both implicitly and implied. Doak, Doak and Root (1996) describe the issue as:

Those with low literacy skills can't read pamphlets or booklets, directions on a bottle of aspirin or the explanations for a food exchange list. Vocabulary is not their only limitations; often they can't understand the illustrations and medical pictures used in

health-care materials (p. 1).

Furthermore, Serper et al., (2014) investigated the potential of an association between health literacy and cognitive ability. In their study of 832 adults, which included two structured interviews, surveys of functional health status, health literacy and a cognitive assessment they found, “evidence from multivariable models suggests that health literacy, as measured by these tests, is largely representative of cognitive function,” (p. 1259). The researchers go on to say:

...our results show that additional abilities beyond just reading and numeracy are likely to be very important to health. This is logical when considering the patient’s role in maintaining personal health, especially in the presence of chronic conditions. An individual must engage in active problem-solving to successfully navigate a health system, recall doctor instructions, dose out multi-drug regimens, comprehend health insurance information, and maintain daily health-promoting behaviors...While reading and numeracy skills are essential for disease self-management, broader cognitive abilities are also required (pp. 1259-1260).

Maslow

Abraham Maslow (1943) described a theory of motivations based on basic needs of the individual. These needs are: physiological, safety, love, esteem, and self-actualization. He proposed that a person was not likely to be motivated by higher level needs unless the lower level needs were being met (Maslow, 1943). Acton and Malathum (2000) studied 84 patients assessing their basic needs satisfaction and health-promoting self-care. Results showed that persons with higher scores on basic need satisfaction engaged in more health-promoting self-care behavior and those with lower levels of need satisfaction reported fewer positive health-related behaviors.

Noltemeyer, Bush, Patton, & Bergen (2012) studied 389 elementary age children and demonstrate support for Maslow's assertion that academic progress may be positively related to improvements in needs such as safety and love/belonging. From the beginning through the end of life, a patient's immediate needs of health and safety can affect their ability and motivation to learn and make healthy decisions.

Summary of Chapter

Since 7.8 million more rural Americans have access to healthcare due to the advent of the Affordable Care Act, there are more rural patients accessing healthcare, this increase has an effect on the providers who treat patients. Rural patients are more likely to have poor disease management, are in a lower socioeconomic class, have less access to health services, and are more likely to have low health literacy. All of these issues create the need for the provider to care for patients in a way that promotes healing through the use of Jean Watson's Theory of Human Caring. These caring relationships could assist the provider in assessing the cognitive ability of the patient according to Bloom's Taxonomy along with the motivation factors related to Maslow's Hierarchy of Needs.

Chapter 3

Research Methodology

Introduction to the Chapter

When a patient is unable to understand instructions on how to manage their chronic disease there is not only an impact on their health but to the healthcare system as a whole. Low health literacy affects health outcomes, especially for those people who are most vulnerable. One particularly vulnerable population is those living in rural areas. Rural populations are at higher risk for adverse health outcomes due to higher poverty levels, less access to medical specialists and services, lower technologic advances and transportation difficulties (Ross, Benavides-Vaello, Schumann & Haberman, 2013; Anderson et al., 2015). This study investigated the unique aspects of rural healthcare in New England, how medical providers helped their patients navigate the healthcare system and disease management, and what were the considerations rural providers should take into account when educating rural patients with low health literacy. The research asks the following questions:

Main question:

How do rural providers who have fewer resources available to them typically aid patients with low health literacy in chronic disease self-management through authentic relationships, problem-solving and transpersonal practices?

Sub-questions:

- What information do providers look for to assess if a patient has adequate health literacy to manage their chronic disease?

- How do rural providers creatively problem solve and coach their patients in chronic disease management?
- What are the unique healthcare needs and limitations of patients living in rural communities and how do their providers address these needs and limitations?
- How do rural providers impact chronic disease outcomes and quality of life through teaching patients how to manage their chronic disease?
- How does the provider adjust their method(s) of education through informal assessments applying Bloom's Taxonomy and Maslow's Hierarchy of Needs?
- In what circumstances have providers been taught about health literacy needs and risk factors associated with low health literacy?
- In what ways do providers apply the 10 Caritas of Watson's Caring Theory as the bridge between their understanding and that of their patients?

This research used a phenomenological approach for investigation. Since one's healthcare journey is very personal and at its most fundamental point has a defined starting and end point as life and death, I desired to understand how the provider supports the patient in making these life-through-death decisions. The provider has a responsibility to provide education and support to those patients that are at risk for low health literacy. These patients may be functioning at a diminished cognitive level due to their disease process, medications, age, socioeconomic status or educational attainment and who may have significant physiologic or safety needs (Liang & Brach, 2017). How did the rural providers understand the needs of the patient and help them make decisions that will have positive impacts on their life or ultimately death? Using the 10 Caritas in Watson's Theory of Human Caring (Sitzman & Watson, 2014) can be the bridge between provider and patient. A phenomenological approach allows the

researcher to delve deep into how rural providers support their patient's decision making in chronic disease management through applying Watson's transpersonal caring approach.

Rationale for Phenomenological Approach

“Qualitative research involves the collection, analysis, and interpretation of narrative and visual (non-numerical) data to gain insight into a particular phenomenon of interest,” (Bloomberg & Volpe, 2015). This research took place in the realm of human sciences. Noted researcher and writer in nursing practice, Patricia Benner, uses an interpretive phenomenological approach in nursing research to help interpret the effects of not only of the body, but how is the delivery of healthcare to specific populations, cultures, and communities affected by relationships and caring practices (Benner, 1994). Medicine is considered both a science and an art. Health is often seen through the lens of science and scientific theory. If the medical community only studies medicine in the realm of the physical, a large component of the patient's needs will not be met. Fjelland & Gjengedal (1994) discuss how the humans are spiritual animals and that caring for a patient should take into consideration their spiritual/non-physiologic needs. Phenomenology considers the lifeworld as how the world is experienced in everyday existence (van Manen, 2016). Since the research not only described the experiences of providers as they provided care and cared for patients, but I offered interpretations of the experiences based on the common or compelling themes that emerged. The very act of caring is not as likely to be captured in quantitative research and is more adequately described by hermeneutic inquiry (Dunlop, 1994) as a means to enhance understanding of the role of the provider in caring relationships to promote disease management.

Max van Manen (2014) describes the phenomenologist as “driven by a pathos to discern

the primordial secrets of the living meanings of the human world” (van Manen, 2014, p. 17). Van Manen (2016) also describes four fundamental lifeworld themes for reflecting on human experiences: lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relationships (relationality). These lifeworld themes are evident in the writings of Benner (1994) in her description of nursing as a caring practice. It is within each of these themes that providers worked to assist their patients in chronic disease management. How the providers maneuvered through these lifeworld themes may instruct others who find themselves in similar experiences. These four themes drove the interview process in *getting to* the lived experience of providers and their interactions with their patients. The four lifeworld themes encompass the totality that makes up each individual. Because of this, I investigated how the lifeworld themes influence how the provider interacts with their patients and impact their health through the lens of Watson’s Caring Theory.

Bracketing/Epoche’

The tenant of epoche’ in phenomenology is central to the research process. Epoche’ is described by van Manen (2014) as a suspension of preconceived notions, biases, awarenesses, and experiences. Van Manen says, “Bracketing mean parenthesizing, putting into brackets the various assumptions that might stand in the way from opening up access to the originary or the living meaning of a phenomenon” (p. 215). I, as a researcher involved in a phenomenological approach, confronted these “preunderstandings” so they could be addressed in a way that allows the researcher to see past what they believed to be to see what really is. Often considered the founder of phenomenology, Edmund Husserl (1931), states regarding the role of the bracket (epoche’):

Thus all sciences which relate to the natural world, though they stand never so firm to me, though they fill me with wondering admiration, though I am far from any thought of objecting to them in the least degree, I disconnect them all, I make absolutely no use of their standards, I do not appropriate a single one of the propositions that enter into their systems, even though the evidential value is perfect, I take none of them, no one of them serves me for a foundation-so long, that is, as it is understood, in the way these sciences themselves understand it, as a truth concerning the realities of this world. I may accept it only after I have placed it in the bracket (Introduction, The Phenomenological section, para 5).

In order to gain the full benefit of the phenomenological approach, I practiced the epoche'. As a respiratory therapist having worked in the medical field for over 25 years in hospitals of variable sizes and locations, I needed to actively reflect on my own lived experiences to understand how those experiences have shaped my beliefs. Interview questions were developed to ensure the questions were not leading questions that supported biases but questions were asked that allow those interviewed to describe their lived experiences. I needed to name present biases so that if the research brings information that is inconsistent with held beliefs and expectations that I would not attempt to transform the experience of the participants to meet preconceived ideas. The phenomenon was allowed to be expressed as purely as the provider described their experiences, not imposing currently held views of what the I thought the phenomenon should be.

Researcher Identity

As someone who has worked in healthcare my whole adult life, I have witnessed and experienced how providers explain health information to patients and families. To be an

effective researcher and phenomenologist, I recognized that I first needed to reflect on what was experienced at the bedside and how that have shaped my perceptions and biases. In 1991, I began as a respiratory therapist. In this role, I provided direct care to patients of all ages that were having difficulty breathing as a result of asthma, premature birth and underdeveloped lungs, cancer, chronic obstructive pulmonary disease (COPD), surgeries, and any other ailment that can affect the ability to breathe. I have performed cardiopulmonary resuscitation that successfully brought someone back to life and removed a breathing tube and ventilator support to allow someone to die. Living all of these experiences has demonstrated to me the sanctity of life and the inevitability of death. The roles the caregivers play in this life through death process are evident in the interactions between caregiver and patient. Many different care providers impact the path the patient takes but it is often the provider that is the director of the care. Just as in a symphony, each instrument has a role and without that particular instrument or musician, the music is lacking a crucial part, rhythm or harmony. As the symphony needs a conductor to make sure the musicians work together, have the timing right and that each instrument is heard; the provider is the conductor of the patient's medical care. The provider orders medications, diagnostic tests, therapies, and consultants. The provider has to know how medications interact, what to do with the information acquired, and how all the care team will coordinate to strive for improvement of the patient's health or quality of life. It is often the provider who needs to explain to the patient their disease process, medical options for care, risks, and benefits. As a care provider at the bedside, the researcher has seen this education and support delivered masterfully and abysmally. As my role in the healthcare setting has transitioned from a bedside care provider to an educational support role, I am obligated to think more critically about how healthcare providers not only educate staff to provide care, but how do healthcare practitioners

educate their patients in a way that is culturally and developmentally aware?

As a member of the healthcare community, I recognize healthcare practitioners and providers in particular, are taught a whole new language of medicine. The words spoken are based on the traditions of Greek and Latin. The words are a second language to the provider, or even a primary language given the number of years in school and in practice. When the provider attempts to educate patients using words like inflammation, malignancy, hypertension, cardiac, etc. the patient does not speak the same language and may not be able to make informed decisions that will impact the course of their disease. I wanted to hear from the providers themselves how they successfully (or unsuccessfully) educated and supported their patients through the continuum of chronic disease management. How did these providers assess the needs of the patient and their level of understanding? With appointment times shorter, diseases and their related regimens more complicated, how did providers prioritize education? What was in the provider experience that created a bond of trust and communication that promoted health and healing?

Researcher Assumptions

As I prepared to interview providers as to their experiences, I needed to reflect on my own experiences and address the biases present based on those experiences. The first assumption is that patients that have providers who take the time to explain information in the way the patient can understand and in a way that they respond to emotionally, will have better health outcomes and quality of life. Every patient, disease, situation, and level of social support is different for each individual. Patient's disease management may have more to do with familial and social supports, genetics, or other medical support such as social workers, the nursing staff or therapists that also participate in care and educate the patient. The providers may not have the

education and training to identify the cognitive needs of the patient and to be able to identify how non-medical needs impact the patient's ability to make the desired lifestyle changes.

A second assumption is that vulnerable patient populations do not want to ask questions or question the orders of the provider and the provider does not recognize the language they use is not familiar to the patient. Do the patients feel as though they do not have the right to question due to social expectations or cultural norms? Do they not want to feel "stupid" by asking questions they "should know" the answer to? Or do they feel they don't have options and the provider is providing them with their only choice? Do they rely on friends and family members to "translate" the information provided in their appointment?

There may a gap caused by providers not realizing they are using words the patient does not understand. This was recently highlighted when I was asked to review some patient education material a provider wanted to give to patients about a medication they were being prescribed. The provider and nurse worked for a long time to simplify the information. When the documents were reviewed as part of hospital policy, it was determined to still be written at a college level according to multiple readability scales. After working together, we were able to get the document down to approximately a fifth-grade reading level. The provider and nurse didn't realize that the patient may not understand topics such as tuberculosis, dosing, interactions, symptoms or bacteria even though those terms are common to the providers and other medical practitioners. Do providers think they are talking down to patients when they use "living room language"?

The third assumption is that through a provider's personalized approach to chronic disease management, a provider can help the patient have improved health outcomes and quality of life.

Building relationships based on trust and communication can result in a patient who will provide the provider with all the information needed and will trust the care plan suggested by the provider.

Above all, it is my bias that providers want to provide excellent care to their patients but are given less time, resources and educational support to effectively teach their patients. I also believe there are some providers who seem to be able to accomplish effective education within the same conditions. What is the difference in how they approach patients and the educational process? What connections do the providers make that enable them to support these vulnerable patients and are these connections representative in Watson's Caring Theory?

Theoretical Framework

It is from the above assumptions that the theoretic framework has been developed to demonstrate the utilization of Watson's Caring Theory (1988) as a tool to decrease the gaps in patient understanding and their ability to make decisions that will affect their health. The review of the literature demonstrates the impact rurality has on both the patient and the provider. There are fewer resources (affordable healthy food and access to specialists), a higher incidence of poverty and higher incidence of chronic diseases. In order for providers to impact the patient outcomes, there may be a common instrument they use to assist their patients in understanding their disease and how to improve their quality of life. This researcher suggests that a caring relationship, as described by Jean Watson's Caring Theory, may be the implement that helps bridge the gaps caused by the provider and patient's rurality.

Participant Selection

According to van Manen (2016), "the aim is to collect examples of *possible human experiences* in order to reflect on the means that may inhere in them," (p. 313) so it is imperative

to select participants that have actually experienced the phenomena. That experience in this phenomenological approach is a rural provider who is treating and supporting patients in their disease self-management when the patient is at risk for low health literacy.

To appreciate the lived experience of these providers, interviews were done with six rural providers in New England who have patients with suspected low health literacy. This sample size is consistent with other phenomenologists in the human sciences (Dukes, 1984; Creswell, 2013). The semi-structured interviews invited the providers to recall specific encounters with patients with whom they have had to provide individualized chronic disease management education. The providers were asked about the specific difficulties these patients encounter within the healthcare system and how they felt they were able to impact the health and quality of life of the patient. This qualitative study elicited the common themes the providers experienced as they educated their patients. A qualitative approach allowed the researcher and readers to gather a holistic understanding of a phenomenon. In this situation, the phenomenon was the experience of rural New England medical providers educating and coaching their patients through chronic disease management where the patient's lack of understanding of their own health situation could have impacted their ability to make healthcare decisions. The experiences of these providers could help other healthcare practitioners working with similar patient populations provide meaningful support to improve health outcomes and/or quality of life.

Research Sample

This study took place in rural New England. Since most research in healthcare and health literacy is done in urban areas, there is a lack of understanding of the unique issues surrounding access to healthcare for those who live in rural areas (Gurley, 2016). Rural patients have different cultural characteristics than their urban counterparts as do the many of the health

providers who live and work in their communities (James, 2014; Bushey, 2000). Rural residents often (but of course not completely generalizable) have certain characteristics based on their interdependence upon family, friends and neighbors and based on the economic drivers of the community, and geographical isolation from services. Dunkin's Framework for Rural Nursing Interventions (Dunkin, 1997) describes features that influence how rural people utilize health services. This framework describes three factors which are: structural, financial and socio-cultural. Structural factors influence healthcare decisions through the distance or available transportation to health resources such as clinics, specialists, pharmacies, hospitals and emergency medical services. Financial factors include income, insurance (including the ability to pay premiums, co-pays, and deductibles) and access to safety nets that provide support when the first two financial factors do not meet the needs or ability to pay for services. Socio-cultural factors include health beliefs, self-reliance, language and educational/literacy levels. Dunkin (1997) also discusses how participation mediators influence rural healthcare through relationships with others (family, neighbor, and friends), distrust of outsiders, lack of anonymity and isolation. All of these factors are intertwined and affect how rural dwellers view their disease as well as the decisions made in regards to disease management or lack thereof.

In addition to the characteristics of the rural patients, the rural provider practice is different from their urban colleagues (Weeks & Wallace, 2008). The rural provider is more of a generalist rather than a specialist due to lack of specialists in the community at large (Harris & Leininger, 1993; Douthit, Kiv, Dwolatzky & Biswas, 2015; Garcia et al., 2017). They are often residents of the community where they work so are more likely to see their patients at the grocery store, community and school events. The number of available providers in the community can result in one provider caring for most people in the community. This can be a

benefit or a curse in that the provider may have more awareness of socio-cultural issues within a family group or community as a whole that can impact their ability to care for the patient, positively or negatively. Because the provider may live in or have close ties to the community, issues surrounding confidentiality can become more problematic. On the other hand, the provider's intimate knowledge of the patient and their family/social group(s) can allow the care provided to meet more emotional and spiritual needs that an urban provider may not be aware of.

The research sample was a criterion-based purposeful sample of six providers who work in a rural medical practice in New England. According to Patton (2015), "Purposeful sampling: selecting information-rich cases to study, cases that by their nature and substance will illuminate the inquiry question being investigated" (chapter 5, module 30, paragraph 1). Purposeful sampling ensures all of the participants share a common phenomenon, allowing the themes to emerge out of the interview data. It is preferred that these providers will have at least three years of practice experience within this community. The criteria of at least 3 years within that community practice allows the provider to have established some experience within the community, time for relationships to develop with the patient population and for the community to see the provider as one of their own (not transient). Table 1 provides the demographic information of the providers interviewed. The potential names of providers were gathered from choosing names from the yellow pages phonebook of a rural community, just as a rural patient may find the name of a provider. Potential participants were also employed at rural health practices, free health clinics that serve the medically underserved, and Federally Qualified Health Centers (FQHC). The providers were contacted via a phone call or email to inquire if they would be interested in being interviewed for this research. They were given the purpose of the research and the inclusion criteria as previously described. Once the sample of appropriate

practitioners was established, interviews were scheduled and set up in a location convenient to the practitioner that allowed for confidentiality and a recordable environment. The interviews were conducted in the provider's office, an empty exam room, a conference room in a local hospital or in the home of the provider.

Table 1. Provider Demographics

Type of provider	Number of years in practice	Number of years in rural practice	Location of medical training
Physician	34	34	University of Vermont
Physician	24	12	Eastern Tennessee State University
Physician	26	26	University of Vermont
Physician	36	36	Hahnemann Medical College
Nurse Practitioner	8	8	Boston College
Physician Assistant	8	8	Mercy College

Overview of Information Needed

The data collection process began with approval from the institution's internal review board. An advisory group of four health practitioners with no other relationship to the study was developed. The advisory group reviewed the interview protocol and questions and provided feedback on the quality of the questions and any biases that may be present in the questions. The advisory group consisted of: Masters prepared Registered Nurse who is a clinical instructor, an Organizational Development Manager who is experienced in interview techniques, and a

Cardiologist who has rural patients and instructs medical students. After the advisory group reviewed and provided feedback on the interview protocol and questions, the interview questions were revised and fine-tuned to ensure the questions could be tied back to the main and sub-research questions. The advisory group also reviewed the questions to ensure they were not leading the providers to a particular response.

Research Design

Semi-structured interviews with providers were recorded with two devices and transcribed verbatim. The transcripts were read numerous times by myself at three different levels to find themes and insights. Van Manen (2014) suggests reviewing the transcript at a wholistic level, selective and detailed review. The wholistic reading takes the entire transcript and finds an overarching theme or significance. The selective reading reviews the texts for statements or phrases that describe the true essence of the phenomenon. Those phrases were saved for later use in describing the phenomenon through the eyes of the provider during the writing phase of the research. The final review is a detailed reading that looks at every sentence to elicit themes regarding the phenomenon. After the themes are developed, the researcher used the themes to describe the essence of how rural providers impact their patient's health outcomes and quality of life through the application of the 10 Caritas as described by Watson's Theory of Caring Relationships. How did the provider demonstrate authentic and caring relationships to support and understand patient needs through assessment in relation to Bloom's taxonomy and Maslow's Hierarchy of Needs? Common themes that emerged that may be applicable to other caregivers in similar settings were highlighted and described as a potential lesson to aid those who support patient education.

Research Questions

Main Question:

How do rural providers who have fewer resources available to them typically aid patients with low health literacy in disease self-management through authentic relationships, problem-solving and transpersonal practices?

Sub-questions:

1. What information do providers look for to assess if a patient has adequate health literacy to manage their chronic disease?
2. How do rural providers creatively problem solve and coach their patients in disease management?
3. What are the unique healthcare needs and limitations of patients living in rural communities and how do their providers address these needs and limitations?
4. How do rural providers impact chronic disease outcomes and quality of life through teaching patients how to manage their disease?
5. How does the provider adjust their method(s) of education through informal assessments applying Bloom's Taxonomy and Maslow's Hierarchy of Needs?
6. In what circumstances have providers been taught about health literacy needs and risk factors associated with low health literacy?
7. In what ways do providers apply the 10 Caritas of Watson's Caring Theory as the bridge between their understanding and that of their patients?

Identification of Themes

The methodology to identify the major themes resulting from the interviews with the

providers was developed utilizing approaches consistent with those practiced by Saldana (2013) and van Manen (2014). The process of theme identification begins with the wholistic reading approach described by van Manen (2014). The transcripts were read for the “eidetic, ordinary, or phenomenological meaning or main significance of the text,” (p. 320) and overall themes were developed as experienced by the providers. The themes developed through wholistic reading and were further examined as they were related to the main research question and sub-questions. This was done through van Manen’s selective reading approach (2014). Salient phrases, words, anecdotes were highlighted and aligned to each of the research sub-questions.

The selective reading approach is consistent with Saldaña’s (2013) first and second coding methods. The first cycle used was *In Vivo* coding where “a code refers to a word or short phrase from the actual language found in the qualitative data record,” (p. 91). The words and phrases were then second cycle coded for *Patterns*. Saldaña (2013) defines Pattern Codes as, “explanatory or inferential codes, ones that identify an emergent theme, configuration, or explanation,” (p. 210).

A detailed reading approach (van Manen, 2014) was completed via two methods. The first was a manual review of all of the transcripts by the researcher to look for words and phrases that are consistent with Watson’s Caring Theory Ten Caritas such as: kindness, compassion, presence, sensitive, trust, caring, relationships, expression, problem-solving, teaching, learning, coaching, healing environment, human dignity, wellness, spiritual, miracles and words that convey these same meanings. The transcripts were also uploaded into a qualitative research analysis software, NVivo, to ensure no other patterns emerged that may have been missed during the manual process. The word count for words used more than 10 times is in Appendix F. According to this analysis, the word *care* was used 89 times and was the 6th most common word used. The word *understand* was said 41 times, and *help* was used 29 times. The themes that were discovered through the

analysis process are described in detail in chapter 4.

Philosophical Assumptions

Ontological assumptions in phenomenology highlight the differing experiences and realities that the participants divulge during the interview process (Creswell, 2013). Each participant experienced educating patients in a differing manner within their practice. This manner will even have varied from individual patient to patient or situation to situation. There was not be a cookie cutter method of providing education on chronic disease but there were some similarities noted.

Epistemological assumptions take into account the evidence from the participants (Creswell, 2013). Since all those interviewed were providers, their medical expertise was used to help define the issue of low health literacy and the health issues that arise as a result. Direct quotes from providers were as evidence of their experiences with these patients.

Axiological assumptions acknowledge that there were biases based on individual values present within the research process since each participant and the researcher has a different experience and thus value set (Creswell, 2013). The biases and assumptions were discussed in a previous section.

Methodological assumptions were based on the process described by respected phenomenologists in human sciences and especially health and medicine research (Benner, 1994). Following these practices ensure sound and logical processes and the generation of sound data.

Limitations

The first set of limitations are those that result from the researcher and the research

process. The limitations of this study include the challenge of bracketing. As a researcher using a phenomenological approach, bracketing is an essential part of the process. I needed to view the experience through the eyes of the provider and not impose preconceived ideas of what the provider experienced. Another limitation is the ability of the researcher to write and present the provider's experiences in a way that truly expresses the essence of the how the provider experienced the work with the patient.

Another limitation is the small sample size, though the sample is appropriate for a phenomenological approach, it may not be generalizable to the experiences of other rural providers or those outside of the New England geographical area due to cultural differences.

Another set of potential limitations is inherent in the choice of using providers as the subject of the study. There is a possibility that the providers may not have been willing to express experiences that were less successful or those in which the provider felt vulnerable. This may limit the richness of the data obtained if the providers held back information. It is also important to acknowledge that the provider may not have been the person solely responsible for the education and support of the patient. There are nurses, front office staff, case managers that may be added to the education of the patient.

The limitations were minimized through the use of Yardley's criteria for assessing the quality of qualitative research (Marks & Yardley, 2004). These principles are: sensitivity to context, commitment and rigor, transparency and coherence, impact and importance. I have used member checking (Creswell, 2013) to ensure what the researcher has described is consistent with what the participant intended. This has given the participants the opportunity to ensure the writing conveyed the meaning the participant intended and that the researcher's biases did not

influence the outcomes of the result. No feedback was provided by those interviewed.

Summary of Chapter

This chapter discussed the methodology the researcher will employ. The researcher used a phenomenological approach to investigate how do rural providers who have fewer resources available to them typically aid patients with low health literacy in disease self-management through authentic relationships, problem-solving and transpersonal practices? The theoretical framework for the research is described including the characteristics of rurality and the potential utilization of Watson's Caring Theory (1988) by providers. The rationale for the methodology, sample and limitations were discussed as well as the philosophical assumptions and the researcher's identity and biases and the methodology of theme discovery.

Chapter 4

Analysis and Themes

Introduction to the Chapter

This phenomenological study was conducted to gain insight into how rural providers experience caring for patients with suspected low health literacy as they support their educational needs in chronic disease management. Max van Manen (2014) states, “Phenomenology aims to grasp the exclusively singular aspects (identity/essence/otherness) of a phenomenon or event” (p. 27). In this phenomenological approach, the phenomenon investigated is the interaction the physicians had with the patient as the provider is educating the patient or providing needed support.

Open-ended questions were asked of physicians and nurse practitioners to have them describe their experiences in supporting the educational needs of rural patients with suspected low health literacy. Van Manen (2014) describes the phenomenological interview as, “The interview first of all serves the very specific purpose exploring and gathering experiential narrative material, stories or anecdotes that may serve as a resource for phenomenological reflection and thus develop a richer and deeper understanding of a human phenomenon.” (p. 314). These stories and anecdotes will serve as the backdrop to the research and will be used to tell the shared experiences of these providers.

Study participants

Four physicians, one nurse practitioner, and one physician assistant were interviewed as part of this research, identified as Provider A-F. The participants provide care in a variety of rural settings from small independent practices to rural health clinics and Federally Qualified

Health Centers in rural New England. They have practiced in the rural community for eight to thirty-six years. All participants have made a conscious decision to practice in a rural community even though they have had urban/suburban options available. Some grew up in rural areas and cannot imagine living in an urban area, others have lived in urban areas and prefer the lifestyle the rural community offers their family. Provider B stated,

I really love taking care of the patients in a rural area that are very limited financially, cognitively, and it would kill me to practice in an upscale, urban community where everybody's concerns were about, "Which is the best car seat for my Lexus?" and "Which private school should my kid go to?"

The number of participants in this phenomenological approach is based on recommendations by Creswell (2013) described as, “the exploration of this phenomenon with a group of individuals who have all experienced the phenomenon. Thus, a heterogeneous group is identified that may vary in size from 3 to 4 individuals to 10 to 15,” (p. 78). Van Manen (2014) further describes the purpose of the sample is to find relative examples of the phenomenon. “The general aim should be to gather enough experientially rich examples or anecdotes that help make contact with life as it is lived” (p. 353).

Main Themes Identified

By first using the wholistic reading approach described by van Manen (2014), the transcripts were read for the “eidetic, originary, or phenomenological meaning or main significance of the text” (p. 320) and overall themes were developed as experienced by the providers. The themes that emerges as a result of the wholistic reading (with assigned code in parentheses after):

- Rural patients have unique challenges in accessing healthcare and healthy choices (RUR)
- Chronic disease management is often secondary to acute and episodic care (DIS)
- Socioeconomic situations often negate the patient's ability to make healthy choices (SIT)
- Patient may lack the education or cognition to effectively manage their disease (COG)
- The trust relationships that providers and patients develop over time allow them to become partners in healthcare and disease management (REL)

The themes developed through wholistic reading and were further examined as they were related to the main research question and sub-questions. This was done through van Manen's selective reading approach (2014). Salient phrases, words, anecdotes were highlighted and aligned to each of the research sub-questions. Each of these was given the codes as described above by the parenthetic abbreviation.

The selective reading approach is consistent with Saldaña's (2013) first and second coding methods. The first cycle used was *In Vivo* coding where "a code refers to a word or short phrase from the actual language found in the qualitative data record" (p. 91). The words and phrases were then second cycle coded for *Patterns*. Saldaña (2013) defines Pattern Codes as, "explanatory or inferential codes, ones that identify an emergent theme, configuration, or explanation" (p. 210). The identified words or phrases (*In vivo* code) and the *Pattern* codes associated with the words and phrases are shown in Appendix D.

Figure 2. In vivo codes and pattern codes

Code	COG	DIS	RUR	REL	SIT
	figure out	how many cigarettes	indigent	nurses bringing in food	indigent
	ability to do it	psychiatric	don't have all the studies	send a lot of time	we're not dropping
	can't understand	substitute	lack resources	problemsolve	socioeconomic crisis
	measures	studies	can't get to school	course like	psychiatric part
	to think about	anatomy book	home in time for milking	enlist the family members	socioeconomic ill
	understand	as time	how to run a farm	it's always a deal	quality of life is compromised
	finding the language	killing	plenty of outdoor's peace	shepherding experience	lack resources
	he's school understand	time to call	less health food stores	long, linear care	situation in life
	bits & pieces	AAC	gender	multiple rational	out of hole
	small pieces	diagnosis	notively many gyms	access to me 24/7	live paycheck to paycheck
	work on your number	had you up to a machine	time partition	can call me	survive
	babysitting	nutrition	psychiatrist not available	working on understanding	finance
	reinforcement	pets	don't have the option	negotiation	crisis
	unable	smoking	need a car to get anywhere	relationship	give the man a ride, home
	real importance	one thing they can do	s parts	several touches with me	can't afford it
	radio me	motivational interview	done	You're being a pain in the ass right now	poverty
	repeat again	vaccines	illegal like	finding the language	time partition can be a hindrance
	spell it out	UPToDate	reach out to farms	gone to school meetings	multiple nontraditional kids
	write about	weight is dropping	don't have the resources	plans that gonna work	families not traditional
	illustrate	send home health	limited financially	for the	income rate d
	got on the computer	minimizing the risks	barrier	every time	all
	limited cognitive resources	malms in the ir health	lack of access	report	re-offered
	ADHD	home education, mount	do not want to drive	frank conversations	restaining order
	motivational interviewing	ask for penicillin	distance traveled	communicate	assault
	low cognitive function	not dealing with prevent	manage, more	real importance	s successful
	ability to change	confirm diagnosis	specialist not available	talk down to patients	too cold
	understanding how to use it properly	treat it feel its appropriate		the you could run circles around me	family choices
	what types of things are healthy	BMI		taking care of family	impacting the kids
	literacy level	eat healthy r		they can't if you care	where they're going to sleep
	cognitive inspired	healthy choices		reality care	next meal
	very concrete	pain		know where your heart is	crisis they're dealing with
	called stupid	physicals		building relationships	right now
	re-treated in school	blood work		painfully hard	its pain
	cognitive disability	prevention		love taking care of patients	illegal
	to be low to	bad teeth		one area I'm strong	not being worth anything
	relationship	anxiety		re-living	live in poverty
	mental disability	physical exam		cons ultant	family lives
	understanding correctly	emergency care		large farm	environment is unfathomable
	ask appropriate questions	immunizations		trust relationship	devalued
	compliance	depression gets in the way		frustrated	drug add icted
	can't come up with plan	chronic depression		upset	limited financially
	shakes the ir head yes	medication		they're in charge	attending medications
	don't want to look stupid	take this medicine		we talk	eat health
	repeat back to me	parental mental illness		consultant	pay for my rent or buy groceries
	if they don't get it	drug add icted		expert	can't afford to eat healthy
	ask the m	CHF		mom was happy	a lot of the m's no he
	blank look	COPO		a moment of time	don't have high income
	no one	medications		leave with a mile	situation
	seemingly confused	inhalers and nebulizers		give a high-five	se if need eating
	learning level	wasn't getting better		enlighten me	school
	change way I'm explaining	reduction		enlighten the m	get clean
	assess me nt	take care		I've enjoyed what I do	feed everybody
	questions they're asking	stress test		patient	heart and electricity tured off
	not asking	multiple things		not always easy	not paying bills
	multiple intelligences	physical response		touch food	housing situation
	educating	overutilization		lightbulb moment	stress levels
	can't get the re	you were n't dying		good job	
	accept			weird interaction	
	different methods			be patient	
	drawing picture			s upparative	
	describing			judge mental	
	timing			maintaining a relationship	
	graphs			though love	
	some can understand				
	able to learn				
	able to manage				
	draw it				
	show the m				
	language				
	didn't understand				
	magic words				
	give measures				
	repeat back to me				
	What did I say				
	how often				
	I go back				
	calculators				
	ready to talk				
	learned some thing				
	have the ability				
	feeling motivated				
	feel empowered				
	small chunks				
	feel like they can't follow through				
	overwhelming				
	goals				
	language barrier				
	interpret				
	education about the ir health				
	multiple things at one time				
	utilize language				
	can't read or write				
	don't always tell you				
	need assistance				
	ass uming				
	confusing				
	handouts				
	something simple				
	how to can read it				
	little goals				
	address its lowly				
	forgetting				
	confused				
	nonverbal cues				
	very low education				
	reading levels				

To discover if the theoretic framework of Watson's Theory of Caring (Sitzman & Watson, 2014) was being used by the providers to assist their patients in disease management, a detailed reading approach (van Manen, 2014) was completed via two methods. The first was a manual review of all of the transcripts by the researcher to look for words and phrases that are consistent with Watson's Caring Theory Ten Caritas such as: kindness, compassion, presence, sensitive, trust, caring, relationships, expression, problem-solving, teaching, learning, coaching, healing environment, human dignity, wellness, spiritual, miracles and words that convey these same meanings. The transcripts were also uploaded into qualitative research analysis software, NVivo, to ensure no other patterns emerged that may have been missed during the manual process. The word count for words used more than 10 times is in Figure 2. According to this analysis, the word *care* was used 89 times and was the 6th most common word used. The word *understand* was said 41 times, and *help* was used 29 times.

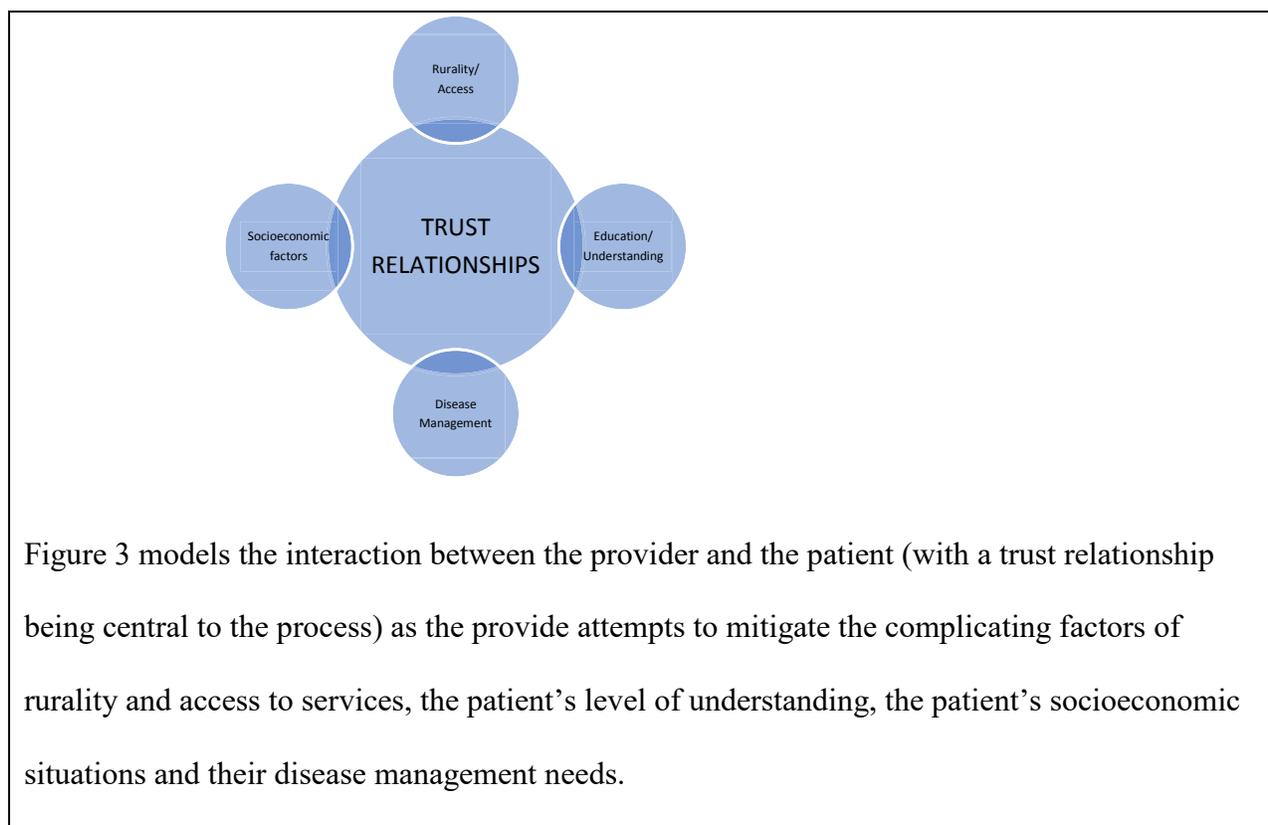
In the data analysis, the in vivo codes that related to the 10 Caritas were identified. These phrases were primarily labeled as Relational and Cognitive codes since those codes were the words and phrases most commonly related to the spirit of the Caritas. Table 2 lists the words and phrases that related to the 10 Caritas. These words and phrases demonstrated how the providers interact with the patients, how they educate and show respect. The words and phrases spoken by the providers interviewed expressed their authentic relationships, problem-solving and transpersonal practices that are the backdrop to Watson's Caring Theory.

Each of the themes identified by the data analysis has a component that relies on the interactions and trust relationship with the provider. The themes are independent of each other but are each impacted by the trust relationship with the provider. This is displayed in Figure 3.

Table 2. Words and phrases that indicate 10 Caritas application

nurses bringing in food	gone to school meetings
spend a lot of time	plan that's gonna work
problem solve	rapport
counselling	frank conversations
enlist other family members	communicate
it's always a deal	taking care of family
shepherding experience	they can tell if you care
long, linear care	really care
multi-generational	know where your heart is
access to me 24/7	building relationships
can call me	love taking care of patients
working on understanding	relating
negotiation	consistent
relationship	trust relationship
several touches with me	they're in charge
finding the language	we talk
	consultant
figure out	expert
ability to do it	mom was happy
can understand	amount of time
measures	leave with a smile
to think about	give a high-five
understand	enlighten me
finding the language	enlighten them
help school understand	I've enjoyed what I do
bite sized chunks	partner
small pieces	not always easy
work on your number	tough cookie
baby steps	lightbulb moment
reinforcement	good job
doable	be patient
real importance	supportive
rationale	maintaining a relationship
repeat it again	tough love
spell it out	environment is unfathomable
write it out	not being worth anything
illustrate	

Figure 3. Interaction between identified themes



Theme 1: Rural patients have unique challenges in accessing healthcare and healthy choices

Consistent with the issues described in Chapters 1 and 2 regarding healthcare in rural areas, the rural providers interviewed described the challenges of providing healthcare to rural patients. Some of the challenges experienced include lack of access to specialists and specialized diagnostic tests, transportation issues, socioeconomic pressures on rural families, and lack of healthy options in rural areas.

Access to Medical Resources

Each of the providers interviewed experienced a lack of access to resources, in particular, mental health services, dental care, and medical specialists. Due to scarcity specialists, the primary physician is responsible for being a generalist and providing care in areas that urban

providers may be able to refer patients to specialists for. Rural communities often lack hospitals, trauma centers, and clinics according to Douthit et al. (2015). The lack of access places a larger burden on the general practitioner. As explained by Provider F,

I don't have a pulmonologist that I can call for this patient with COPD and pneumonia. Or I don't have, you know, this patient is in diabetic ketoacidosis, there is no endocrinologist around. So you have to be able to, while not being overconfident, confident that you can handle what's coming in. And if it gets out of hand, you've got to be able to say, "I don't know this," and send them [to a specialist at a larger medical center].

Each provider interviewed explained the need to address mental health issues on a regular basis. "I do spend time, a lot of time, dealing with the psychiatric part of their healthcare...a lot of counseling comes from me and from the other people in my office," described Provider A. Provider C expressed similar experience with mental health care, "I never treated ADHD and a psychiatrist is not available, and some people will have distinct cases of it, and so I've just had to educate myself on that one." These experiences are in line with rural population's access to mental health services. A review of rural mental health care notes that untreated mental health is a greater problem in rural areas than in urban (Lutfiyya, Bianco, Quinlan, Hall & Waring, 2012). They also note there is a higher rate of suicide, depression, and dementia in rural communities. Due to a scarcity of mental health clinician in rural areas, the role falls to the primary care provider. Provider B estimates the burden as, "2.5% of the kids in the population have an IQ below seventy. They have learning impairment in the school's language, mental retardation in my language. I have 2,000 patients, ...so I have about 45 patients who have mental disability."

The providers each felt they had to provide more specialized services than their urban counterparts due to the scarcity of specialists in mental health, medical specialists (cardiac, pulmonary, nephrology, etc.), and dental care. They recognize they are not the best to provide for these needs but accept their care is better than the patient not receiving any care in those areas. Provider A describes mental healthcare, “75% of what people come to the doctors for is psychiatric based and not physical based. A lot of counseling from me and from the other people in the office that do that.”

Transportation

Transportation in rural areas impacts the patient’s ability to get to scheduled visits to primary care, diagnostic tests (which are often at community hospitals or larger medical centers that can be over an hour’s drive away), or to specialists. New England weather can impact this issue even more with poor driving conditions in snow and the costs of gas and snow tires. Rural patients in poverty experience getting to appointments troublesome as described by Provide A:

Transportation is often an issue of wellness. I have people that walk from ____ to ____ on a regular basis to see me. They have trouble with their Medicaid rides. I guess you have to call them 48 hours in advance to get a Medicaid ride, so if you have a problem that day, you either walk or wait 48 hours to get a ride. They walk and they hitchhike, and sometimes we give them a ride home at the end of the day back to ____.

Other patients who do have reliable transportation will often not travel to a larger town/city for care, “If they're 25 miles they don't think anything about driving here, but it's funny that they don't like the idea of driving to ____, maybe a big city or something,” states Provider C. Chan, Hart and Goodman (2006) and Douthit et al (2015) looked at the distances rural patients were able or willing to travel to receive medical care. They found the patients who had more complex

medical needs, specialists, and procedures would have to travel farther for care than urban patients. The rural patients were more likely to utilize their primary care provider for all care and not travel to urban areas to see specialists according to the Chan, Hart and Goodman study (2006).

Socioeconomic Factors

Socioeconomic factors affecting rural citizens is a well-documented reality for providers to consider during their care. In a study conducted by Ortiz, Meemon, Zhou, and Wan (2013) some of the socioeconomic indicators include:

- Over 14% of rural individuals live below the poverty level (13%, for US overall) and has increased by 8.3% in the years 2000-2007.
- The death rate for rural individuals is 13% higher than those living in non-rural areas.
- There are 10% more individuals over the age of 65 living in rural areas compared to urban.

Douthit et al. (2015) highlight the ongoing disparities between urban and rural populations in less comprehensive health insurance coverage, greater out-of-pocket expenses, and may not be in a state that offers the Medicaid expansion (though this is not the case in New England since the northeast states do offer the expansion). These statistics can be an indicator of the poorer health of the rural population in the United States.

“For all of their socioeconomic ill, it becomes more difficult for them to be compliant with what they should be doing to maintain their health,” according to Provider A. When asked about the socioeconomic factors that impact disease management Provider D commented:

It can be obviously a big barrier, especially when it comes to nutrition I'd say, with kids, which is something I focus on a lot. Nutrition, exercise, health maintenance, illness

prevention. Oftentimes parents cite that as being a barrier, lack of access, lack of ability to put their kids in sports or dance or purchase fresh produce.

The bearing on health for those living in poverty are most impactful when healthcare comes below the family's needs for basic requirements to survive, "Their priority is their next meal or where they are going to sleep at night," according to Provider A. At times simply being rural decreases the options for rural individuals. The providers cite a lack of healthy food options, fewer gyms and healthy activities for both kids and adults, as well as their own financial pressures of caring in a rural community. This is consistent with data from O'Connor and Wellenius (2012). The fewer choices of primary care providers create less choice for the patients. There is a larger provider to patient ratio in rural counties. According to The National Rural Health Association, the patient to primary care physician ratio in rural areas is 39.8 physicians per 100,000 people. This is compared to 53.3 physicians per 100,000 people in urban areas.

The data suggest some providers find the financial pressures of running a practice limiting as stated by Provider F:

Well economics was an issue. We had 20% of our patients on Medicaid. And they were accounting for 60% of our visits. And that's why we had to sell our practice. We couldn't make ends meet with that demographic of payer. So we sold the hospital and let them worry about that part.

The financial pressures being placed on providers causes many providers to join larger medical groups, or sell to a local hospital to manage their business. One provider joined a FQHC practice due to the loan forgiveness program offered to those providers who will work in a rural area. A number of providers are priced out of the market just trying to implement technology

requirements for funding including electronic health records (EHR). Others want to maintain their independence and do so to continue to provide care in the way they feel is best for their patients and for their own lifestyle:

I do not participate in the [local Accountable Care Organization], and I do not participate in any of these per member, per month things because I do not have a clinical EHR that can feed the information into it. I cannot spend my world looking at a computer screen checking boxes because it would be bad for my mental health, and it would slow my productivity (Provider B).

Individuals living in rural areas have unique challenges to access of healthcare and healthy options. Some of these challenges are intensified by rural poverty and geographical location. O'Connor and Wellenius (2012) summarize the issue:

The higher rate of poverty, lower prevalence of insurance coverage and less access to services suggests that many rural residents will be unable to obtain or afford treatment including smoking cessation therapies, diabetic medications and/or gastric bypass surgery. In addition, when compared with urban consumers, persons living in rural areas often have a more limited selection and higher cost for fresh fruits and vegetables.

Limited transportation options and long distances may make grocery shopping difficult, and nutritionists tend to be less available in rural areas. (p. 818)

Rural providers recognize the unique challenges to rural patients. These challenges include less access to medical resources, transportation issues, and socioeconomic factors. The providers address them and try to mitigate these issues as much as possible to allow the patient to focus on disease management. How this is done will be discussed within the following themes.

Theme 2: Chronic disease management is often secondary to acute and episodic care

Though the main research question and sub-questions sought to learn of how providers educate patients with chronic disease, it became clear that primary care is often involved in more episodic care instead. The episodic care can be related to injury, acute illness and mental health crises. Harris and Leininger (1993) describe these situations as, “rural physicians, more than urban/suburban, are practicing ‘crisis medicine’...rushing from one immediate need to another, unable to fully consider the prevention agenda for each patient,” (p. 1115). This sentiment was echoed by Provider A, “They are not dealing with prevention. They are dealing with crises.” The same provider expands on that example,

Having physicals and having screening bloodwork and preventative tests, that’s something that is far away from them, because they are not dealing with prevention. They’re dealing with crises. It’s their bad teeth, and it’s their anxiety from whatever crisis they are dealing with at the moment. And it’s pain. They usually have pain from one thing or another. They’re interested in relief from pain, psychological or physical, and they’re not even thinking about preventative medicine and physical exam and things like that.

Preventative medicine is an integral part of disease management that includes diet, exercise, diagnostic and screening tests, smoking cessation, educational support, and symptom control. Particularly in the cases of diabetes and coronary heart disease, rural patients are at higher risk for these diseases due to poverty, higher incidence of smoking, more overweight and obese individuals, and an older population (O’Connor & Wellenius, 2012). Unfortunately, disease management and prevention often take time the providers do not have. One study suggests that it is physically impossible for providers to include the recommended screening,

counseling, immunizations and chemoprophylaxis without decreasing the number of patient visits in one day (Yarnall, Pollak, Ostbye, Krause, & Michener, 2003). Yarnall et al. (2003) suggest that a provider would need between two and four hours each day in the office to do all of the recommended preventative care and disease management tasks.

One area that has helped the overload on the physicians is the use of physician extenders: nurse practitioners, physician assistants, diabetes educators, nutritionists, physical therapists and home health services. Provider F noted during the interview, “We had an outreach nurse who was employed by the ____ clinic to go to farms, to reach out to farms and get the patients. Make sure they got what they needed, make sure they got their immunizations, things like that.” These relationships and use of other professionals allow the providers to handle the crisis that arises and also collaborate to provide disease management that the patient will access.

Provider B described the relationship between disease management and preventative (well) visits as a building of trust to allow them both to occur:

The well-care I do, I think, is mostly to build a relationship with a family so when they do get sick, they have had several touches with me...it is certainly not just about this visit. It's about the 10 visits before this one and the 10 that come after it.

Primary care is the interplay between medical intervention during a crisis and the long-term sequelae of disease management. Providers invest much of their time in episodic and crisis management and these interactions create the basis for chronic disease management when the patient is able and willing to participate in that level of care. Chronic disease management is a process that takes time. Provider D describes the process of disease management, “...so it's coming up with a plan that's gonna work for them right then. Usually, baby steps are the best

way, whether it's nutrition or pets or smoking or whatever, so minimizing the risk as much as you can, so baby steps.” The same provider stated, “I think it takes multiple visits to really make those changes because it can be very, very overwhelming for people to try to do it all in one visit.” Provider A describes the situation, “Their life is one crisis to the next, so healthcare interventions are not a priority.” Managing crisis after crisis does not leave the provider time to delve into chronic disease management nor is the patient in a cognitive state to be able to focus on interventions that are not relevant to the immediate situation.

Patients often have situations that are more immediate than chronic disease management. Providers identify the patient’s priorities as pain management or psycho-social issues that place chronic disease management further down on the urgency scale for medical care.

Theme 3: Socioeconomic situations often negate the patient’s ability to make healthy choices

Perhaps the most difficult arena of patient care is the socioeconomic situations that patients are in which may or may not be the result of financial limitations or lifestyle conditions they find themselves in. Rural providers often support patients that live in poverty or in difficult social circumstances. “Primary care medicine includes health conditions that are a mix of biopsychosocial factors. Research has highlighted the positive correlation between psychosocial stressors and increased utilization of healthcare services as related to patient’s financial ability to afford these services (Peterson, Turgesen, Fisk & McCarthy, 2017, p. 167). This increased utilization for psychosocial stressors can thus limit the providers’ available time to support chronic disease management in not only the patient being seen for the stressor but also for other patients attempting to schedule visits with that provider.

All of the providers interviewed described situations in which the patient's individual or family situation was the primary challenge in their life, making chronic disease management secondary. An example of a complex family situation is described by Provider B as:

When she delivered her first [baby], he was incarcerated for assaulting her. He was let out of jail, and then re-offended, went back to jail. She had her second. He's now out, and she's acting as his supervising parent. She has a restraining order against her mother, and he can no longer be in his family home because he's assaulted his younger brother. So, very difficult situation.

When a provider was asked about the most common chronic diseases that are treated in their practice, Provider D described the family situations as one of their most common chronic diseases:

I would say it's social complications, so that wouldn't be so much of a medical diagnosis, but I'd say a really complicated social situation, complicated family, whether it's, you know, they're moving all the time, they're living with Grandma, you know, mother or father having drug problems, in or out of rehab, sometimes involved, sometimes not involved...It's pretty time consuming and it's really complicated and I think it's something that we do a good job handling because we tend to know our families pretty well, because of the smaller, 'cause we're a smaller practice.

Many examples were offered during the interviews. The providers described couch surfing (people or families moving from one person's home to another for short time living arrangements due to lack of affordable housing), inaccessibility of affordable healthy foods, or living in a food desert where only convenience stores are within walking or short drive distances,

and all of the implications to families surrounding addiction. Due to the complexities of addiction, one practice will not care for pediatric patients born to addicted moms, they need more support than what the practice can offer without jeopardizing the care of other patients in the practice.

One final situational condition that a few of the providers discussed was that of the immigrant farm workers. Some of the farm workers are legal with green cards, others are smuggled across the borders and brought to farms to work on the crops during the summer months. Provider A relayed this frightening and telling story:

I know, I've seen on TV that a lot of illegal aliens are now just entering Canada to escape the US because of the threat of being deported. I think they don't seek medical care because of their fear of being noticed by the government. Interesting story that happened one night, and this was a local farmer who had Mexican workers on his farm, as many of the farmers in ____ do. These people had come in legally and so they had paperwork. They had the proper paperwork, but Homeland Security made a raid on this farm one night in ____ . As the farmer said, it was like 2:00 in the morning when the helicopters and the trucks with armed men with AK47s arrived at his house and threw him up against the front porch and his wife too when they came out to see what was going on and demanded to see his workers and to see the papers. He eventually was able to show them the paperwork that he was legal and was not breaking the law. They apologized and left after some time.

Often farm workers are likely to seek medical care only in the direst of circumstances (Bushy, 2000; Anthony, Williams, & Avery, 2008). There are some rural programs that do outreach to

the farm workers (legal and so-called illegal) to try to help manage disease, deliver immunizations, and provide general primary care. It takes a great amount of trust, given situations similar to the one described above, for these workers to visit anyone they may consider part of the establishment.

For patients to manage chronic disease, it is more likely that their immediate needs must be addressed. Just as Maslow (1943) described, a person's immediate physiological needs must be met, then issues of safety and security. As the providers describe the situations that are an everyday occurrence for many of their patients, the luxury of disease management can become secondary to lack of food, shelter, the presence of addiction and abuse.

Theme 4: Patients may lack the education or cognition to effectively understand and manage their disease

The language of medicine is complex to the most educated. It can be even more of a challenge for those who have lower literacy or numeracy skills, are Low English Proficiency (LEP), or have cognitive challenges. In a 2014 report by the National Center for Education Statistics noted that those living in rural areas in the United States were less likely to have a high school diploma or receive a college degree. This is most pronounced in the 65 years and older age group as 19% of those over 65-year-old in rural areas in the United States do not have a high school diploma. Dickens and Piano (2013) discuss the scope of health literacy in the United States:

- In a literacy assessment of more than 19,000 adults in the U.S., 43% were found to be at the basic or below basic level in health literacy, this was even greater for non-whites.

- People with less than a high school diploma or GED were more likely to have below basic health literacy.
- Low health literacy was more prevalent as patients were over age 65.
- Patients with illness may be overwhelmed by the health system regardless of literacy level.

Considering that older, sicker and less educated is a high percentage of the providers' patient panel, this can comprise a significant portion of their patient interactions. If most of their patients are over 65 and if 19% of those did not complete high school the likelihood of low health literacy must at least be considered.

Of the six providers interviewed, only one had formal classroom training in their medical program in health literacy and patient education. That provider is the nurse practitioner. Since this has not be readily taught in medical school, the physicians interviewed have had to learn the skills of detecting low health literacy and learns ways to educate patients without formal training. This comes naturally for some, "I haven't had a lot of training, but that's always been one thing that was fairly natural to me. Some people are great clinically but they don't get what people are saying," said Provider C.

In order for the provider to deliver information, it is crucial for them to first assess their patient's level of understanding. The providers interviewed expressed a few different means of eliciting this information. Though they may not have identified the method as such, the providers often expressed using a "Teach Back" approach. Teach Back is a proven approach in which the provider asks the patient to explain in their own words about their disease and how to take medications, interpret results of monitoring tests (glucometers, peak flow, blood pressure, weight, etc.) and other self-management. The Agency for Healthcare Research and Quality

(AHRQ) recommends a few techniques to improve patient understanding: focus on need-to-know/need-to-do, use teach back, demonstrate/draw pictures, encourage questions, make eye contact, slow down, “chunk and check,” and use clearly written instructions (Brega et al., 2015).

Of the providers interviewed, each used at least one but usually more of the approaches recommended by the AHRQ. As an example of teach back, Provider B described his approach as asking the patient, ““What did I say about the medicine? How often are you going to take that medicine?” I wait for them to repeat it back. If they don't get it, then I go back, and we try again until we get it.” Provider D described the process as, “I think one of the things that I will ask is to have them kind of repeat back to me what their routine will be like, or some possible changes they can make.” The providers interviewed can glean the patient’s understanding from the question they ask (or don’t ask), their facial expressions and their level of compliance with the treatment plan. Even when patients nod affirmative or say they understand, the providers should confirm they can follow the directions once at home. “Everybody shakes their head yes... because they don’t want to look stupid,” is a sentiment shared by Provider B in this study.

Once the provider recognizes a lack of understanding, they work to overcome the gap and give the patient the information in a way they can use the information. Every provider interviewed discussed the need to use pictures and diagrams, one of the 4 recommendations by the AHQR. Some have pictures in a book that they use, other draw pictures. One of the providers explained that he draws pictures on the paper that covers the exam table. During his first year in the practices, without his knowledge, the staff in the office collected his drawings and a make a booklet for him that they presented to the provider at an anniversary. Another provider explains, “I used a lot of diagrams that I drew, usually on the spot. I didn't have, let's say a book of diagrams that I used. We'd draw it for the patient, and then I would give it to them,

and I would say, 'Here put this on your refrigerator. If I'm ever famous, I'll sign it.' So I used a lot of diagrams and then would label the diagrams, show them what was happening, things like that.”

Sometimes the provider needs to recognize when the patient, whether for a cognitive or behavioral reason, cannot or will not comprehend the information and be motivated to make the appropriate changes:

for a diabetic patient, our goal is to get their sugar under control with a measurement of the A1C less than seven. I have patients whose A1Cs are 10. They just don't... We've been trying for years, and they can't get there. I guess I just accept that that's the way it's going to be with some people (Provider A).

The rural providers often need to spend time translating what other providers or specialists have “educated” patients about “I've seen a lot of physicians also that talk down to patients, and so you've got to get that balance between realizing that they could run circles around me about how to run a farm,” explained Provider C. To mitigate this issue Provider B explains his process:

About a third of the patients that see a specialist ultimately come back to me to understand what the specialist said, and I would say it's probably 30% of the time. I have a long relationship with them. I have a trust relationship with them, and I try to interpret for them in language that I think they probably understand what happened. So, if they go to see the cardiologist, in my office, they go to see the heart doctor.

And sometimes, the provider has to use a tough-love approach to get the patient's attention as in this example by Provider B:

I can think of a time when a mother with a very disabled boy was very upset with not being taken care of. I said, "You're being a pain in the ass right now." Now, you know, I, "Oh my God, I'm going to lose my license," but in her world, that's what she needed to hear." From that day on, she was fine. Finding the language, it's oftentimes hard to find the language to help people understand.

In this interaction, the provider used language (telling the mother that she was being a “pain in the ass”) to get her attention even though he felt that in some situations this could be considered unprofessional conduct. It was how he was able to get the patient to start listening and in the end, improved their communication.

Even though five out of six of the providers interviewed had no or very minimal training in health literacy per se, each of them has developed methods consistent with the recommendations from the AHRQ. These include using language the patient can understand and apply, using pictures and diagrams, checking for application of knowledge through teach-back, and using clear written directions.

Theme 5: The trust relationships that providers and patients develop over time allow them to become partners in healthcare and disease management

The providers interviewed expressed the need for a relationship of trust when caring for the patients' chronic diseases. Chronic disease management is not a single episode of care but includes many aspects of care over time. A study done by Cramm & Nieboer (2014) highlights the importance of a patient-professional relationship in chronic disease management. Healthcare used to be delivered in an atmosphere of role-based power between the provider and the patient. Newer models of care expect the patient to be an active participant in the decision-making process. In order for this to be successful, “This calls for a patient-centered approach with

professionals performing their role in a less authoritarian manner.” (p. 898). The authors continue, “Productive interaction between patient and professionals may be recognized by accurate, frequent, and problem-solving communication that is supported by relationships based on shared goals and mutual respect...that foster attentiveness to the situation and one another” (Cramm & Nieboer, 2014, p.898).

All of the providers interviewed for this research spoke of the need for having a relationship with the patient that extends beyond the physical exam and diagnostic test. Since the patient’s socioeconomic status can be problematic and care is often delivered as the result of an acute situation as described earlier in this chapter, the rural provider cares for the patient over time and thus learns what their issues and needs are. This knowledge over time allows the provider to customize the care based on the patient’s needs and situation.

The relationships that the providers have with their patients enable them to build trust which in turn allows the providers to have the hard conversations when needed and also to be able to negotiate when that is appropriate. “They can tell if you care. They can tell by the amount of time you spend with them, I think, the way you are in the room. I think the families can really tell if you truly care. I think that's important,” explained Provider D.

If the provider were to function in an authoritarian way, the patient would most likely be non-compliant with the plan. When the provider and patient come up with a plan together, the plan is more likely to fit within the capabilities of the patient, their family, and their situation. All of the interviewed providers described the need to compromise, take baby steps, make small changes and negotiate to encourage the patient to make desired changes to improve disease management. In cases like asthma, have the pets not sleep in the bed, then not in the bedroom,

make changes in stages. The providers don't expect a patient to all of a sudden stop smoking, eat healthy, exercise and manage their many medications accurately. Changes and behavior change over time, "When I'm teaching medical students, I often tell them, 'It is certainly not just about this visit. It's about the 10 visits before this one and the 10 that come after it.' I have the experience of long, linear care, multi-generational," states Provider B. Provider D expressed the relationship as,

I would say the longer you stay, the longer you're at a place, the better you're able to know the patients and the families and the better you know them, the easier it is to take care of them and the better you can take care of them, the more fun it is to take care of them as you watch the families grow. It's rewarding for me as a provider to watch those kids grow, to see the changes.

All of the providers expressed moments where they developed trust relationships through honesty, time, genuine expressions of caring and understanding of the patient's socio-economic condition and needs. This trust allowed the building of relationships that in turn allowed the providers to support the patient's longer-term chronic disease needs.

Analysis of Watson's Caring Theory

Watson's Caring Theory (1988) was used in the theoretic framework of this study. It is suggested by this research that providers use the 10 Caritas of Watson's Caring Theory (Sitzman & Watson, 2014) to overcome the issues surrounding rurality and the specific needs of rural patients. The following section provides analysis specific to Watson's Caring Theory and the 10 Caritas.

Application of Watson's Caring Theory

“Transpersonal caring relationships are the foundation of Watson’s work. Transpersonal caring occurs when the one caring connects with and embraces the spirit of the other through authentic, full attention in the here and now, and conveys a concern for the inner life and personal meaning of another,” (Sitzman & Watson, 2014). The application of Watson’s Caring Theory is summarized as the use of authentic relationships, problem-solving and transpersonal practices to manifest both the art and science of medicine.

The graphic in Figure 3 displays the encircling of Watson’s Caring Theory in the interactions between provider and patient as they work together to improve the health of the patient and their family.

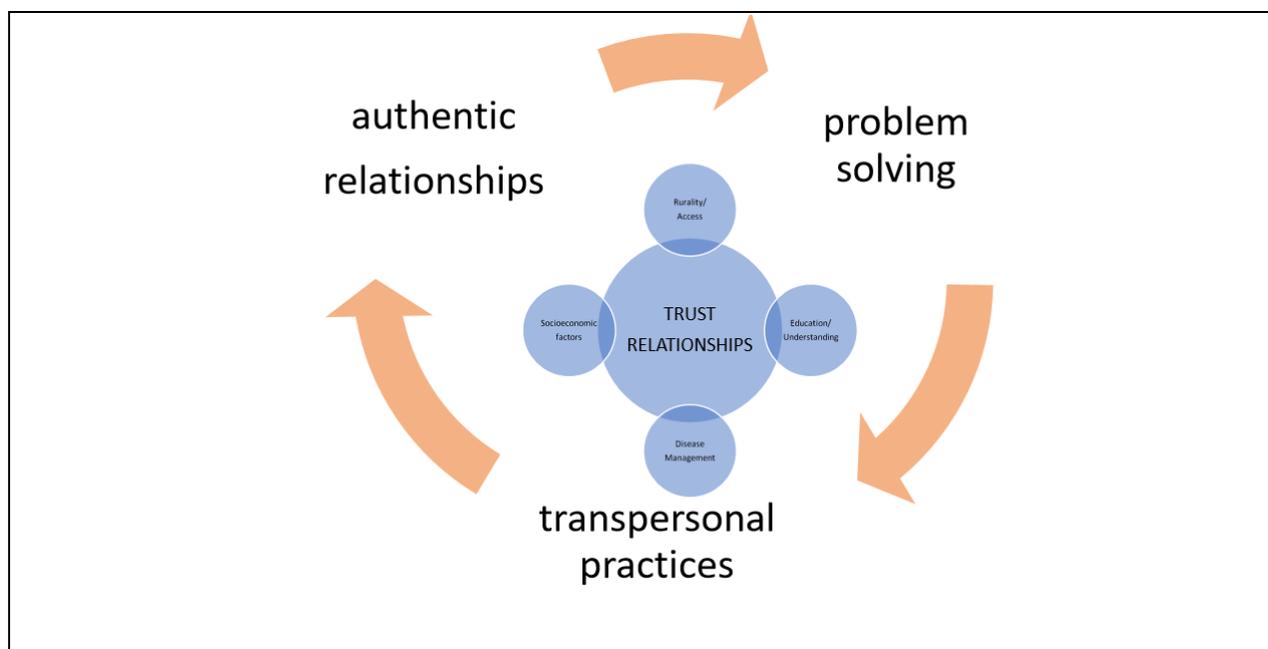
The 10 Caritas as Theoretical Framework

The analysis of the data presented from the interviews with the providers expressed the use of the 10 Caritas as part of the care for the patient by the provider. The establishment of the trust relationship is developed over time by the use of the Caritas in the clinical setting. Each of the 10 Caritas is discussed individually with examples of the provider’s demonstrations of each if the Caritas was present in the provider’s description of their practice.

1. Sustaining humanistic-altruistic values by practicing loving kindness, compassion, and equanimity with self and others.

The first Caritas was demonstrated in many ways by the providers. The providers demonstrated a desire to care for rural patients as they identified the socioeconomic characteristics of the rural patients and the care they need. The providers were able to meet the patient where they were emotionally and physically and did not place themselves on a higher plane than the patient.

Figure 4. Watson's Caring Theory encircling and supporting the interactions between provider and patient



Provider C described this, “I’ve seen a lot of physicians also that talk down to patients, and so you’ve got to get that balance between realizing that they could run circles around me about how to run a farm, and it happens to be that the area that I know a little better than they do is medicine.” Provider B stated, “I like rural people.”

2. Being authentically present, enabling faith/hope/belief system; honoring subjective inner, life-world of self/others.

This Caritas was demonstrated through the time the providers spend with the patient as the patient describes their situation and the provider offers a solution. The providers assisted the patients in working through issues that were not related to their physical health but needs related to basic human requirements, mental health, and educational support. They cared for the patients in the situation they found themselves in, recognizing the need to support the patient in their current state. Provider A described

this situation, “He's a drug addict. He's on the Suboxone program. Our nurses are bringing food into the office for him, because his weight is dropping.” Another provider, Provider B went to a school meeting with a parent as support:

I'd gone to school meetings with her. I tried to help the school understand that this environment for this boy is unfathomable. The mom was happy to have me come and champion with her school stuff because she had a very rough ride that she remembers through school.

3. Being sensitive to self and others by cultivating own spiritual practices; beyond ego-self to transpersonal presence.

The providers did not specify any spiritual practice as part of their care. This was not an aspect of practice that was specifically asked about in the interview process.

Though it was not specifically asked in the interview questions, nor were questions asked about the other Caritas in any of the interviews. In one provider office where an interview was conducted, there was some religious artwork and icons on the walls of the private office of the provider. There was no mention of any spiritual practices by this or any other provider interviewed.

The lack of obvious spirituality may be an indicator that spiritual practice is not part of their medical practice. It is unclear if this is a cultural norm of the geographic location or if the absence of spiritual practices is a function of the small sample size.

4. Developing and sustaining loving, trusting-caring relationships.

All of the providers described a relationship with the patient that developed over time from acute visits to assisting with chronic disease management. The patients were able to present their issues to their provider without feeling judged or marginalized.

Provider E describes the time it takes to develop a relationship:

Certainly, the first time I meet people, I don't feel like I'm gonna be breaking down these walls to help them, but after being in there so long, I definitely feel like I can have a conversation, and I can be frank with some people about what's going on and what they need to do versus being very cautious about it. I think it takes multiple visits to really make those changes because it can be very, very overwhelming for people to try to do it all in one visit.

5. Allowing for expressions of positive and negative feelings-authentically listening to another person's story.

The providers allowed the patient to tell their stories without judgment. The patients were given “tough love” when needed, or a gentle nudge at other times. The patients responded to these interactions by providing honest stories about their conditions (physical and psychological/emotional) so the provider could understand the situation as a whole. Provider B described a situation:

I have a teenager right now who's not participating in high school because her asthma's so bad. It took a long time for the family to understand that the cats and the dogs were essentially killing this kid. It took about a year, year and a half to two years of trying for the family to understand that this was really, really bad for her.

6. Creatively problem-solving-“solution-seeking” through caring process; full use of self and artistry of caring-healing practices via use of all ways of knowing/being/doing/becoming.

Through the knowledge of the patient's situations and abilities, the provider could make recommendations that were achievable by the patients or break down tasks into smaller goals and actions. This allowed for small wins to gain confidence and see successes. Provider F described the problem-solving process as using a variety of resources:

Sometimes you enlist other family members to bring pressure. Sometimes, depending upon what their situation is, send home health in to intervene. Use a mental health agency. You know, try to bring everything, all the tools to bear that you can.

The same provider described this problem-solving approach:

It's always a deal. I mean, as an example, like, you have somebody that's working and you know, they're supposed to take this medicine every six hours. Well that's not going to work. They're never going to do that. So you have to compromise and say, "Okay, take it at breakfast, lunch, supper, and bedtime." So that may turn out to be every four to five hours, but that's the compromise. And you have to ...otherwise it's not going to get done at all.

7. Engaging in transpersonal teaching and learning within context of caring relationship; staying within other's frame of reference-shift toward coaching model for expanded health/wellness.

Each provider interviewed described how they watch and listen to the patient to gauge their level of understanding. How the patient answers or doesn't answer the questions gives feedback on the education and support needed. This could include

drawings, charts, simple instructions or tasks, and recommendations within the patient's ability. Provider C described a process as,

Probably one area that's kind of typical is when we're talking about heart workups. We draw an illustration of the heart, the arteries, what the stress test shows us, what it doesn't show us and so on like that. So that's one area where I really feel like, and again probably in large part because of how crucial the heart is obviously

8. Creating a healing environment at all levels; subtle environment for energetic authentic caring presence.

The providers each described their office environment where the entire staff was involved with the patient care. They described bringing food, providing transportation and utilizing any community resources available to help support the patient. Provider F described the care of the patient as the responsibility of the entire practice, not just the provider:

We never considered the patients his patients and my patients. They were considered the patients of the practice. And that meant everybody. And so we always, the whole staff, had lunch together every day. So what we would do is, we would share information that the front office staff might have about the patient that I didn't know, I might have stuff that they didn't know, the nurses would have stuff. So it was the practice, truly was everybody in the practice, was taking care of the patient.

9. Reverentially assisting with basic needs as sacred acts, touching mindbodyspirit of other; sustaining human dignity.

Each provider described at least one situation where they and their staff needed to assist with the most basic of human needs; food, housing or significant social issues. The providers understood the need to meet these requirements prior to delving into chronic disease management. Provider A used other office personnel to assist patients, “we have a counselor and a social worker in our office, and so they spend a lot of time trying to help people to problem-solve their socioeconomic crises.” A person is unlikely to be able to engage in disease management if they have food insecurity, are couch hopping or are in an abusive situation.

10. Opening to spiritual mystery, unknowns-allowing for miracles

As with Caritas #3, miracles did not come out in the interviews with the providers. It would appear, since there was no mention of these two Caritas by any of the providers, that this is not a priority in their patient care. It may also not have been discussed because spirituality is a deeply personal belief that the providers may not have felt comfortable discussing.

Summary of Watson’s Caring Theory Application

The interview process did not specifically ask any of the providers about the aspects of Watson’s Caring Theory using the terms within the 10 Caritas. The interview questions were created to not be leading and biased towards the Caritas. The words trust, relationship, caring, help, communication, became evident during the analysis of the interviews. Two of the terms in the Caritas that did not emerge were spiritual and miracles. It is not clear if these are not part of the provider’s demonstration of care or if the interview questions did not explore this aspect of care.

It does appear through the analysis of the data, that the general principals of Watson's Caring Theory applying authentic relationships, creative problem-solving, and transpersonal practices underpin the relationships between provider and patient. These relationships allow the provider to understand and address issues of rurality, socioeconomic factors, patient educational needs and the disease management process. The providers interviewed expressed examples of caring through many interactions. They attempted to assist in making changes where they could and accepted where changes were not able to be made. They helped provide food, transportation, affordable medications, counseling and emotional support. They did not judge based on the socioeconomic situations the patient may have found themselves in but understood and helped the patient and family work through them. They did not want the patient to feel foolish so they were gentle and approached the patient in the way that worked for the patient. They each individualized the approach to the patient and situation, allowing the care provided to happen in a respectful manner.

Summary of Chapter

To investigate if Watson's Theory of Caring is used by providers to assist their chronic disease education of patients with suspected low health literacy, a phenomenological approach was utilized. Five rural providers who cared for patients in rural New England were interviewed. The interviews were recorded and transcribed verbatim. The transcripts were reviewed using multiple techniques. The first was van Manen's wholistic, selective, and detailed reaching approaches. The data was also reviewed with Saldaña's *In Vivo* and *Pattern* coding. The use of NVivo software confirmed the appropriate themes were developed and that no other patterns emerged that had not been previously identified. The following are themes that emerged and the codes that were assigned (in parenthesis)

- Rural patients have unique challenges in accessing healthcare and healthy choices (RUR)
- Chronic disease management is often secondary to acute and episodic care (DIS)
- Socioeconomic situations often negate the patient's ability to make healthy choices (SIT)
- Patient may lack the education or cognition to effectively manage their disease (COG)
- The trust relationships that providers and patients develop over time allow them to become partners in healthcare and disease management (REL)

These issues present in the themes were moderated by the provider's application of Watson's Caring Theory. By seeking words that relate to the three overarching premises of Watson's Caring Theory (authentic relationships, problem-solving and transpersonal practices), the researcher identified means by which the provider established and maintained a trust relationship which allowed both the art and science of medicine to be performed.

The following anecdote from Provider F. He described the interplay and potential outcomes of the themes and the application of Watson's Caring Theory in a provider/patient interaction:

Okay, so this elder farmer from _____ came to see me. And he was so bent over from having milked cow for so long, that his back and legs were like at a 90-degree angle. But when he came to see me, he always wore his best bib Sears overall. And his wife always came. And they have a dog, a miniature poodle, that never learned to walk because its feet never touched the ground. She carried it everywhere. So he came in ... I remember this because this is like one of my funniest stories ... He comes in and he holds his finger out, got it caught in a baler two weeks ago. And it was all gangrenous. It was just terrible. So I said, "Well, I don't think you're going to be able to save it." "Oh, I've been putting

that there drawing salve on it." And it's all just totally black. And, "Just give me some antibiotics." And so, okay, "I'll give you some antibiotics, but you have to agree to come back in two days." So okay. So there's the compromise. I knew what was going to happen, but, okay. And it's probably, it's certainly a non-judicious use of antibiotics. But it was the deal we made, okay. So he came back in two days, and my nurse says, "Yeah, I think he's here. I smell him in the waiting room." So he comes in, and it looks just as bad, if not worse. And she's sitting there. And I'm looking at it, and I go to touch it, and the dog starts barking at me because the dog thinks I'm going to hurt him. So I said, "I don't think we're going to be able to save it." "Yeah, that's right." I said, "I think it's going to need to be amputated." And the wife leans over and says to me, "Doc, will he be home in time for milking?" And I said, "I'm not sure, but I'll see what I can do." So I called up the surgeon. He did it under local anesthetic over in the Emergency Room, and the guy was home for milking.

In this scenario, each theme has been addressed. The provider acknowledged the culture of the rural patient to first use home remedies (drawing salve) and to go to the provider only when desperate after a farming accident (totally black finger as a result of going into the baler). Disease management (back and legs at 90 degrees from milking all his life) was not as important as the job he needed to do. He only went to the provider when his finger was black in hopes that antibiotics would reverse the results of the injury. The situational needs of the patient to be back on the farm in time to milk were respected by the provider who made arrangements for the finger to be amputated in a timely manner in the emergency department. The provider made a call to the surgeon to get this done in a way the patient could continue to work. The final theme addressed is the relationship. The provider first gave the patient the antibiotics he was

requesting, knowing they were not going to work. But in giving the prescription, the patient felt listened to and came back as promised for the follow-up. This provider knew the patient, respected his needs and worked within the boundaries for this patient and his wife.

Chapter 5

Findings and Recommendations

Introduction to the Chapter

There are some common themes that the interviews with these rural New England providers brought forth. Caring for rural patients often involves more than ordering medications and diagnostic tests to manage chronic diseases. These patients often have socioeconomic and situational limitations that need to be addressed before a patient is able to engage in disease management discussions. The patient may also have limited health literacy which, if not addressed, also limits their ability to understand directions from the provider and may inhibit their willingness to make the desired lifestyle changes as recommended. The trust relationship that the providers establish over time can be the bridge between the patient's situation and ability to make changes and their disease management outcomes despite social determinants of health that are not in the patient's favor.

Summary of the Study

This study intended to understand the experiences of rural Licensed Independent Providers as they support their patient's comprehension of chronic disease self-management when the patient is at risk of having low health literacy. The purpose of this phenomenological approach was to explore with a group of rural providers how they support their patient's chronic disease self-management through individual interviews with rural New England providers. The interviews were transcribed verbatim, then analyzed for themes. The analysis was done using a variety of methods including *wholistic*, *selective* and *detailed* reading as described by van Manen (2014) and using Sandaña's (2013) first and second cycle coding of *In vivo* and *Pattern* coding. The final stage of this phenomenological approach was to analyze the themes that emerged from

the interview data. The themes are related to the research questions and proposed theoretic framework. The analysis will answer the main research question: How do rural providers who have fewer resources available to them typically aid patients with low health literacy in disease self-management through authentic relationships, problem-solving and transpersonal practices? The application of this data will be discussed with the recommendations for further study. Analysis of the interviews resulted in the overall themes described in Chapter 4 and the major findings below.

Significance of the Study

The importance of this research extends beyond the interactions of providers with their patients and in all types of communities, not only rural. All healthcare workers are obligated to provide information to patients in a way they understand according to The Joint Commission, U.S. Department of Health and Human Services, U.S. Department of Disease Prevention and Health Promotion and The American Medical Association to name a few.

During the course of this research, I had an interaction with a colleague that highlighted the issue of health literacy understanding. The colleague had some patient education materials that needed to be reviewed for health literacy considerations as is hospital policy. The material was assessed for reading grade level using recommended readability scales. The result was the patient education handout was at a college level and included words and phrases such as: pathological tissue, neuro-anatomy, integrate, biochemical change, filament, and reflex arc. When I explained that the material was written at a college level and offered suggestions for how the material should be presented to patients with health literacy in mind, the colleague responded that the rewrite watered down the material too much and was then useless. The colleague also stated that since this procedure would only be offered on a cash basis, it is unlikely that patients

with low health literacy would be utilizing this service, the assumption being that only patients with low socioeconomic status would have low health literacy. This troubling interaction only solidifies the need for all healthcare workers to understand the incidence and impact of health literacy.

Education provided to physicians for Continuing Medical Education (CME) credits states, “It is important, however, to keep in mind that persons with limited health literacy do not fit into easy stereotypes. Indeed, one study of affluent individuals living in a geriatric retirement community found that 30% scored poorly on a test of functional literacy in healthcare situations,” (Weiss, 2007, p.11). Any patient, regardless of educational level, age, socioeconomic status, or profession can have low health literacy. According to the U.S. Department of Health and Human Services, only 12% of U.S. adults have proficient health literacy (<https://health.gov/communication/literacy/issuebrief/>). The impact of low health literacy on patients include poor disease management, decrease utilization of preventative screening and vaccinations, higher emergency room utilization, higher healthcare costs and poorer health outcomes (Weiss, 2007).

There is a perception in healthcare that if the patient is given a document with all of the risks and potential complications the entity is protected from legal action if something goes awry. True *Informed Consent* requires that the patient has a legitimate understanding of the information, not just a signature at the bottom of a document. Courts have consistently ruled that the physician is responsible for making sure the patient understands the document they are signing (Weiss, 2007).

Educating all who work in healthcare about the risks, impacts and outcomes relating to health literacy can have a positive effect on patient’s lives through better care, more compliance

with treatment plans and appropriate use of resources (Doak & Doak, 2010; Dicken & Piano, 2013; Nielsen-Bohlman, Panzer & Kindig, 2004). This research investigated the experience rural providers have when caring for patients at risk for low health literacy. The experiences the providers described highlight the everyday struggles of their patients and how the relationships they establish can support the patient's educational needs in chronic disease management. A study in Wales by Edwards, Wood, Davies, and Edwards (2012) discussed the use of health literacy as an asset rather than a risk. By helping patients develop their own health literacy the patient can become a partner in their disease management and better able to advocate for their own needs.

Another area of significance is that this study was done in a rural area. There is less research done in and about rural areas. "Progressives in government, universities, and nonprofits did not accord equal attention to the rural pathologies that resulted from the mechanization of agriculture and the oppressive class structure of many rural economies. For most Americans, rural poverty remains unseen," (Gurley, 2016, p. 591). Since rural populations have some unique challenges (including higher levels of poverty, food/housing insecurity, an aging population, less access to healthcare, lower educational levels and less healthy lifestyle choices), there are specific needs that must be addressed in order to support this population (Bushey, 2000; James, 2014; Bolin et al., 2015). People living in rural areas are more likely to have low health literacy due to the social determinants of health and research in the area of their needs may be of benefit:

Although there is a long-standing awareness of the health inequities for people living in the inner city, there is an emerging body of research acknowledging the importance of

rurality in social epidemiology as well as the vulnerability of this specific population (p. 620, Lutfiyya et al., 2012)

Research Questions

This research used interviews with six providers in New England to collect data on their experiences as rural providers who educate patients about their chronic diseases. Due to the patient demographics, these patients may be at risk for low health literacy.

The study was based on the following 7 research questions:

1. What information do providers look for to assess if a patient has adequate health literacy to manage their chronic disease?
2. How do rural providers creatively problem solve and coach their patients in chronic disease management?
3. What are the unique healthcare needs and limitations of patients living in rural communities and how do their providers address these needs and limitations?
4. How do rural providers impact chronic disease outcomes and quality of life through teaching patients how to manage their chronic disease?
5. How does the provider adjust their method(s) of education through informal assessments applying Bloom's Taxonomy and Maslow's Hierarchy of Needs?
6. In what circumstances have providers been taught about health literacy needs and risk factors associated with low health literacy?
7. In what ways do providers apply the 10 Caritas of Watson's Caring Theory as the bridge between their understanding and that of their patients?

There were 10 interview questions which were designed, with the help of the Advisory Group, to answer the research questions. The interview questions were linked to the research sub-questions as demonstrated in Table 2. Appendix E shows the relationship between research questions, interview questions, themes and findings.

Table 3. Link between the research questions and the interview questions that answered each sub-question

Research Sub-question	Interview Question #s
What information do providers look for to assess if a patient has adequate health literacy to manage their chronic disease?	6, 7
How do rural providers creatively problem solve and coach their patients in disease management?	8, 9
What are the unique healthcare needs and limitations of patients living in rural communities and how do their providers address these needs and limitations?	1, 2, 3
How do rural providers impact chronic disease outcomes and quality of life through teaching patients how to manage their disease?	6, 9, 10
How does the provider adjust their method(s) of education through informal assessments applying Bloom's Taxonomy and Maslow's Hierarchy of Needs?	2, 3, 9
In what circumstances have providers been taught about health literacy needs and risk factors associated with low health literacy?	4, 5
In what ways do providers apply the 10 Caritas of Watson's Caring Theory as the bridge between their understanding and that of their patients?	8, 9, 10

Research Question 1: What information do providers look for to assess if a patient has adequate health literacy to manage their chronic disease?

The providers interviewed highlighted their methods of informal assessment for health literacy as described in chapter 4. They discussed the types of questions they ask of the patients to check for understanding: "What did I say about this medicine?" "How often are you going to

take that medicine?’ ‘What foods are you eating?’ They also made assessment based on a lack of questions from the patient or questions that do not align with the situation, ‘‘They don’t ask the appropriate questions, they just don’t.’’, ‘‘Everybody shakes their head yes.’’ Since they often know their patients and their families, they have insight to the patient ability over time and not only for that one visit, ‘‘the longer you stay, the longer you’re at a place, the better you’re able to know the patients and the families and the better you know them, the easier it is to take care of them and the better you can take care of them.’’ They also relied on information from the office staff who may observe the patient’s inability to complete forms, asking their family member for assistance or stating they forgot their reading glasses, ‘‘We would share information that the front office staff might have about the patient that I didn’t know.’’

The signs that the providers observed are consistent with the experts in the field. Doak, Doak, and Root (1996) and Osborne (2013) describe situations in which the patient does not understand the instructions given. They site situations where the patient takes medications incorrectly, misses appointments, classifies information incorrectly (do not associate fried chicken with poultry), misinterprets instructions, and does not ask appropriate questions as cues that the patient has low health literacy. They describe how patients try to hide their difficulty understanding the information the providers give. Weiss (2007) provides case studies describing patients unable to complete questionnaires and forms, not knowing what their medications are for and undergoing surgery without knowing what the surgery was when she could not read the Informed Consent form.

Providers use a variety of information to help assess the patient’s need including specific questions about care, what questions the patient asked, observations from the staff as a whole, and knowledge over time about the individual and their family.

Research Question 2: How do rural providers creatively problem solve and coach their patients in disease management?

The providers interacted with their patients over time. This longer-term relationship allowed the provider to know the individual and family history. This wholistic view of the family and situations the patient had been involved in gave insight to what the patient can do at that moment: instead of getting rid of the pet, don't allow the pet in the bedroom, rather than taking that medicine four times a day, prescribed a medication that needed to be taken twice a day or having suggested home health visits instead of traveling to physical therapy. In many cases, they offer explanations in the way of pictures and drawings as described in chapter 4.

Health literacy experts describe providing information in small chunks that the patient can easily apply before moving on to more complex tasks (Bushey, 2000; Doak, Doak & Root, 1996; Weiss, 2007). Small and early wins established trust in the provider and success can breed success. They suggest using living room language, teach-back, printed material at a 5th grade reading level, and creating a shame-free environment.

The providers use their knowledge of the patient and their family to tailor their approach to what they know the patient is able and willing to do at that time. They recognized that small steps, achievable goals, and honest discussions helped the patient make progress in disease management.

Research Question 3: What are the unique healthcare needs and limitations of patients living in rural communities and how do their providers address these needs and limitations?

As highlighted in chapter 4, the providers all mentioned transportation being a limiting factor for rural patients. When patients do not have reliable or any transportation (and there is no public

transportation in most rural areas) it becomes an issue getting to appointments or getting to a store that sells healthy food options. Rural patients are often reluctant or afraid to leave their rural community to travel to “the city” for care even if they are able. Chan, Hart and Goodman (2006) report that rural patients travel two to three times farther to see medical specialists. Due to the distance, many patients rely on their local general practitioner to provide specialized care (Harris & Leininger, 1993). The providers overcome these limitations in access to specialists by becoming generalists in practice. Rather than referring to specialists they provide the care themselves in their office ranging from psychiatric/mental health care, dental care, diabetes education, and simple procedures.

The providers also indicated a lack of technology available to their patients. This is often due to the distance they patient must travel for high-level diagnostic tests (MRI, CT scans, nuclear stress tests, etc.). Reliable internet access can be inconsistent in rural areas making access to up to date information difficult. Fortune reported that 39% of rural Americans do not have access to fast and reliable internet (Darrow, 2017). The high costs of electronic medical records (EMR) systems are also limiting to small rural practices. Incentives offered to rural health clinics have helped rural providers adopt EMRs which can provide faster test results and improve outcomes (Hargraves, 2010). Some providers feel the EHR would be a detriment to the care they provide. Provider B stated, “I do not have a clinical EHR that can feed the information into it. I cannot spend my world looking at a computer screen checking boxes because it would be bad for my mental health, and it would slow my productivity.”

The providers interviewed have chosen to live and/or work in a rural area due to the lifestyle rural life offers. They recognized the limitations of transportation and access to specialists and technology in the form of diagnostic tests. Being aware of the limitation, the

providers recognize these and work within the geographic and technologic availabilities afforded them and their patients.

Research Question 4: How do rural providers impact chronic disease outcomes and quality of life through teaching patients how to manage their disease?

The providers interviewed described the constant need to educate and amend the education on a person by person basis as described in chapter 4. They each used drawings of some kind, either in a book or ones they drew themselves for the patient. They asked the patient to describe what was taught to check for understanding. They celebrated the small wins with the patient and made a plan for the next step. They also recognized when the patient was not ready or was unable to make positive changes to impact their disease and accepted that and thus the patient. The providers allowed themselves to be taught by the patient to establish a mutual relationship of trust and respect. This relationship allowed the provider to have the tough conversations when needed.

Smith, Wolf, and von Wagner (2010) identified the need of the health provider to ensure patient understanding of disease information through teach-back, use of clear and simple diagrams and charts, and patient empowerment. The relationship that the provider established with the patient allows for the empowerment and improved outcomes. “Patient satisfaction, adherence, and physical health outcomes were all associated with patient-activated consultations,” (Smith, Wolf & von Wagner, 2010, p. 197).

The providers all discussed the need to make the complicated information easier for patients to understand by using drawings, simple language, and teach-back to ensure they can start to take the needed steps to manage their disease.

Research Question 5: How does the provider adjust their method(s) of education through informal assessments applying Bloom's Taxonomy and Maslow's Hierarchy of Needs?

“The rural homeless in America include families with children, children who have been abandoned and runaways, single women and female heads of households, migrant and seasonal farm workers, elderly and mentally ill people with no one to care for them,” (Bushey, 2000, p. 127). This picture of homelessness and food insecurity are clear in the experiences of the rural providers in this study as demonstrated in chapter 4. Since the providers were involved with the patient over the longer-term, they knew the socioeconomic needs of the patient and their family. The providers were aware if there was food or housing insecurity, domestic abuse, drug addiction or mental health issues that became the priority for the family rather than chronic health management. Chronic disease management takes a back seat when the immediate needs for food and shelter are uncertain. Maslow's Hierarchy of Needs describes the need for basic human requirements to be met before higher level needs (Maslow, 2012). As a patient struggles with food or housing insecurity, abusive relationships, and depression the management of a chronic disease can seem inconsequential to the patient.

Bloom's Taxonomy (Anderson & Krathwohl, 2001) describes the cognitive process. The provider's assessment of the patient's ability to remember, understand, apply, analyze, evaluate and create is obtained through the questions the provider asks and the means that the patient responds to the question. If the patient cannot remember to take a prescription, the provider may recommend setting a daily alarm for the times the medication is due. To improve understanding, the providers used picture and drawings, they used graphs and charts to help a patient who struggled to know how much insulin to take for a specific blood sugar. The providers are asking questions, requesting the patient to explain back to them what they know and are giving

education in small chunks that can be digested and acted upon rather than giving all the information at once that overwhelms the patient.

When needed, the providers referred to other education specialists within the community such as diabetes educators, social workers, and home health to ensure the patient received the education and support over time. The providers also recognized when the patient was not at a physical or emotional place to be able to make recommended changes and respected those choices.

By using all the resources available to them in the forms of relationships over time, questions asked of the patient and the questions the patients themselves ask, the providers adjust their delivery of education to meet the patient where they are at in a way they can receive the information provided.

Research Question 6: In what circumstances have providers been taught about health literacy needs and risk factors associated with low health literacy?

All of the physicians interviewed declared they received no formal education in health literacy and in fact, asked the researcher for a definition of health literacy. Once a definition was provided, they all understood the concept as they personally experienced it in their own patients. They could identify situations where the patient did not understand what was taught and took the time to find an alternate method of educating about that issue. The nurse practitioner and physician assistant were more familiar with the term health literacy. This may be a function of a more patient-focused approach in their education instead of curriculum based on diagnostics and therapeutics. There was not a formal curriculum on health literacy but it was embedded in their clinical experiences.

The lack of training in health literacy is consistent with the research done by Dr. Coleman and colleagues (2010; 2011; 2012; 2013; 2015; & 2016) and Dickens & Piano (2013). Their research described the lack of formal training in health literacy. All of the providers expressed learning about the existence of and how to respond to health literacy as they worked with a variety of patients with multiple levels of ability and understanding.

None of the providers reported using any of the health literacy assessment tools such as: REALM, Newest Vital Sign, SAHL-S&E, and STOFHLA (Osborne, 2013). Most researchers recommended having a universal approach, assume that all patients have the potential for low health literacy (Osborne, 2013; Dickens & Piano, 2013; Weiss, 2007).

Regardless of the provider's lack of training, they were all able to identify when the patient had a deficiency of understanding and make adjustments in their approach to maximize results. I believe it is their own heart for patients that have brought them to the rural community. This love and respect for their patients enable them to educate in a way the patient understands and can appropriately respond to.

Research Question 7: In what ways do providers apply the 10 Caritas of Watson's Caring Theory as the bridge between their understanding and that of their patients?

Of the Ten Caritas in Watson's Caring Theory, it seemed the providers demonstrated consistent use of eight of the Caritas. In general, the providers were patient, took time to listen and to educate, they respected where the patient was in life without judgment and allowed the patient to make choices based on their own needs. The providers expressed true joy in caring for the rural patient with acceptance of their limitations and strengths. The providers acknowledged

being just one member of the team caring for the patient and that each member of the care team was equally important, this included the patient.

A summary of Watson's Caring Theory (Sitzman & Watson, 2014) describes three overarching premises: authentic relationships, creative problem-solving, and transpersonal practices. These principles are also described similarly by Cramm & Nieboer (2015):

Joint decision making and responsibility taking are achieved through open communication, cooperation, and mutual respect for each other, with negotiation of treatment options to accomplish mutually defined goals. Productive interaction between patients and professionals may be recognized by accurate, frequent and problem-solving communication that is supported by relationships based on shared goals and mutual respect (p. 898).

The providers recognize the patients are not going to make the needed lifestyle changes or follow the directions given by the provider if the patient doesn't feel respected or listened to by the provider. Watson's Caring Theory documents the components of these relationships and how it can affect patient care in a positive way.

Major Findings and Recommendations

Through analysis of the themes and how they can be applied to patient care as a whole, three major findings were uncovered. The first finding identifies that despite a lack or presence of minimal formal education in health literacy, the providers are able to assess the patient's abilities and needs in order to give the education appropriate for the situation and patient's level of understanding. The second finding reveals that the relationship between the provider and the patient can be a catalyst to improve the health of the patient. The third finding is that the Ten

Caritas described by Watson's Theory of Caring were interwoven in the interactions between the patient and provider. The interactions built mutual respect and trust which allowed for authentic interactions and care management.

Finding 1: Despite a lack or minimal training in health literacy, providers assessed patient needs and provided appropriate education and support

According to Dr. Clifford Coleman and colleagues (2010; 2011; 2012; 2013; 2015 & 2016), medical schools and residency programs provide little to no formal training in health literacy. Their research describes a few hours of education early on in the medical school curriculum but that it is not followed up upon. This is consistent with the physicians who were interviewed for this study. The nurse practitioner and physician assistant recall a small amount of education but felt it was embedded in their clinical experiences with their clinical instructors and preceptors.

Chapter 4 provided examples of the experiences of providers using different techniques to aid patient's understanding. All of the providers interviewed proclaimed little or no education on health literacy. Despite a lack of training, each provider described examples of using recommended techniques to ensure patient understanding: use of drawings, simple language, teach-back, asking questions and "living room language". How did they learn the health literacy skills? Did they choose to work in an environment where their natural skills in communication and collaboration were necessary to gain the patient trust and establish relationships? Or did they need to develop those skills over time in order to be successful in their environment with the patients in their practice?

There are certain characteristics that most rural providers seem to bring to their practice. They see the relationship with the patient over time as a key component of care. Since they are

working with a patient, and often the patient's entire family, there is the ability to build trust. The long-term relationships they build allow for authenticity and respect. This respect is a two-way street that both the provider and the patient establish over time. The providers enjoy the "characters" they get to interact with and "like rural people". They don't want the hustle and bustle of an urban environment. In that, their personality and personal/professional needs bring them to a rural practice where they can develop the kinds of relationships they value.

This does not mean they have health literacy figured out at the onset of their practice. The rural providers learn as they go what works, what cues the patient is giving them, and different options available to them. Provider C explained, "I haven't had a lot of training, but that's always been one thing that was fairly natural to me." "One of the things I will ask is to have them kind of repeat back to me what their routine will be like, or some possible changes they can make, whether it's nutrition. I'll ask them if they understand, sometimes I'll write it down," reported Provider D.

The providers would all benefit from some training and support in this area of health literacy. There are many online learning opportunities to the providers through professional and governmental organizations such as the American Medical Association, The Joint Commission, The Center for Disease Control, and many others. All healthcare workers can benefit from reminders on the risks for low health literacy and techniques that can be used when low health literacy is suspected (Doak, Doak & Root, 1996). There are many screening tools available (Doak, Doak & Root, 1996; Altin, et al., 2014) but they may not be practical as the assessment could take valuable time that can be better spent in the direct education of the patient. If a Universal Precautions approach is used, whereby the healthcare worker assumes the patient may have low health literacy (remembering that people with high literacy levels can have low health

literacy due to illness, stressors, age, etc.) and uses the techniques that have been shown to be successful.

Health literacy education for healthcare workers is easily accessible, free and in many ways common sense. Once a person is aware of the potential for low health literacy, the tools to help educate the patient are readily available. It is often as simple as changing the approach from, “Do you have any questions?” where the answer is almost always “No” to “Can you tell me when you are going to take this medication?” This allows assessment of the patient’s knowledge and how they will apply the information. If the patient is unclear, the healthcare worker can re-explain.

Health literacy awareness is promoted by respected healthcare experts and organizations. Reminding providers, through online resources or CME (Continuing Medical Education) programs are ways to support providers in the use of evidence-based health literacy techniques.

Finding 2: The relationship between the provider and the patient was a catalyst to improve the health of the patient

Cramm and Nieboer (2015) highlight the need for quality patient-professional interactions in chronic disease management, “high-quality chronic care delivery and productive interaction between patients and healthcare professionals are expected to lead to better patient outcomes,” (p. 897). They continue by stating, “Productive interactions are based on high levels of shared goals, shared knowledge, and mutual respect that together foster attentiveness to the situation and to one another,” (Cram & Nieboer, 2015, p. 898). Cramm and Nieboer highlight the need for relational competence which includes the, “ability to see patients’ perspectives, empathize with their situations, and respect their needs and choices,” (p. 901).

Each of the providers interviewed described situations in which they used the relationship they cultivated with the patient to provide education and support which demonstrates their relational competence. Examples were discussed in Chapter 4 through analysis and application of the themes. The providers expressed that they often need to address more basic needs of the patient before the patient was ready or able to attend to chronic disease management. These issues included the need for housing, food, mental health, acute pain, transportation, and safety. The provider's relationships with their patients allowed the patient to have a resource during times of crisis that develops trust and consistency for longer term disease management. This included smoking cessation, healthy food choices, exercise and the monitoring of disease indicators (blood pressure, blood glucose and A1C measures, shortness of breath, and weight to name a few). The evidence of the relationships was described through the bringing of food, going to school meetings with a parent, having tough conversations, compromise, and acceptance.

Experiences described in Chapter 4 describe how some of the providers were also able and willing to have some "tough love" conversations with patients when the situation and relationship warranted this discussion. It is unlikely these difficult conversations could occur or be effective if the providers had not established a relationship of trust through demonstrations of caring. Those discussions surrounding healthy choices, family relationships, mental health and disease management were created by an environment of mutual respect and trust. Jean Watson (2009) speaks of this need for relationships:

Practitioners and patients alike require caring relationships and healing environments, if caring healing practices are to be sustained within any healthcare setting. The evolving caring-healing practice environments are increasingly dependent on relationships,

partnerships, negotiation, coordination, new forms of communication patterns and authentic connections. This awakening includes a shift toward a spiritualizing of health, in contrast to the more conventional medical-clinical, techno-cure orientation to health and illness. (p. 470)

Providers who knew their patients could find the words and the tools the patient needed to work towards disease management. These tools can be honest discussions, problem-solving with the patient and needs assessments. When the patient and provider had a trust relationship, the pair worked in combination to find solutions to a healthier lifestyle.

Finding 3: Watson’s Theory of Caring was interwoven in the interactions between the patient and provider

In a rural setting where social determinants of health are multifactorial including biological, genetic, behavioral and sociological causes, there is a need for an understanding of the unique issues that are present in this specific population (Lutfiyya et al., 2012). The providers interviewed for this researcher exhibited the understanding of the community in which they serve as well as caring, compassion, respect, and love. “Transpersonal caring relationships are the foundation of Watson’s work. Transpersonal caring occurs when the one caring connects with and embraces the spirit of the other through authentic, full attention in the here and now, and conveys a concern for the inner life and personal meaning of another,” (Sitzman & Watson, 2014).

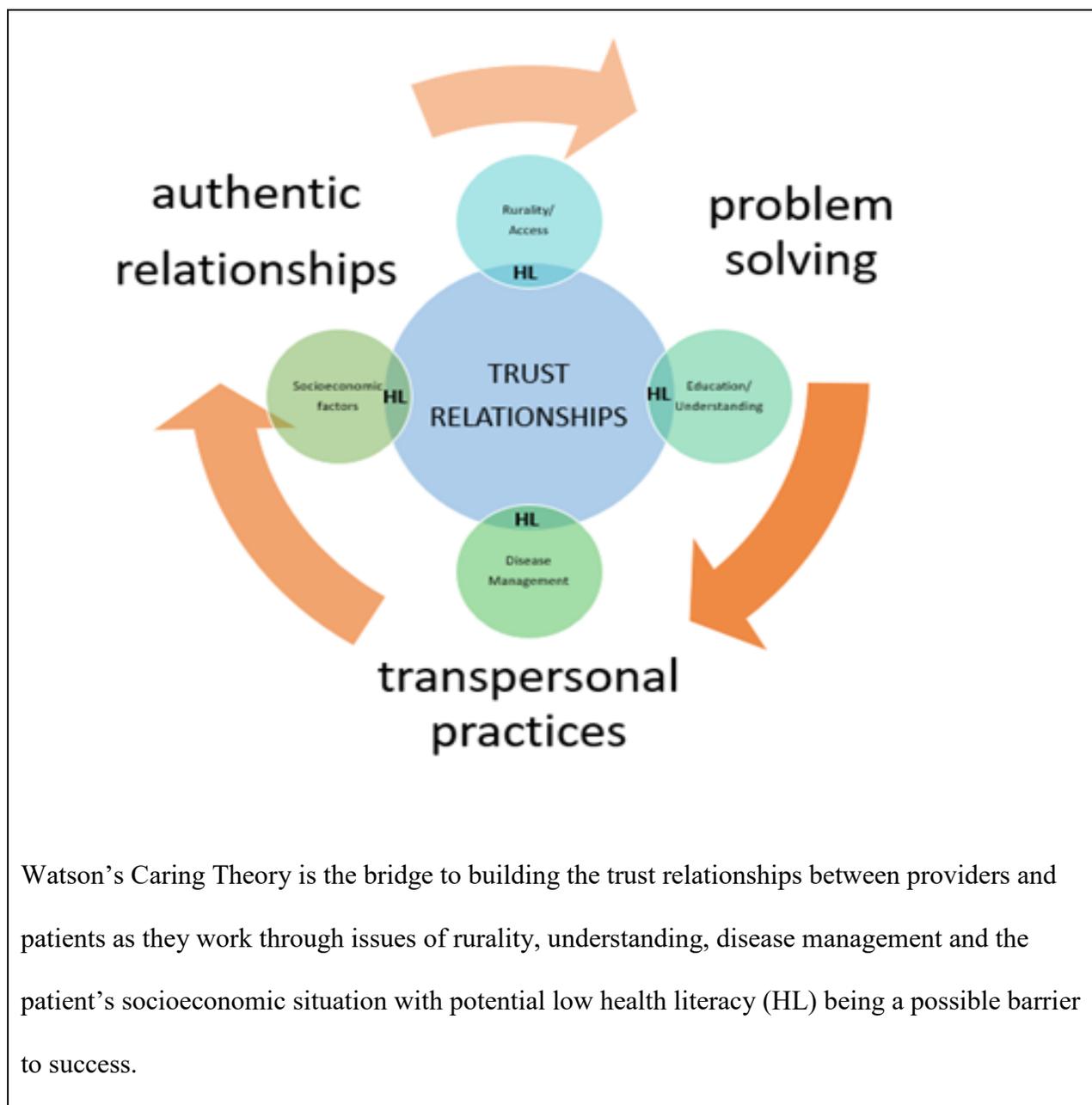
Each of the providers expressed their authentic relationships, problem-solving, and transpersonal practices in many ways. Often this was done by giving the patient the time they needed and accepting the patient as they were, as well as having a non-judgmental attitude towards the patients. There were examples of helping provide for most basic needs, going to

school meetings, having tough conversations, and appreciating the person as they are and the skills and gifts they displayed. The providers noted the need to accept when the patient was unwilling or unable to make the necessary changes to manage their disease or situation.

The interview process did not specifically ask any of the providers about the aspects of Watson's Caring Theory using the terms within the 10 Caritas. The interview questions were created to not be leading and biased towards the Caritas. The words trust, relationship, caring, help, communication, became evident during the analysis of the interviews. Two of the terms in the Caritas that did not emerge were spiritual and miracles which may indicate those are not utilized or if the provider did not feel comfortable discussing these aspects of care.

It does appear through the analysis of the data, that the general principals of Watson's Caring Theory (applying authentic relationships, creative problem-solving, and transpersonal practices) underpinned the relationships between provider and patient. These relationships allow the provider to understand and address issues of rurality, socioeconomic factors, patient educational needs and the disease management process. The overall relationships between these themes, the interaction of health literacy within the process, and Watson's Caring Theory are graphically represented in Figure 5.

Figure 5. The interplay of themes and findings



Revisiting the Theoretic Framework

The theoretic framework proposed in Chapter 1 included the characteristics of both rural patients and providers with Watson’s Caring Theory being a driving force in disease management. The framework was graphically represented by a flow diagram process. As a

healthcare practitioner, this “if-then” progression made sense to the researcher. Through the process of practicing a phenomenological approach, the representation of the theoretic framework morphed into a design that represented the inter-relatedness of the factors involved. The providers discussed the use of trust relationships to aid their patient’s disease management. The ever-changing circumstances of life and health are better represented by a circular pattern instead of the linear depiction of the connection.

Using a phenomenological approach to this study provided the opportunity to view these relationships in a deeper and more authentic manner rather than a strictly diagnostic process.

Limitations and Recommendations for Future Study

The phenomenological approach in this study has some limitations. The first is the small sample size. Six providers were interviewed in this study. Typically, in healthcare, large and quantitative, double-blind studies are the norm and most readily accepted. This study used a qualitative approach that utilized a smaller sample size with rich examples of the provider’s experiences. This sample size is appropriate for a phenomenological approach according to van Manen (2014) and Creswell (2013). The six providers were consistent in their approach to rural patient care and health literacy considerations. Their ability to support patients’ disease management without access to many medical specialists, high technology diagnostic testing, and other resources indicates that the same level of engaged care could be provided in most any health setting. They were not reliant on technology but on their own interpersonal skills.

This research included only rural providers in New England. There may be differences in the practices and patient populations in other rural areas of the United States. It is believed that this information is useful to practitioners regardless of where they practice. If these providers can make an impact on patient care through establishing trust relationships, that providers should

be able to apply the techniques used by these providers to engage patients in disease management. The research specific to rural populations can be applied to other rural communities where even more sociocultural determinants of health are prevalent.

This study also only obtained the providers' experiences. Future studies could include the patient voice through interviews and/or quality of life and disease management surveys. Getting the patient voice may gather information from the patient perspective that the provider does not have and gain more understanding on what the patient experiences in chronic disease management.

Another recommendation for future study is to investigate the different perspective of practitioners based on the type of education and training they received. Is there more or less training in health literacy for medical doctors, osteopathic doctors, nurse practitioner or physician assistants? Do caregivers entering these specific programs enter them because they have a bias or belief system that increases their sensitivity towards patient education and communication which makes some disciplines more or less attractive?

Research could be done to assess before and after health literacy training for rural providers. Researchers could investigate if patients feel the education they received was more appropriate to their needs after the training is completed.

Since the question of spirituality and belief in miracles in their patient care interactions was not directly addressed in interviews, further information could be gathered on this topic. Watson's Ten Caritas includes these two aspects of caring theory. There was no specific question about spirituality in the results. There were religious symbols in the offices of a couple

of the interviewed providers but since not all interviews took place in their practices, this was not able to be consistently observed.

Finally, research could be conducted comparing the rural providers to those in urban areas. Do both groups share the same experiences in caring for patients with suspected low health literacy? How are these issues mitigated in each setting? Are there different outcomes for rural versus urban patients?

Summary of Findings

This research adds to the body of literature in the realms of health literacy, rural healthcare and disease management. I asked the question: How do rural providers who have fewer resources available to them typically aid patients with low health literacy in disease self-management through authentic relationships, problem-solving and transpersonal practices? Through a phenomenological approach, six rural providers were interviewed to ascertain their lived experience in caring for and educating patients who have suspected low health literacy. The research investigated the possibility of Watson's Caring Theory (Sitzman & Watson, 2014) as the agent that enables education and support to be delivered through 10 Caritas summarized as transpersonal practices, creative problem-solving and authentic relationships.

Interviews were done with six rural providers. The interviews were transcribed verbatim and analyzed for themes and major findings. There were five themes identified through the analysis of the provider interviews:

- Providers described many rural patients as having unique challenges in accessing healthcare and healthy choices

- Providers report that patient often seek care for acute and episodic care. Chronic disease management is often secondary to this acute and episodic care
- Providers state that they believe socioeconomic situations often prevent the patient's ability to make healthy choices
- Providers state their patients may lack the education or cognition to effectively manage their disease
- The trust relationships that providers and patients develop over time allow them to become partners in healthcare and disease management

These themes were found to be consistent within all of the interviews conducted with the providers. The themes that came out of the data lead to three findings that relate back to the main research question: How do rural providers who have fewer resources available to them typically aid patients with low health literacy in disease self-management through authentic relationships, problem-solving and transpersonal practices? The three themes identified were:

- Despite a lack or minimal training in health literacy, providers assessed patient needs and provided appropriate education and support;
- The relationship between the provider and the patient was a catalyst to improve the health of the patient;
- The Watson's Theory of Caring was interwoven in the interactions between the patient and provider

These findings demonstrated the ability of providers, in spite of limited access to resources, can be a valuable support to the patient and their families. This is done by establishing a relationship during acute and episodic care that will develop trust in the provider. This trust relationship

allows the provider to encourage chronic disease management in ways that are achievable for the patient.

Jean Watson (2008) summarizes the interplay of the themes that came out of this research:

Learning is more than receiving information, facts or data. It involves a meaningful, trustful relationship that is intersubjective...there is an honoring of the whole person. The content as well as [readiness to receive] information are critical variables. The meaning the content has for the person-intellectually, symbolically, and culturally as well as literally-affects his or her ability to receive and process the information. The process of genuine teaching becomes transpersonal, in that experience, the relationship, and the meaning and significance of the experience affect both parties within the teaching encounter. Thus, the relationship lives on beyond the context of teaching, informing the life and behavior and actions that flow from the experience. (p. 125-126)

Relationships are not only crucial in the interactions between providers and their patients. These principals can be applied in the everyday exchanges at home, work, and play. Say things in a way that the person receiving the information can understand, know your audience, and above all care for one another. A trusting relationship can diminish misunderstandings and enhance the quality of life.

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Appendix A Institutional Review Board Approval

Proposal # 2017-036 Version # 1

Research Proposal Cover Page Issued by the IRB

The following is to be filled out by the principal investigator of the proposed study:

Researcher(s) involved with the proposed study:

Michelle M. Carner

Faculty Advisor (if Applicable)

Date Submitted: 8/4/2017

Address of Principal Investigator:

18 Sonya Rd. Milton VT, 05468
Michelle.carner@snhu.edu

Title of proposal:

What methods do rural providers employ to educate patients and provide care to patients with suspected low health literacy: a phenomenological approach

Type of Review: Exempt Expedited Full

The Decision of the Committee is as follows:

Approved

Approved with the following recommendations/ comments:

Disapproved

Comments:

Reviewer(s) Signature(s):

SLL mail

Chair, IRB

Date

[Signature]

Provost/Designee

8/22/2017

Date

Appendix B Informed Consent

Informed Consent/Assent for Participation in an interview

This informed consent form is for Licensed Independent Practitioners (LIP) providing care in a rural community who are willing to participate in research interviews for the dissertation titled, “What methods do rural providers employ to educate patients and provide care to patients with suspected low health literacy: a phenomenological approach” by Michelle M. Carner, M.Ed. at Southern New Hampshire University.

Part I: Information Sheet

Introduction:

I am Michelle Carner, a doctoral student at Southern New Hampshire University. I am doing research on the experience of rural physicians helping patients with low health literacy manager their chronic disease. You are being asked to participate in an interview as part of a dissertation study for a Southern New Hampshire University Educational Leadership Doctoral Program. I am going to give you information and invite you to be part of this research. Please read this form and ask questions of any aspect of the form and your participation. You do not have to decide today whether or not you will participate in this research. Before you decide, you can talk to anyone you feel comfortable with about the research. Your participation is voluntary. This consent form will summarize the research and the methods that will be used. Please stop to ask me any questions you have and I will take time to explain. If you have questions later, you can ask them of me or of my committee chairperson.

Purpose of Study:

The purpose of the study is to gather information on your experience as a rural medical provider caring for patients who have chronic disease and the potential for low health literacy. The interview will last approximately one to two hours and is held at the location of the participant’s

choosing. There will be five to eight providers interviewed at separate times. Participants will be asked what they experienced and witnessed in regards to assessing and caring for rural patients with low health literacy. If a participant does not feel comfortable answering specific questions for any reason, he/she does not need to answer. The interviews will be digitally recorded and transcribed to maintain accuracy.

Type of Research Intervention:

The research being done will include interviews with 5-8 Licensed Independent Practitioners (LIP) that care for rural patients. The interviews will last for 1-2 hours.

Participant Selection:

You are being invited to take part because you have the medical experience with rural patients that may have low health literacy. This research is specifically interested in how rural providers help their patients with low health literacy manage their chronic disease and your education and experiences can contribute to my knowledge of rural health needs.

Voluntary:

Participation in the interview is voluntary and you may stop at any time or skip a question you do not want to answer.

Procedures:

I will be asking you to tell me your experiences helping to support and educate patients about their chronic disease and how you assess their knowledge and motivation to make changes to impact their chronic disease. I will sit down with you in a location that you are comfortable, free from interruptions and distractions and confidential. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question. No one

else but I will be present during the interview. The interview will be digitally recorded and no one expect for me will have access to the interview or the transcripts of the interview. The recording will be electronically stored and password protected with only the researcher having knowledge of password. The recordings will be erased after the conclusion of the research.

Duration:

The research will take place over the course of four to six months. With each participant being interviewed one time for 1-2 hours. There may be a request for some clarifying information at a later date that could be obtained electronically through email, video conferencing or another means convenient for the participant.

Potential Risks:

It is possible that participants may recall difficult experiences regarding caring for patients who are involved in life altering decision making. This recall may evoke painful emotions from serious situations. The interviewer will actively be engaged to provide the safest environment possible.

Benefits:

Open and honest discussion about a very real situation can be cathartic but also awareness can bring forth understanding and solutions to providing culturally competent care and more self-awareness of how the provider communicates with his/her patients.

Compensation:

There will be no monetary compensation for participation.

Confidentiality and Privacy of Data:

The interview will be digitally recorded and records will be kept confidential, with pseudonyms used to later identify participants. The interviewer asks that the participants do not disclose any

protected patient information as required by HIPAA (Health Insurance Portability and Accountability Act of 1996). If you do not feel comfortable answering specific questions for any reason, you do not need to answer.

Access to the recorded interview will be limited to the researcher and transcriber of the recordings. Information obtained during the interview will be anonymous and no identifiable data will be used in any public presentation. The participants will have the opportunity to review the written study results prior to public presentation to ensure the accuracy of the results.

Sharing the Results:

Nothing you share in the interview will be attributed to you by name. The knowledge I get from this research will be shared with all of the participants before it is presented and made available to the public as part of the dissertation defense process.

Right to Refuse or Withdraw:

You do not have to take part in this research and you may stop participating in the interview at any time. I will give you an opportunity at the end of the interview to review your comments and you can modify your responses if you do not agree with my notes or if I did not reflect your experiences accurately.

Who to Contact:

If you have any questions about anything you have read here or regarding your participation in the interview, please direct them to the researcher, michelle.carner@snhu.edu or at 802-363-1540. If you have questions regarding your rights as a participant in research regarding human

subjects, please contact the Dissertation Committee Chairperson, l.murray-chandler@snhu.edu.

This proposal has been reviewed and approved by the SNHU IRB, which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about the IRB, contact irb@snhu.edu or 603-645-9695.

Part II: Certificate of Consent

I have been invited to participate in research about the experiences of rural providers caring for patients with low health literacy and how the provider supports the patient's educational needs of the patient with chronic disease.

I have read the foregoing information about the interviews and the research study. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Day/month/year

Appendix C Interview Questions

Title of research: What methods do rural providers employ to educate patients and provide care to patients with suspected low health literacy: a phenomenological approach

Demographic Questions

How long have you been in practice?

How long have you practiced in a rural Community?

Where did you go to medical school and do residency?

1. Why have you chosen to provide care in a rural community?
2. How have you experienced the impact of socioeconomic factors on a patient's disease management?
3. Describe the psycho/social/economic or medical characteristics of your practice's patient population.
4. Tell me about the education you have received on health literacy.
5. How has that education influenced your assessment of the patient's ability to learn and their motivation to make changes in chronic disease management?
6. What are some of the most complicated chronic diseases about which you educate patients?
7. How do you know when a patient does not understand the education you are providing to them?
8. Tell me about a time when you adjusted your education delivery method to the patient based on some kind of formal or informal assessment of their educational needs.

9. Describe a situation where there were psycho/social/economic/medical barriers that influenced the patient's ability to manage their disease. What did you do to coach the patient through those barriers?

10. When you have educated a patient with suspected low health literacy, what are some positive outcomes you have been able to witness?

Appendix D Codes, In Vivo and Pattern

In Vivo and *Pattern* Codes from Interview Transcripts

	<i>PATTERN CODE</i> COG-words/phrases that indicate the provider was assessing the educational needs of the patient and what they did to help the patient understand their disease process and management
<i>In Vivo Codes</i>	
	ability to change
	ability to do it
	able to learn
	able to manage
	accept
	address it slowly
	ADHD
	ask appropriate questions
	ask them
	assessment
	assuming
	baby steps
	bite sized chunks
	blank look
	calculators
	called stupid
	can understand
	can't come up with a plan
	can't get there
	can't read or write
	change way I'm explaining
	cognitive disability
	cognitively impaired
	compliance
	confused
	confusing

	describing
	didn't understand
	different methods
	doable
	don't always tell you
	don't want to look stupid
	draw it
	drawing picture
	educating
	education about their health
	feel empowered
	feel like they can follow through
	feeling motivated
	figure out
	finding the language
	forgetting
	give measures
	goals
	got on the computer
	graphs
	handouts
	have the ability
	help school understand
	how often
	how you can read it
	I go back
	if they don't get it
	illustrate
	intellectual level
	interpreter
	IQ below 70
	language
	language barrier
	learned something
	learning level
	limited in cognitive resources
	little goals
	low cognitive function
	magic words

measures
mental disability
motivational interviewing
multiple intelligences
multiple things at one time
need assistance
nonverbal cues
not asking
overwhelming
questions they are asking
rationale
reading labels
ready to talk
real importance
reinforcement
repeat back to me
repeat back to me
repeat it again
retardation
retreated in school
routine
seeming confused
shakes their head yes
show them
small chunks
small pieces
some can understand
something simple
spell it out
timing
to think about
understand
understanding correctly
understanding how to use it properly
utilize language
very concrete
very low education
what did I say
what types of things are healthy

	work on your number
	write it out

Pattern Code DIS-Words/phrases that indicated the providers involvement with disease management or the inability to focus on disease management

In Vivo Codes

A1C
 anatomy book
 anxiety
 ask for penicillin
 asthma
 bad teeth
 bloodwork
 BMI
 CHF
 chronic depression
 confirm diagnosis
 COPD
 depression gets in the way
 dialysis
 drug addicted
 eat healthier
 emergency care
 healthy choices
 hook you up to a machine
 horrendous-looking mouths
 how many cigarettes
 immunizations
 inhalers and nebulizers
 killing
 maintain their health
 medications
 medicine
 minimizing the risks
 motivational interview
 multiple things
 not dealing with prevention
 nutrition

one thing they can do
 overutilization
 pain
 parental mental illness
 pets
 physical exam
 physical response
 physicals
 prevention
 psychiatric
 reduction
 send home health
 smoking
 stress test
 studies
 substitute
 take care
 take this medicine
 time to call
 treat if I feel it's appropriate
 UpToDate
 vaccines
 wasn't getting better
 weight is dropping
 you weren't dying

Pattern Code REL-words/phrases that indicate a caring, trust-relationship between provider and patient

In Vivo Codes

access to me 24/7
 amount of time
 be patient
 building relationships
 can call me
 communicate
 consistent
 consultant
 counselling
 enlighten me

enlighten them
enlist other family members
every time
expert
finding the language
for them
frank conversations
frustrated
give a high-five
gone to school meetings
good job
It's always a deal
I've enjoyed what I do
judgmental
know where your heart is
leave with a smile
lightbulb moment
long, linear care
longer term
love taking care of patients
maintaining a relationship
mom was happy
multi-generational
negotiation
not always easy
nurses bringing in food
one area I'm strong
painfully hard
partner
plan that's gonna work
problem solve
rapport
real importance
really care
relating
relationship
several touches with me
shepherding experience
spend a lot of time
supportive

taking care of family
 talk down to patients
 they can tell if you care
 they could run circles around me
 they're in charge
 tough cookie
 tough love
 trust relationship
 upset
 we talk
 weird interaction

Pattern Code RUR-words/phrases pertaining to rural life and barriers patients experience as a result

of living in a rural area

In Vivo Codes

barrier
 can't get a test done
 dance
 distance traveled
 don't have all the studies
 don't have the option
 don't have the resources
 don't want to drive
 garden
 home in time for milking
 how to run a farm
 illegal alien
 indigent
 lack of access
 lack resources
 less health food stores
 limited financially
 manage more
 need a car to get anywhere
 not very many gyms

plenty of outdoor space
 psychiatrist not available
 reach out to farms
 specialist not available
 sports
 Transportation

Pattern Code SIT-words/phrases that indicate the patient's situation is a barrier to health and disease management

In Vivo Codes

a lot of them smoke
 affording medications
 alcohol
 assaulted
 can't afford it
 can't afford to eat healthy
 crisis
 crisis they're dealing with
 devastated
 don't have high income
 drug addicted
 eat health
 environment is unfathomable
 families not traditional
 family chooses
 family lives
 feed everybody
 finance
 get clean
 give them a ride home
 heat and electricity turned off
 housing situation
 illegal
 impacting the kids
 incarcerated
 indigent
 isolation
 its pain

jail
lack resources
limited financially
live in poverty
live paycheck to paycheck
multi-generational Medicaid use
next meal
not being worth anything
not paying bills
out of hole
pay for my rent or buy groceries
poverty
psychiatric part
quality of life is compromised
re-offended
restraining order
right now
self-medicating
situation in life
socioeconomic crisis
socioeconomic ills
stress levels
successful
survive
too cold
transportation can be a hindrance
weight is dropping
where they are going to sleep

Note. *In Vivo* Codes were identified in transcripts. The *In Vivo* codes were then grouped into *Pattern* codes COG=cognitive; DIS=disease management; REL=relational; RUR=rural; STI=situational

Appendix E

Relationship between Research Questions, Interview Questions, Theme and Findings

Research sub-question	Interview questions	Themes	Findings
What information do providers look for to assess if a patient has adequate health literacy to manage their chronic disease?	6, 7	COG/DIS	1
How do rural providers creatively problem solve and coach their patients in disease management?	8, 9	RUR/DIS/SIT	1 & 2
What are the unique healthcare needs and limitations of patients living in rural communities and how do their providers address these needs and limitations?	1, 2, 3	RUR/COG/SIT	2 & 3
How do rural providers impact chronic disease outcomes and quality of life through teaching patients how to manage their disease?	6, 9, 10	DIS/RUR/ COG	1, & 2
How does the provider adjust their method(s) of education through informal assessments applying Bloom's Taxonomy and Maslow's Hierarchy of Needs?	2, 3, 9	SIT/RUR/COG	2 & 3
In what circumstances have providers been taught about health literacy needs and risk factors associated with low health literacy?	4, 5	COG	1