RURAL SENIORS' MEDICATION ACCESS: THE PROBLEM OF STRUCTURAL HEALTH LITERACY IN THE SAN LUIS VALLEY

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Thesis directed by Professor Steve Koester.

ABSTRACT

Purpose: The purpose of this study is to explain the major barriers to medication access in rural seniors. How seniors access their prescription medications and make choices access helps to explain what seniors consider to be major barriers. This project has five goals: (1) describe what barriers rural seniors perceive that hinder access to their medicines and thus interfere with adherence to prescribed medication regimens; (2) understand what seniors perceive to be facilitators to accessing their prescriptions; (3) learn how or if social support networks play a role in helping rural seniors make decisions about how to use their resources to get their medications; (4) define the process that rural seniors use to move from potential access — the desire to get their medications, to revealed access — the actual ability to get their medications; and (5) describe what health care providers believe are the barriers that rural seniors face to getting their medicines.

Methods: I interviewed 19 low-income seniors in five towns in the San Luis Valley using semi-structured interviews, along with one pharmacist from each of seven pharmacies. A card study was conducted in nine clinics of the Valley Wide and Rio Grande systems. The interviews were coded using the grounded theory method. The card study survey was administered to primary care providers in eight clinics to gauge understanding of elderly patients' potential for barriers to access of medications.

Results: The primary finding is that poor structural health literacy (SHL) is the major barrier to access of medications, and to healthcare access generally. SHL is a factor in the more widely discussed barriers such as cost and transportation.

Discussion: SHL increases the chances that seniors will have access to healthcare by helping seniors learn how to take advantage of programs that enhance their ability to afford medications. Public Health agencies must work with community leaders to ensure that seniors are aware of their options for accessing medications, including financial and transportation options.

The form and content of this abstract are approved. I recommend its publication.

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TABLE OF CONTENTS

CHAPTER I

INTRODUCTION

In healthcare, "disparity" has become a buzz word that attempts to convey the disconnect between the access that people should have and the access they do have, while, at the same time, putting the onus on individuals to be responsible consumers of healthcare and "take care of themselves." The myth of "personal responsibility" permeates the American healthcare culture and, through the structural organization of the healthcare system, increases the very disparities that clinicians, policy makers, and scholars would like to eliminate. Through an investigation into the barriers that preclude access by elderly rural residents to their medications, I address the problem of a mismatch between what rural seniors know about the healthcare system and what they need to know to increase their access. While the operationalization of "access" is debated in the literature (see Definitions below), in this study, medication "access" means the ability to purchase prescribed medications, and healthcare "access" means the ability to receive healthcare from a professional provider.

In healthcare, disparities are well documented in non-dominant groups that include the poor, minorities, and the elderly. This study investigates the structural problems that lead to disparities in the access to medications by low-income, elderly people living in the rural San Luis Valley of Colorado, the link between access and adherence, and how they make choices if they do not have consistent access to their medications. I address the gaps in the literature about medication access and challenge readers to look beyond the myth of "personal responsibility" that blames seniors for their poor level of adherence to treatment plans prescribed by their healthcare providers.

As I describe throughout this manuscript, seniors' adherence to their medications has implications for their general health and well-being, yet there can be no adherence without access; access and adherence are two sides of the same coin. The importance of this study lies in understanding the multiple ways that rural seniors cope with access problems and the battles that seniors fight with the structures that make up both the healthcare system and the entitlement systems on which seniors often depend. The concept of access to medications is important to seniors because having their medicines can both improve their quality of life and increase their life span (Chia, Schlenk, & Dunbar-Jacob, 2006; Hiscock, Pearce, Blakely, & Witten, 2008). Conversely, lack of access results in the inability to adhere to a prescribed medication regimen, which, in itself, produces consequences that range from increased morbidity, including adverse drug events, to institutionalization and death (Paez, Zhao, & Hwang, 2009; Wroth & Pathman, 2006). I hope to add a different dimension to the conversation being waged in professional circles about how to support low-income seniors so that a more equitable distribution of healthcare services may ensue.

The overall aim of this study was to understand how seniors in the San Luis Valley make choices about their prescription medication if they have inconsistent access. This project has five goals: (1) explore barriers that hinder rural seniors' access to their medicines and thus interfere with adherence to prescribed medication regimens; (2) understand what facilitates access to prescriptions; (3) learn how social support networks play a role in helping rural seniors make decisions about how to use their resources to get their medications; (4) define the process that rural seniors use to move from potential access — the desire to get their medications — to revealed access, the actual ability to get

their medications (Lin, Crawford, and Salmon, 2005); and (5) explore what health care providers believe are the barriers that rural seniors face to getting their medicines.

Establishing the Problem

The San Luis Valley, home to approximately 46,000 residents in an area about the size of New Hampshire, has a density of 5.6 persons per square mile.[1] The population of the Valley is aging, with the median age at 42.9 years compared to the rest of Colorado with a median age of 36.1. People over the age of 65 comprise nearly 15 percent of the population of the Valley overall; however, in some counties, the elderly population is over 20 percent. In nearly every town in the Valley, the population has decreased in the last decade. The average weekly income of $563 is well below the state average of $901. The poverty rate for residents over 65 in the counties that I studied is 16.7 percent, double the state rate of 8.4 percent. There are seven pharmacies in the Valley, mostly concentrated in a one-square mile area in Alamosa, which is roughly in the center of the 8,000 square mile Valley.

The problem of access to medication is widespread in rural areas. The literature on medication access in rural elderly populations is scant, focusing mainly on cost and distance barriers that are prevalent in rural areas. Furthermore, little is known about how seniors who live in rural areas deal with poor or inconsistent access to medication; thus, the research questions guiding this study are:

1. **What barriers prevent seniors living in rural areas from having consistent medication access?**
    a. **How do seniors cope with barriers?**

[1] All statistics from the 2010 Census. See Appendix H.

2. **What do providers perceive are barriers to rural seniors' ability to access prescription medication?**

Studies show that rural seniors are more likely to be low income, have less education, suffer from chronic diseases, and take more medications than urban seniors (Cromartie, 2009; Hart, 2000; United States Department of Agriculture Economic Research Service, 2004). Low-income elderly adults living in rural and frontier areas of the United States are at high risk of morbidity and mortality from drug-related causes that include the inability to get the medicines they need to counteract chronic diseases. Hiscock and her colleagues (2008) report that unequal access to health care and, by extension, medications may explain up to 15 percent of socioeconomic differences in health and mortality. For example, Soumerai and his colleagues (2006) showed that nearly 30 percent of disabled Medicare beneficiaries were non-adherent as a result of medication costs, and people with multiple comorbidities had much higher rates. Compared to those with private insurance, uninsured people had 2.5 times greater odds of reporting that they were unable to get their prescriptions (Shi, Lebrun, & Tsai, 2010). In 2007, about 10 percent of the non-institutionalized population of the United States were either unable to get or experienced a delay in getting their prescriptions in the previous 12 months (Chevarley, 2010b).

People aged 65 and older make up 20 percent of the total U.S. rural population (National Rural Health Association, 2013). Of the total rural population, seniors account for a larger proportion of the total U.S. rural population — nearly 15 percent compared to seniors in urban populations (American Public Health Association, 2005; Kaiser Family Foundation, 2002; Lin, 2004; U.S. Census Bureau, 2010b) but account for 34 percent of

prescription medication use. Of the population between 75 and 85 years old, 36 percent take five or more prescription medications (Rochon, 2012), and of those aged 65 years and older, 60 percent have at least three medications prescribed (Morton and Weng, 2013).

Seniors who are minorities have an especially difficult time with medication access and adherence, often because of language or cultural barriers. In fact, minority ethnicity (non-white populations) is a negative predictor of adherence among the elderly (Shi et al., 2010). Together with the unique rural culture (Foster and Frazier, 2008; Goins, Williams, Carter, Spencer, & Solovieva, 2005) that may breed mistrust between seniors and health care providers (Balkrishnan, 1998), rural minority seniors are less likely to get medical care than white seniors, and they tend to wait longer before seeking care (Shi et al., 2010). These seniors often have different cultural practices that may include the use of alternative treatments and medicines, healers, differences in health beliefs, gender roles, and what constitutes taking personal responsibility for their health from the mainstream health care practitioners who may have moved to the area from an urban center.

Access and Adherence

Tinetti and her colleagues (2004) estimate that 20 percent of Medicare recipients have at least five chronic conditions, and 50 percent take at least five different medications. Consider that a senior who has type 2 diabetes, osteoporosis, hypertension, arthritis, and chronic obstructive pulmonary disease would be prescribed 12 different medications (Rochon, 2012) and would probably take over the counter (OTC) medicines for the occasional headache, medicine for a cold, and perhaps a multivitamin. Such a

conglomeration of medications could be detrimental if the medications are not taken in their proper order or if medicines are skipped.

The consistent and proper use of prescribed medication regimens can be a factor in controlling the effects of the multiple chronic illnesses, yet seniors who want to get their medications (potential access) but cannot, will have problems adhering to prescribed medication regimens, which is essential to achieving the therapeutic results of the medication. If a patient is taking medicine differently from the way that it is intended, which includes skipping doses or taking smaller doses, treatment benefits are reduced. Researchers believe that between 30 to 50 percent of cases, where the patient is not adhering to their medication regimen, fall short of the therapeutic goals (Wroth and Pathman, 2006).

The consequences of poor access and the resulting inability to adhere to medication regimens are costly in terms of quality of life as well as dollars and cents. Complications of non-adherence include increased morbidity and mortality, poor prognosis, and increased emergency room visits and hospitalizations (Chia et al., 2006; Hiscock et al., 2008). Furthermore, non-adherence increases the chances of institutionalization for the most frail elderly (Wroth and Pathman, 2006).

Another concern of rural seniors is the decreased access to pharmacies that provide them with their medications. This study investigates the nature of pharmacies and the role that pharmacists play in seniors' access to their drugs. There is a body of research that shows that access to rural pharmacies is diminishing due to factors like pharmacist attrition, closure of pharmacies, and the increase in telepharmacies and mail-order pharmacies (Boyle, Ullrich, and Mueller, 2011; Klepser et al, 2008; Richards, n.d.). As a

result, seniors have less contact with pharmacists, who are often the most accessible health care providers in a community (Sunderland et al, 2006). In fact, during this study one of the four remaining independent pharmacies in the San Luis Valley went out of business.

Pharmacists assist seniors with everything from instruction on the proper use of a medication to filing Medicare and Medicaid paperwork (Xu and Rojas-Fernandez, 2003). Barriers to pharmacy access impede seniors' ability to take advantage of pharmacists' knowledge and monitoring of their multiple drugs. When a senior has limited or no access to a pharmacist, he or she loses one layer of scrutiny and healthcare. Given the multiple medications that many seniors need, it is imperative that they have access not only to their medications but also to a pharmacist who can monitor drug interactions and help them with information about how to safely take medications.

Barriers to prescription medication access take many forms, some more easily identifiable than others. Regardless of the type of barrier that a senior encounters, he or she must find ways to cope and navigate through the hardships. How providers, including pharmacists, perceive barriers that seniors face can be a factor in what medications are prescribed, what types of regimens are recommended, and how information and instructions are given to seniors and/or the people who help them. Coping with barriers to medication access is a topic that has implications for health care professionals and policy makers; for example, understanding what facilitates seniors' access to medications and what hinders access can influence adjustments to prescribing methods and policy and affect how seniors are perceived relative to their ability to take personal responsibility for their adherence.

Seniors' ability to take responsibility for their health is often challenged by structural factors that impede their access to medications. Structural factors like a lack of public transportation, long travel distances, geographic isolation, poverty, and misunderstood cultural practices are common in rural areas (Rosenbloom, 2003). Institutional structures such as government and corporate policies play an even bigger role, as will be seen.

Theoretical Background

In trying to understand the factors that either facilitate or decrease medication adherence in the elderly, numerous theoretical constructs, frameworks, and models have been used by scholars and clinicians including Health Belief Model, Cognitive Aging Theory, Behavior Care Utilization Model, Self-efficacy framework, Theory of Planned Behavior, Transtheoretical Model, and more (see Appendix A). The primary focus of studies using these models and frameworks is to understand why seniors do not adhere to medication regimens and to find ways to increase adherence. What these models have in common is that there is an underlying assumption that seniors' medication nonadherence is primarily a function of the aging process that includes cognition, attitudes, self-efficacy, and beliefs that develop as a result of growing older. Furthermore, each of these models puts the onus on the individual to be responsible for his or her adherence because overall, the models do not consider whether or not medications are accessible.

The major theories and frameworks that are cited in the literature explain parts of the indicators of adherence such as whether a senior believes that he or she needs the medication, but no theoretical framework explains how seniors make decisions about what to do when they cannot access their medications. Furthermore, these theories, while

touching on some external factors such as cost, rarely take into account a senior's multiplicity of concerns, both with regard to their health as well as other urgent life issues, as factors that influence decision-making regarding how, when, or why to adhere to a particular medication regimen when access is a concern. As researchers have asked why seniors do not adhere to their medication regimens and what would make them adhere, various interventions have been either tried or suggested. Some of the interventions have included educating seniors using written materials like pamphlets or handouts. Other interventions rely on the health care provider to educate the senior and monitor the senior's adherence either in person or remotely. Still other interventions have nurses developing strategies tied to their understanding of a senior's medication-taking routine.

In a study of medication adherence, Murray and his colleagues (2004) cite the use of Cognitive and Behavioral Theory, Behavior Care Utilization model, and Cognitive Aging in an attempt to alleviate non-adherence in seniors. They discuss how aging affects memory and comprehension and the idea that many seniors have low health literacy. They suggest that providers should address the barriers that are related to aging such as improving seniors' comprehension and communication by providing them with handouts in large print and using simple language and icons to relay information about medications and how to take them. They also point out that providers could use cues that help seniors remember to take their medicines and also cues that remind them when the dose has already been taken. The Behavior Care Utilization Model is suggested as a means to understand the effects of age-related factors on medication adherence and to relate choices to environmental and population characteristics. Ultimately this meta analysis concludes that increasing adherence in older adults will require a multidimensional series

of strategies that consider age-related, environmental, and social factors; however, what those strategies might be is not spelled out.

The Health Belief model is cited in several studies (Balkrishnan, 1998; DiMatteo, 2004; M. J. Johnson, Williams, & Marshall, 1999; McElnay, McCallion, Al-Deagi, & Scott, 1997) as a predictor of adherence. In each of these studies, the Health Belief model is used as a framework from which to understand how to get seniors to adhere to their medications. Each author, however, has a different method for understanding adherence using this model. Johnson and his colleagues (1999) focus on how nurses can develop strategies for patient adherence once the nurse understands whether the patient has a medication-taking routine as a result of the patient's belief that he or she needs the medication. Balkrishnan (1998) did a meta-analysis of studies on predictors of adherence in elderly patients from 1962 to 1997 that showed that understanding of medication adherence in elderly patients is incomplete but that patient education programs should be targeted to non-white seniors in order to improve medication adherence. DiMatteo's (2004) meta analysis of 733 studies that used the Health Belief model, along with other theories and frameworks including the Theory of Planned Behaviors and Transtheoretical model to analyze how researchers focus on "understanding, predicting, and improving adherence" (p. 200), concluded that after 50 years of research there is not enough data to adequately conclude why patients do not adhere to their medications. She further concluded that additional conceptual studies are needed to "focus on the meaning of adherence" (p. 208).

McElany and his colleagues (1997) showed that counseling and education improve adherence; however, in attempting to create regression models for adherence, a

number of theories were used. The Health Belief model explained 20 percent of variability when combined with the Theory of Reasoned Action. When used alone, the Health Belief model accounted for only 10 percent of variability. When used with other models, including Health Locus of Control Model, Health Decision Model, and Rotters Social Learning Theory the results were inconclusive. Thus, McElany and his colleagues (1997) concluded that a strong model for adherence does not yet exist.

Finally, Osterberg and Blaschke (2005) looked at self-efficacy as a theoretical framework for adherence. They concluded that adherence is enhanced by a simple regimen, customization to the patient's lifestyle, and an emphasis on the importance of the medication. They further suggest that new technologies such as cell phones and pillboxes with paging systems might be useful in helping patients adhere.

While studies on adherence are numerous and have been carried out for decades, the studies and meta-analyses mentioned above are a representation of the extant literature on adherence by the elderly. What these models and studies have in common is that they all assume that seniors have access to their medications and that they should take personal responsibility for adherence. In many of the models, providers are admonished to educate, monitor, and counsel seniors, thus taking on the responsibility for seniors' adherence. The other commonalities are the absence of social science theory (Burke, Joseph, Pasick, & Barker, 2009) and the complete disregard for the social context and structural factors. These representative studies are illustrative of the "blame the victim" mentality rampant in adherence literature.

Definitions

Access

Disagreement on the definition of "access" is only surpassed by the attempt to operationalize it. "Access" is defined differently throughout the health literature (Aday and Andersen, 1974). Definitions include anything from entry into the health care system to "socio-organizational attributes . . . of the resources, other than spatial attributes, that either facilitate or hinder the efforts of the client to obtain care" (Aday & Andersen, 1974, p. 209). One definition in the literature relates to the ability to gain entry into the health care system and the availability of services when and where they are required (Aday & Andersen, 1974; Hart, 2000). Another definition relates to characteristics of people and their ability to access care. These characteristics may include age, race, or sex; community characteristics such as those found in rural or urban areas; financial resources; or structural resources (Aday & Andersen, 1974).

What access is not is another component of available definitions; access is not "the mere existence or availability of resources at any given time" (Aday and Andersen, 1974, p. 210). The "Healthy People 2020" (2013) Web site states, "access to health services means the timely use of personal health services to achieve the best health outcomes. It requires three distinct steps: 1) gaining entry into the health care system. 2) accessing a health care location where needed services are provided. 3) finding a health care provider with whom the patient can communicate, and trust." Thus, even if care is available to a patient, if it is not used, there is no access. Often, the concept of access is described from a political standpoint, but rarely is there agreement as to the definition, and the definitions are dependent on circumstances. For example, Aday and Andersen

(1974) believe that health policy is the starting point for access because policy has a direct effect on the health delivery system. Access is also commonly defined as the ability and/or willingness to use the available health care system (Penchansky & Thomas, 1981).

Based on the literature and the varying definitions of access, for the purpose of this study, "access" is conceptualized to mean the ability of patients to purchase prescription medications in sufficient quantity to follow a health care provider's recommendations without the need to sacrifice other basic needs such as food, housing, or transportation. In other words, if a senior only has enough money for either food or medicine and chooses medicine, that does not constitute access.

Barriers

As noted in the literature review, there are multiple types of barriers to access. Barriers are conceptualized as any obstacle(s) that interferes with seniors' ability to get their prescribed medications. These obstacles may be structural, political, social, cultural, or even temporary, e.g. weather-related. They may include advice from members of the senior's support network that dissuades a senior from purchasing a medication, fear of a medication's effects, an injury that prevents a senior from driving, a policy that hinders availability, or any other perceived obstacle.

Facilitators

As noted in the literature review, indicators of access are those that increase the chances that seniors will be able to get their medications; as such, those indicators act as facilitators. Social support may facilitate seniors' ability to get their medications; thus, facilitators are conceptualized as something or someone that makes it easier for a senior

to get their prescribed medications. Facilitators may include social support, medication that is stocked by a provider, the operating hours of a pharmacy, or money to pay for food and living expenses.

Rural

The term "rural" has multiple definitions that relate to distance from urban centers, lifestyle choices, types of industry, and government definitions (K. Mueller, Slifkin, Shambaugh-Miller, & Randolph, 2004). There is no consensus on the definition of "rural"; thus, researchers suggest that "rural" be defined according to the needs of the study being performed ("How is 'Rural' defined?," 2013). How one counts the rural population depends on one's definition, but in the United States, between 10 and 28 percent of the population lives in rural areas. Furthermore, about 75 percent of the counties in the U.S. are considered rural. The term "rural" implies a geographic area with a low population density, not adjacent to an urban area, that is relatively isolated and has an agricultural economic base (Youmans, 1977). Furthermore, "rural" invokes the idea of poverty and folkways. Based on the literature that suggests that "rural" be defined according to the needs of the study, I define "rural" as an area that is geographically isolated from urban areas and has a population that considers itself 'rural' regardless of the size of the community or distance from an urban center.

Rurality

The concept of rurality is important to this study because of the geographic distance from the San Luis Valley to urban centers. The more rural a location is — the more isolated from an urban center — the bigger the cultural difference from its urban counterparts (K. Mueller et al., 2004). Increasing rurality, while subjective, implies that

there is increased isolation from the geographic and cultural areas of urban centers; thus, cultural practices change with increasing rurality (K. Mueller et al., 2004). Based on the literature regarding rural cultural practices, rurality is conceptualized as cultural norms and practices that are unique to individual rural settings.

Seniors

Throughout this study I use the terms "senior," "elderly," and "older adult" interchangeably. For the purpose of this study, these terms refer to adults who are 60 years old and older.

Structures

Structures are operationalized in this study to mean those entities created by government and corporate institutions such as Medicare, whose policies affect access to medications in ways over which seniors have little to no control. Policies may include pricing of services or commodities, policies that create or remove services such as transportation within a community, or rules that govern access to entitlements like food stamps. The stable arrangement of institutions and their structures are such that change in their policies requires effort that is typically outside the ability of the individual. Other entities such as transportation are classified as logistical here so as not to confuse them with structures.

CHAPTER II

REVIEW OF THE LITERATURE

Access to medication as a part of healthcare is a social justice concern and a fundamental human right (Farmer, 2003). The denial of access because of institutional or structural constraints such as government or corporate policies exposes seniors who are poor and live in rural and remote areas to a level of structural violence (Quesada, Hart, & Bourgois, 2011) that is manifest in increased morbidity and premature mortality. Low-income seniors are at the mercy of the profit-driven medical system that is inequitable, ineffective, and unresponsive to seniors' needs, especially minority seniors, who need more time with providers, more explanations about medications, more support from their social networks, and better structural resources (Artnak, McGraw, & Stanley, 2011). Poor access activates a cycle of structural violence that begins with inconsistent medication access and the senior being blamed for irresponsible behavior and non-adherence, when the lack of adherence is due, in many cases, to the lack of access.

Structural violence has not been applied to access to medications either directly or as an extension of access to healthcare; the construct has dealt with the outcomes of power, poverty, and marginalization (Farmer, 2003, 2004; Tim Rhodes, Singer, Bourgois, Friedman, & Strathdee, 2005). However, Galtung's (1969) partial explanation of structural violence, "resources [that] are unevenly distributed, as when income distributions are heavily skewed, literacy/education unevenly distributed, medical services existent in some districts and for some groups only . . . [a]bove all the power to decide over the distribution of resources is unevenly distributed" (p. 171) is appropriate here. As will be seen, resources that affect access to medications, including income, pharmacies, and the drugs themselves are unequally distributed resulting in negative

health outcomes for rural seniors. A risk environment is created by this unequal distribution that puts rural seniors who are poor in danger of harm from an inability to have their medical conditions treated. Rhodes (2002) describes the risk environment as "a space — whether social or physical — in which a variety of factors interact to increase the chances of harm occurring" (p. 88).

The literature in public health primarily uses behavioral theories to explain healthcare access, as will be seen below. There is a dearth of social science theory within public health literature, yet social contexts comprise the bulk of reasons for health disparities (Burke et al., 2009), i.e., race, socioeconomic status, ethnicity, age, residence. While this study is not about health behavior, it is, in part, about health decision making, which is a social scientific, social network, event-driven phenomenon (Pescosolido, 1992). The literature explicated here infrequently focuses on the social contexts beyond those that emphasize individual factors such as self-efficacy (Bandura, 1994) or cognitive factors such as how seniors interpret information (Burke et al., 2009). Furthermore, as will be seen, poor access leads to social suffering that is manifest in multiple ways, including physically, emotionally, and socially. For example, seniors who do not understand the healthcare system, who take opiates for pain management, or whose cultural practices are somehow different from the expected practices found in the dominant culture can feel marginalized and can feel that their dignity is diminished. As Farmer (2004) explains, "cultural difference is one of several forms of essentialism used to explain away assaults on dignity and suffering in general" (p. 278).

What is known about rural seniors' access to medication is fragmented; that is, researchers have studied medication access as a subset of healthcare access as a whole. Some aspects of medication access, such as the role of medication cost, are well

documented, while other aspects, such as whether social support systems influence seniors' medication access, have not been studied. My intent in this study is to consolidate existing data with new data that is specific to medication access, apart from healthcare access generally, and to understand the impact of barriers.

The literature review encompasses four major themes of this study: Access to pharmaceuticals and its indicators, barriers to pharmaceutical access, social support and its implication in seniors' ability to access their medications, and providers' perception of the barriers that seniors face. Within these four major themes, I include literature that covers the five goals of this study: (1) describe barriers; (2) understand facilitators; (3) identify social support networks; (4) define the process of decision-making; and (5) describe health care providers' perception of access. Because access to pharmaceuticals by rural seniors has not been extensively studied, some of the literature that I review is concerned with access to health care generally in rural areas. Thus, I must extrapolate from the general health care access literature in order to frame the problem of access to pharmaceuticals.

There are many types of barriers that can be generally categorized as structural, logistical, personal, and cultural. While some barriers are not place based — they can be a factor in both urban and rural areas — seniors living in rural areas experience challenges that are not necessarily found in urban areas such as long travel distances (Hiscock et al., 2008; Williams, 1993). There is little documentation, however, about how rural seniors navigate these barriers that lead to poor or inconsistent access to prescription medications. Studies on barriers to access tend to focus on health care in general versus pharmaceuticals. Thus, we know little about how rural seniors perceive medication

barriers and how those barriers actually affect decisions about how to handle inconsistent medication access.

Adherence to Prescribed Medication

Adherence studies go back more than 50 years. Researchers and clinicians have long tried to solve the problem of non-adherence without success. While it is outside the scope of this study to delve deeply into the adherence literature, it is important to acknowledge that research on medication adherence has been focused on behavioral concepts and personal responsibility of both the patient and the providers. As such, while the value of medication adherence is not in dispute, and most research has been done using secondary analysis, surveys, or other quantitative methods, researchers have not been able to agree on even how to measure adherence.

Adherence to prescribed medications is touted as a necessary part of effective treatment for chronic disease (Balkrishnan, 1998). Previous researchers have determined that non-adherence results from a multiplicity of factors (see Appendix B), but predicting adherence remains an elusive goal (Balkrishnan, 1998). Adherence to medication regimens is a continuing problem for rural seniors as evidenced by the large number of studies of adherence rates in seniors. Previous studies have shown non-adherence rates from 14 percent to 77 percent, depending on the method of measurement and the type of disease (Chia et al., 2006; Kripalani et al., 2006; Wroth & Pathman, 2006). In a national survey, Kripalani and his colleagues (2006) found that 30 percent of patients took prescription drugs less often than prescribed, 26 percent delayed filling a prescription, 21 percent stopped taking their medication before the course was finished, 18 percent never filled their prescription, and 14 percent took less than prescribed.

The consequences of nonadherence can be grave in the case of illnesses like heart disease, chronic obstructive pulmonary disease, diabetes, and cancer. The lack of access to prescription medication also brings with it a number of consequences for patients, providers, and the health care system at large, including susceptibility to adverse drug events, increased hospitalization and emergency room visits (Chia et al., 2006; Hiscock et al., 2008), nursing home admission, poor prognosis, or death (American Public Health Association, 2005; Chia et al., 2006). Research suggests that non-adherence increases the chance of hospitalization for seniors by more than 10 percent (Chia et al., 2006) and increases the chances of institutionalization for the most frail elderly (Wroth & Pathman, 2006).

Adverse drug events are not only a product of improper use or overdose but also include conditions that worsen because medication is not available such as hyperglycemia or hypertension (Stephenson, 2009). Budnitz and his colleagues (2011) found that from 2007 to 2009, adverse medication events accounted for nearly 100,000 emergency hospitalizations in seniors 65 years and older. Beijer and deBlaey (2002) found that seniors had four times higher rates of hospitalization for adverse drug events than younger adults and, of those, 88 percent were preventable. The lack of essential medications increases the morbidity of seniors who might otherwise be able to manage their diseases and be self-sufficient (Budnitz et al., 2011). The American Public Health Association (2005) reports that approximately 60 percent of older adults take prescriptions improperly — that is, they take too many, not enough, take them out of sequence or against medical advice, or in ways that are either contrary to the way the

medicines are intended by the manufacturer or the provider — and approximately 140,000 die each year as a result.

Along with the increased hospitalization and its inherent cost, the annual economic costs from the various consequences of non-adherence were estimated at $300 billion in 2001 (Chia et al., 2006). These consequences included extra doctor and emergency room visits, hospital and nursing home admissions, adverse drug effects, and premature death. The suffering that ensues from the lack of medication and from the concerns about how to get medications becomes chronic and cumulative (Frost & Hoggett, 2008).

Reasons for non-adherence

Adherence to a medication regimen can be difficult for a senior who takes multiple medications. Seniors who have physical or mental impairments; for whom medication regimens are culturally different; who mistrust the providers and/or the medication; or who, for any other reason, cannot or do not want to adhere, may be categorized as personally irresponsible (Turner, 1989) and, therefore, undeserving of the extra time and attention that may be required to help them get a regimen that works for them. These factors create a risk environment that may play a role in the level of access to pharmacists and medications while creating the perception that seniors are not "taking care of themselves," are irresponsible, or do not care about their health because they cannot be adherent to their medication regimen. Seniors become vulnerable not only to increased health problems but also to social pressures from providers and the community at large if it appears that they are not taking responsibility for their own health care. The

result is that the senior is blamed for non-adherence rather than being flagged by the provider as someone who might need help alleviating a barrier to access.

As noted in Appendix B, researchers have listed many reasons for non-adherence. Some of those are explained here. While following a medication regimen is often the best way to mitigate the effects of disease, seniors living in rural areas, especially those who are of minority populations, sometimes do not understand how or why medications work. Often seniors have cultural beliefs and practices that have been used in their families for generations (Magilvy, Congdon, Martinez, Davis, & Averill, 2000) — such as using certain home remedies, the use of healers, or the use of rituals — as well as attitudes about the importance of following their providers' advice, and beliefs about health care that are influenced by spirituality and cultural norms (Chia et al., 2006; Murray et al., 2004). These practices and beliefs can intersect with modern medical practices to create confusion or contradictions in how a disease should be treated (Magilvy et al., 2000). Cultural discrepancies can contradict a practitioner's desire that the patient change his or her behaviors and beliefs to accommodate the Western medical model (Quesada et al., 2011). The Western model is based on a white, male, middle-class view of how diseases should be treated and how patients should do what they are told by their practitioners (Quesada et al., 2011). As a result, rural seniors can have a difficult time adhering to medication regimens.

Rural seniors who suffer from chronic diseases, disabilities, or cognitive deficits are at higher risk for non-adherence to their medications for other reasons too. They may have difficulty getting to a pharmacy as a result of their disability, forgetfulness, or low comprehension (Lin, 2004; Murray et al., 2004). Age-related factors such as memory loss,

inability to perform activities of daily living, or self-reliance (Lee & Winters, 2004) may be coupled with low health literacy, complex medication regimens, poor coping and problem-solving skills, poor communication skills (Chia et al., 2006; Kripalani et al., 2006; Murray et al., 2004) and multiple structural barriers such as time allotted for patient visits, policies that govern insurance, drug prices, and transportation (Quesada et al., 2011) to create a situation where seniors are unable to adhere to their medication regimens.

Medication adherence is also associated with trust, which affects patient-provider communication (Balkrishnan, 1998; Wroth & Pathman, 2006). Patient-provider trust can mitigate seniors' fear about adverse effects of medications as well as a perception about tolerance or addiction (Balkrishnan, 1998) and the efficacy of health services (Averill, 2002).

Seniors whose income and insurance coverage do not allow for either the purchase of medicine or the doctor visit to get a prescription in the first place will have difficulty adhering to a prescribed drug regimen (Goins et al., 2005; Jones, Parker, Ahearn, Mishra, & Varlyam, 2009). In rural areas, seniors must also take distance and transportation into account when deciding whether or not to fill a prescription. Seniors tend to report medication non-adherence as a result of difficulties in getting to a pharmacy; however, there are few studies that specifically document a link between transportation concerns and medication adherence (Wroth & Pathman, 2006), although numerous studies point to a link between transportation and distance and the utilization of health care services generally (Gellad, Grenard, & Marcum, 2011; Grymonpre & Hawranik, 2008; Wroth & Pathman, 2006).

Barriers

In this section, I will summarize first the literature that is specific to medication access barriers, which is primarily related to cost, and then the literature that discusses access barriers to health care generally. Barriers to medication may not necessarily differ from barriers to health care generally; however, inconsistent access to medications has different consequences for seniors, as explained above.

Whether the barrier is transportation or mistrust of a medication, Thorpe and his colleagues (2011) noted that at least 25 percent of seniors are highly likely to perceive barriers, and most seniors who perceive barriers identify multiple barriers to access. Averill (2002) found that nearly all participants in her study believe that perceived barriers are of concern to rural seniors. In a study conducted by Shi and his colleagues (2010), Blacks and Latinos perceive fewer barriers than their white counterparts; however, they also report fewer doctor and dentist visits than their white counterparts. Whether Blacks and Latinos in this study were healthier than whites is unknown.

Barriers to Prescription Medication Access

Financial barriers are generally reported as the largest barriers to medication access (Lin, 2004). Financial barriers, as described in the literature, include the cost of medications, patients' income, external financial support, and insurance coverage (Balkrishnan, 1998; Chevarley, 2010a; Goins et al., 2005; Murray et al., 2004; Stuart, Shea, & Briesacher, 2001; Williams, 1993). According to Averill (2002), seniors' ability to purchase the medications that they need to manage their multiple chronic illnesses and increasing debilitation has reached a "crisis point for most elders" (p. 659). Part of the reason for this crisis is that rural seniors are more likely than urban seniors to have lower

incomes and higher poverty rates and lack comprehensive prescription drug coverage (Lin, 2004). In fact, Brown and Hirschl (1995) note that there are rural areas that have similar levels of poverty as inner-city ghettos. As a result, a large number of rural seniors tend to get supplemental health care coverage from Medicaid (C. Mueller & Schur, 2004).

While average out-of-pocket costs for some of the most expensive drugs for seniors (Lipitor, Plavix, and Nexium) decreased from 2005 to 2006 (Chevarley, 2010a), many drugs have now increased in price by as much as 2,000 percent (Rosenthal, 2014). Furthermore, while per capita expenditures were, on average, $660 per month for medications for both rural and urban seniors in 1992[2], by 2008 the average senior paid $2,834 with seniors who have five chronic diseases paying an average of $5,300 in prescription drug costs (Federal Interagency Forum on Aging-Related Statistics, 2012). Sometimes, seniors may be able to get samples from their providers, or the providers may stock some basic medicines, but even if providers stock medications in their office or have samples, their supply is typically limited to basic antibiotics or more commonly used topicals. Furthermore, there may be legal concerns that prevent providers from stocking medications in their offices if they are not considered community clinics (Budnitz et al., 2011; Chia et al., 2006; Hiscock et al., 2008; Wroth & Pathman, 2006).

Concerns over the inability of many seniors to afford their medications helped lead to the passage of the Medicare Prescription Drug Act (Wroth & Pathman, 2006), a recognition by the federal government that seniors need help with the cost of medicine. However, regardless of an increase in Medicare benefits, financial problems remain barriers to accessing medication when Medicare does not provide sufficient coverage;

[2] $660 in 1992 is equivalent to $1,005.25 in 2008 dollars.

when there is inadequate or non-existent private insurance; when seniors are ineligible for Medicare, Medicaid, or other entitlements; and when the cost of prescriptions is unaffordable (Goins et al., 2005).

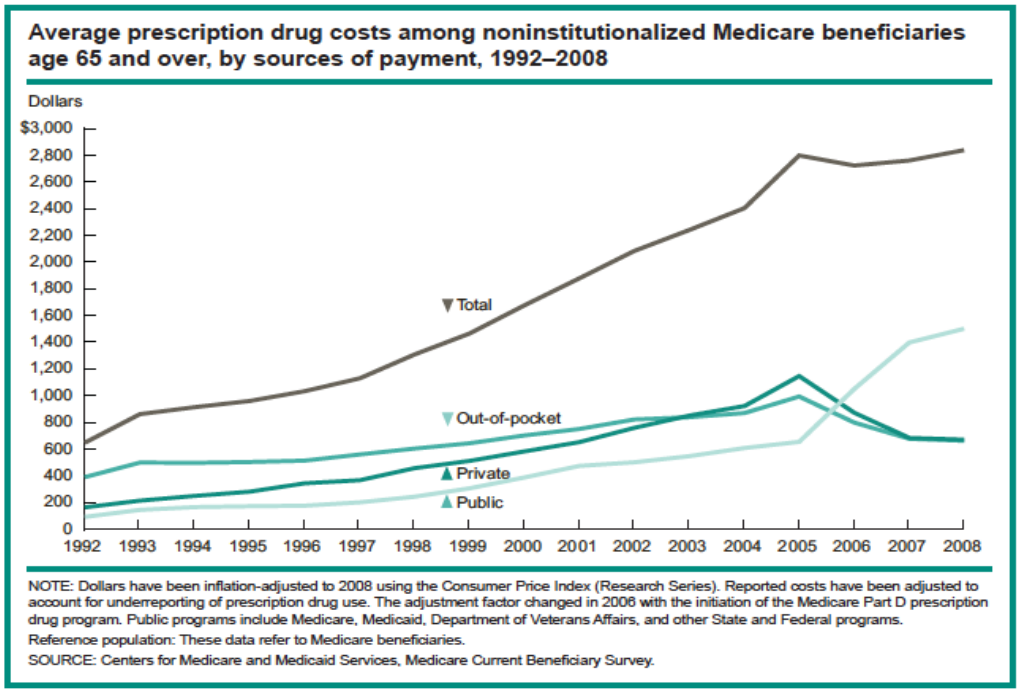

Figure 1 Average prescription drug costs among noninstitutionalized Medicare beneficiaries age 65 and over, by sources of payment, 1992-2008.

Furthermore, in rural areas, despite the increase in medication cost and out-of-pocket expenditures, some seniors purposefully do not enroll in Medicare Part D (drug) plans. Rural seniors may have cultural practices such as a mistrust of providers or a preference for alternative treatments and medications that keep them from accessing Western medications, and others do not understand how the Medicare system works and have erroneous beliefs about their eligibility. In a report from Office of External Affairs Strategic Research & Campaign Management Group Division of Research (2014) of the

Centers for Medicare and Medicaid Services (CMS), the authors noted the following barriers to Medicare Part D enrollment of rural seniors:

- A strong sense of pride and desire for independence is a barrier. Some equate it to asking for a handout, getting welfare, and feeling stigmatized in their communities.
- Although grateful for Medicare, they have very little awareness of any mailing or other communication from CMS and therefore no "relationship" with them.
- Some rural respondents assume they will not qualify based on their stocks, land, or other investments.
- Some rural respondents are hesitant to call CMS or SSA (Social Security Administration) for help due to a sense of intimidation. They have little experience contacting them for any reason.

Table 1

Part D benefit categories	*June 2006*	*October 2011*
All Medicare enrollees age 65 or over	36,052,991	40,752,219
Enrollees in prescription drug plans	18,245,980	23,832,723
Type of plan		
Stand-alone plan	12,583,676	14,325,499
Medicare Advantage plan	5,662,304	9,507,224
Low-income subsidy		
Yes	5,935,532	6,392,018
No	12,310,448	17,440,705
Retiree drug subsidy	6,498,163	5,850,214
Other	11,308,848	11,069,282

Reference population: These data refer to Medicare enrollees.
SOURCE: Centers for Medicare and Medicaid Services, Management Information Integrated Repository.

Table 1 shows the number of Medicare enrollees age 65 and over who enrolled in Part D prescription drug plans or who were covered by retiree drug subsidy payments, June 2006 and October 2011

While government insurance programs can be a lifeline for seniors, they have important limitations. For example, seniors who do not have at least a 10-year history of

paying into Medicare are not eligible (U.S. Department of Health and Human Services, 2013); these seniors may be eligible for Medicaid. In rural areas, seniors historically pay higher premiums for Medicare coverage than urban seniors because of the types of plans into which they enroll. Urban seniors are more likely to enroll in health maintenance organizations (HMO) plans with or without prescription drug coverage (69% in urban areas vs. 30% in rural areas) (Kemper et al., 2012). The main reason for the increased cost in rural areas comes from higher costs of establishing provider networks in rural areas due in part to low population density and few providers. However, rural Medicare enrollment has increased to over 700,000 rural seniors in the Medicare Advantage Preferred provider organizations (PPO) plans and over 450,000 seniors in the HMO plans (Kemper et al., 2012). While the increase in enrollment is a positive step, many seniors still have little to no coverage.

Without health insurance, seniors are much more likely to report multiple, co-occurring health problems and inability to access medications due to cost (Thorpe et al, 2011). The cost of care, including medications, can bankrupt a family and can have the effect of ill seniors postponing provider visits until their condition becomes urgent (Portes, Fernandez-Kelly, & Light, 2012), which can leave seniors who are unable to consistently access their medications at higher risk for institutionalization as their conditions worsen (Balkrishnan, 1998). Finally, the literature shows that medication non-adherence is a major consequence of financial barriers (Balkrishnan, 1998; Bengle et al., 2010; Goins et al., 2005).

Government programs as structured are not a panacea of access compared to higher priced private insurance. For example, elderly patients on Medicare and Medicaid

are much more likely to report access problems than seniors with private coverage (Carper & Machlin, 2009). Artnak, McGraw & Stanley (2011) found that there is a high percentage of rural residents who are subsidized and uninsured and who often do not qualify for Medicaid; thus, their ability to purchase medications is limited if they have a co-pay. Furthermore, there is the Medicare coverage gap or "donut hole," (Dismuke & Egede, 2013), the point at which Medicare Part D (Medicare's prescription drug plan) stops paying for drugs until a ceiling is reached by the patient, at which point Medicare once again pays for a percentage of the drug. The "donut hole" severely limits seniors' ability to afford their medication once they have reached the coverage gap (Department of Health and Human Services, 2013). In fact, upon entering the Medicare gap, those seniors without gap coverage are twice as likely to stop taking medication as those who have gap coverage (Lau & Stubbings, 2012). Kaplan and Zhuang (2013) found that seniors on Medicare are more likely to stop taking their medications as they approach the "donut hole" and then reinitiate their prescriptions in January when Medicare kicks back in.

Aside from the consequences listed above, seniors who experience financial barriers in accessing their medications often find ways to cut back on either medications or essential needs in order to make ends meet (Bengle et al., 2010) choosing between purchasing medications or paying living expenses (Averill, 2002) resulting in non-adherence (Morton & Weng, 2013). Averill's (2002) study looked at Cost-Related Non-adherence (CRN) among seniors and found that CRN is higher among uninsured patients. CRN patients report between four and seven chronic conditions and report that drug costs and poor drug insurance are associated with a higher likelihood of CRN. These patients

take less of their prescribed medications, import medications from other countries, switch to over-the-counter medicines, borrow money, and choose between food and medicine. The cost of prescriptions and the lack of insurance, as well as low income (less than $25,000), are associated with whether seniors take their medication, even when controlling for education and employment (Wroth & Pathman, 2006). These barriers are especially significant for sick and frail seniors who have high rates of non-adherence because they engage in self-restriction (Balkrishnan, 1998; Goins et al., 2005; Murray et al., 2004). Along with low socioeconomic status, food insecurity, a consequence of low income, also predicts CRN, especially in African Americans, by 2.9 times after controlling for confounding factors (Bengle et al., 2010).

In fact, Balkrishnan (1998) found that race is associated with medication adherence. For example, Goins and his colleagues (2005) found that low-income African American seniors in the rural south reduce the dosage of medications or do without altogether, limit other expenses, rely on other family members for assistance, supplement with alternative medicines, and use home remedies. A study of African Americans with osteoarthritis reported that a fear of medication costs is worse than the severity of their pain (Rosenthal & Fox, 2000).

Barriers to General Health Care Access

The literature classifies barriers to access to health care for seniors in rural areas generally into three broad categories: Personal — physical/cognitive concerns and subjective barriers such as those that are based on a senior's personal comfort zone or likes/dislikes; cultural — perceptions about their health, health care, and medications that stem from a cultural understanding; and structural — barriers over which the senior has

little or no control such as policies that govern access to entitlements. The literature on barriers to health care is extensive; however, each study has its own list of barriers gleaned primarily from secondary data. Few studies interviewed seniors either independently or in focus groups. Appendix C shows the list of barriers that I found in reviewing the literature on health care access. The reader should note that these researchers' lists are primarily aimed at health care access generally, not at medication access specifically. Selected barriers are described below.

Personal Barriers

Knowledge/Literacy

Health literacy is defined in some of the literature 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, Institute of Medicine (U.S.) & Committee on Health Literacy, 2004). Low health literacy has consequences associated with it, including poor medication management, decreased medication adherence, and mistrust of health care and providers (Kripalani et al., 2006; Murray et al., 2004; Schectman, Bovbjerg, & Voss, 2002). Persons who have low health literacy include those with less educational attainment, minorities, seniors, people with low cognitive abilities, and the poor (Berkman et al., 2004). Health literacy affects a senior's ability to function in the health care environment as well as patient-provider communication and knowledge about pharmacy practices that can impede access to prescriptions (Berkman et al., 2004). Health literacy does not address access but only behavior once access is attained.

Trust Barriers

While there is little literature on how trust affects medication access, the few studies there are suggest that trust affects access to medication and health care because seniors who do not trust their providers are less likely to fill their prescriptions and thus adhere to their medication regimens (Wroth & Pathman, 2006). Trust also affects patient-provider communication, which is associated with medication adherence (Balkrishnan, 1998) partly due to seniors' fear about adverse effects of medications as well as a perception about tolerance or addiction (Balkrishnan, 1998) and the efficacy of health services (Averill, 2002).

Physical/Cognitive Barriers

Access to medications is often hampered by physical and cognitive problems that limit seniors' mobility (Lin, 2004). Seniors who suffer from chronic diseases, disabilities, or cognitive deficits are at higher risk for non-adherence to their medications partly because it is difficult for them to get to a pharmacy and partly because of forgetfulness or comprehension (Lin, 2004; Murray et al., 2004). Age-related factors such as memory loss, inability to perform activities of daily living, or self-reliance (Lee & Winters, 2004) may be coupled with low health literacy, complex medication regimens, poor coping and problem-solving skills, and poor communication skills (Chia et al., 2006; Kripalani et al., 2006; Murray et al., 2004) to create a situation where seniors are unable to purchase their drugs and adhere to their medication regimen.

The factors that contribute to seniors' decreased mobility and cognitive functioning also impede their ability to access medications and adhere to their regimen without help. For example, seniors who have impaired hearing or vision are unable to

drive even short distances to a pharmacy; a 40-mile trip becomes impossible (Lee & Winters, 2004; Murray et al., 2004). Isolation due to geographic distance or to cognitive functioning reduces seniors' ability to rely on others to help them (Derose & Varda, 2009). Furthermore, cognitive deficits may affect a senior's relationships, trust in friends or family, self-esteem, and sense of personal safety (Derose & Varda, 2009). Thus, many seniors have only pets for companionship, and this reality severely limits their ability to access their medications and adhere to the potentially complex regimens that their illness or disability require (Averill, 2002).

Cultural Barriers

Cultural barriers are predominantly mentioned in the literature in regards to health care access generally. In rural areas, researchers define culture generally as: (1) the ethnic culture and beliefs of seniors, including spiritual beliefs, food preferences, or family rituals; and (2) the norms and values of rural life, which include resistance to outsiders and a hesitation to seek health services (Foster & Frazier, 2008; Goins et al., 2005). These definitions reinforce the belief that health behavior is "individually defined and independently produced . . . uninfluenced by . . . rules, values, and resources of social structures and contexts" (Burke et al., 2009, p. 60). Culture is contained in Bourdieu's (1990) idea of *social practice* — the idea that behavior is influenced by "its immediate and broad context [and] both contributes to and alters that context" (Burke et al., 2009, p. 62). Central to Bourdieu's concept of social practice is *habitus* — "embodied history, internalized second nature" (Bourdieu, 1990, p. 56). Thus, cultural practices in the Valley are internalized ways of being that stem from seniors' history not only as individuals but also as part of their environment and designation as "poor," "rural," and "old." Cultural

discrepancies are ways of living that are perceived differently by providers of health care and by seniors living in rural areas.

Williams (1993) notes that ethnic and cultural discrepancies create a "gulf" between providers and seniors that involves impersonal services and a lack of outreach and follow-up that seniors find inappropriate according to the habitus that they employ. He also notes that the current reimbursement system aids in the lack of culturally sensitive services because there is a premium placed on diagnostic and therapeutic services rather on personal contact such as teaching and counseling, that are time-consuming. While Williams' information is 21 years old, the reimbursement structure has not changed much, and providers still spend little time with their patients and often deliver impersonal services; the healthcare system has not made progress in working with patients who need more time, attention, and follow-up. Difficulty in accessing pharmacies may also have cultural components that include cultural insensitivity, the atmosphere of the pharmacy, interpersonal dynamics, or language differences (Lin et al., 2005).

Individual differences between men and women, ethnicities, and income levels may also influence cultural barriers. For example, Clark and Leipert (2007) found that men tend to rely on their wives for assistance and support because they have a harder time asking outsiders for help. There are long-standing traditions that are based on folk culture in rural areas, including the use of herbal medicines, a sense of individualism, or adapting to fewer amenities than are found in urban areas (Youmans, 1977) and on intergenerational differences. Differences in behaviors, outlook, technology, and other types of modernization can be traumatizing for older adults, especially those from

minority groups (Youmans, 1977). Migrant groups, many of whom have settled in rural areas, often lack information about available services and facilities that work with rural seniors (Portes et al., 2012), and, depending on their immigration status, may fear the authorities (Raffaelli & Wiley, 2012). Minority seniors in rural areas often have different communication experiences with providers than whites because of differences in cultural practices that can lead to decreased adherence and increased mistrust of providers (Schectman et al., 2002), providers' competence in prescribing the correct medication, and even in seniors' decision to take their medications (Chia et al., 2006).

Cultural discrepancies between providers and seniors can create significant barriers to accessing health care, including medications, thus decreasing adherence and leading to increased morbidity (Chia et al., 2006; Williams, 1993). These beliefs about medical care and health are part of a "sociocultural predisposition" (Aday & Andersen, 1974) inherent in rural seniors. The culture of the health care system, furthermore, can be intimidating to seniors whose habitus and culture are ingrained in rural, ethnic, and/or class status (Williams, 1993). This difference in attitudes, norms, vocabulary, and even physical environments can easily overwhelm seniors who have not spent much time navigating the health care system (Office of External Affairs Strategic Research & Campaign Management Group Division of Research, 2014; Williams, 1993). Other barriers include a lack of understanding about the role that medications play in the disease process, attitudes about the importance of following providers' advice, and beliefs about health care that are influenced by spirituality and cultural norms and practices such as the use of healers (Chia et al., 2006; Murray et al., 2004). Finally, the literature supports the idea that class differences between providers and seniors play a

role in sustaining cultural barriers (Allen, Ball, & Alston, 2010; Artnak et al., 2011; Williams, 1993). If providers perceive seniors in poverty as lazy or undeserving (Williams, 1993), then culturally insensitive care and marginalization may exist in delivery of services, especially to minority seniors (Averill, 2002). Lack of English fluency and cultural understanding can create significant hardships for seniors and for providers who may have trouble diagnosing and providing instructions to seniors about their medications so that seniors can follow instructions (Averill, 2002; Portes et al., 2012).

Rurality

According to the extant literature on rurality and access to pharmaceuticals and health care, living in a rural area increases the risk for ambulatory care-sensitive conditions (ACSH) (Laditka, Laditka, & Probst, 2009), those conditions that require access to care and to prescriptions but do not require hospitalization or institutionalization. Such conditions may include diseases such as hypertension, diabetes, heart disease, or lung disease. Laditka, Laditka, and Probst (2009) point out in their study of seniors in eight states that ACSH rates tend to increase for adults over age 65 with increasing levels of rurality and also with increasing distance from urban centers. They further found that accessibility to health care decreases and access disparities increases with increasing rurality.

Increased rurality also tends to change the scope of health care options that are available. Areas with less population density tend to have smaller patient volumes, leading to a higher cost structure and less financial support than their urban counterparts (Jones et al., 2009). Communities have a difficult time recruiting providers, and providers

have a hard time remaining in rural communities (Artnak et al., 2011; Borders, Aday, & Xu, 2004; Harris et al., 1999; Mueller & MacKinney, 2006). As a result, rural seniors do not have the same amount of access to health services due, in part, to a smaller pool of providers and facilities such as pharmacies, and seniors have more problems maintaining access to services (Goins et al., 2005; Hiscock et al., 2008; Laditka et al., 2009; Thorpe et al., 2011). Living in a rural county increases the likelihood that seniors will have no health insurance and will report multiple problems with access to services (Thorpe et al., 2011); must purchase prescriptions by mail (Lin et al., 2005); will receive less primary health care, including pharmacy services (Laditka et al., 2009; K. Mueller et al., 2004); and will report multiple barriers to accessing care, including pharmacy services (Goins et al., 2005).

Rurality also brings a difference in attitudes, culture, and values (Youmans, 1977). For seniors living in rural areas, there are distinct challenges to obtaining not only their medications but also all levels of health care. These challenges are not only related to the relative isolation of rural areas but also to a lifestyle that is markedly different from that of urban seniors, such as closer community ties and greater self-sufficiency (Foster & Frazier, 2008; Goins et al., 2005).

Structural (Logistical) Barriers

Structural barriers, as described later in this study, have not been specifically explicated in the literature as creating access problems. Some barriers that are classified as "structural" are really logistical, such as transportation; however, often structures, i.e. policies, create logistical barriers. For example, municipal policies may or may not prioritize providing public transportation. As shown in Appendix C, researchers have

listed a number of specific barriers that participants have named as having a negative effect on health care and/or pharmaceutical access that are structural or logistical in nature but do not encompass the full range of structural barriers, including structural violence and risk environment, that result from government and corporate policies. Rural areas have specific problems with services due to geographic and cultural differences from urban centers. For example, it is more difficult to recruit and retain providers, thus decreasing the choices that seniors have (Hiscock et al., 2008), health services tend to be fragmented (Averill, 2002; Williams, 1993), hours of operation are often inconvenient for seniors who are employed (Lee & Winters, 2004), and accessing specialists is difficult because there may not be any (Carper & Machlin, 2009). These structural barriers often determine whether a senior living in a rural area seeks health services in the first place and the level of satisfaction that he or she experiences (Aday & Andersen, 1974).

Government and corporate policies create structural barriers that have an impact on access through, for example, the increasing price of drugs, Medicare enrollment dates, and eligibility for services. As noted above, seniors often have erroneous information about entitlements that preclude them from even attempting to sign up for benefits. Seniors are often unaware of eligibility requirements or of the nature of benefits, i.e. something that they have a right to access versus a "handout." In some cases, services are not available to seniors because of government policies; for example, while Medicaid in Colorado has agreed to pay for some dental services, the reimbursement structure is such that no dentist in Colorado accepts Medicaid (Kessler, 2104). These structural barriers are discussed in detail in the following chapters. For this review, I will focus on one of the biggest logistical barriers for rural seniors that are described in the literature.

Travel/Distance/Transportation

Travel, distance, and transportation are often cited as barriers to access of health care and medications. Distance, sometimes referred to as "geographic accessibility" (Aday & Andersen, 1974), is defined in the literature as the "time and physical distance that must be traversed to get care" (Aday & Andersen, 1974, p. 209) or "the separation between the rural participants and their health care resources" (Lee & Winters, 2004, p. 55). Thus, how far seniors have to travel and how long it takes them to get there defines this category.

Long travel distances have the effect of isolating seniors, particularly those who have difficulty getting around on their own (Youmans, 1977). Seniors must learn to deal with the distance from both health facilities and from those who help them with health-related activities (Lee & Winters, 2004). While some seniors do not feel isolated despite long distances from health facilities and from personal contacts (Lee & Winters, 2004), transportation and distance have emerged frequently as barriers to health care access (Goins et al., 2005; Hiscock et al., 2008; Lee & Winters, 2004; Williams, 1993; Youmans, 1977). Studies have suggested that rural seniors have greater transportation problems and travel longer distances than their urban counterparts to access health care generally (Goins et al., 2005). In some cases, rural residents may be as far as 200 miles from health care resources (Williams, 1993); however, for elderly patients, even a distance of 10 miles has been shown to be a problem (Lin, 2004).

Travel and transportation are also factors in health-related inequalities, particularly in rural areas (Hiscock et al., 2008); they contribute to increased disease severity in seniors because of missed provider appointments (Wallace et al., 2005) and

failure to fill prescriptions (Wroth & Pathman, 2006) that ultimately can result in more costly medical care (Wallace et al., 2005). In a study by Goins and his colleagues (2005), study participants reported that they sometimes drive the long distance to urban areas because their medical needs cannot be met in their rural communities.

The ability to drive is known to affect initial entry into the health care system (Aday & Andersen, 1974), even for those seniors who have financial resources (Rosenthal & Fox, 2000). Driving, however, can be dangerous for seniors who are older, ill, or lack reliable vehicles; in fact, motor vehicle accidents is a major cause of death for seniors (Morton & Weng, 2013). In many rural areas, roads are poorly maintained, the terrain is mountainous or monotonous, weather is a concern, and roads are isolated (Goins et al., 2005), yet seniors must continue to drive or have someone drive them because there is no other form of transportation (Johnson, 1998).

Lack of transportation also correlates to lower incomes and less use of prescription medications. Seniors who report that they cannot afford their medications are more likely to also report that they lack access to transportation (Levine et al., 2007). Providers sometimes feel that even writing a prescription can be a waste of time if they know that the patient will be unable to fill it because the pharmacy is too far away (Williams, 1993).

Seniors living in rural areas must take distance and transportation into account when deciding whether or not to fill a prescription, and they tend to report medication non-adherence as a result of difficulties in getting to a pharmacy. There are, however, few studies that specifically document a link between transportation concerns and medication adherence (Wroth & Pathman, 2006). Wallace and his colleagues (2005)

found that about 10 percent of Americans do not get medical care (and presumably medications) because of transportation problems. These individuals tend to be female, poor, old, minority, and have low educational attainment; however, elderly men tend to be less willing than women to travel to obtain health care (Thorpe et al., 2011). Using the National Health Interview Survey (NHIS), Wallace and his colleagues (2005) have tried to address transportation concerns relative to access to care. They found that patients who missed health care appointments due to transportation problems had a much higher prevalence of disease and co-morbidities than patients who had adequate transportation. In rural areas that have no daytime bus service or community transportation, residents have significantly higher health needs and lower levels of personal mobility than residents who live in areas with some level of public transit (Lovett, Haynes, Sunnenberg, & Gale, 2002). Thus, if seniors do not drive due to illness, disability, or poverty, they can be stranded at home and be unable to get prescriptions (Hiscock et al., 2008).

Similar to transportation are travel time and distance to providers. Hiscock et al. (2008) found longer travel times are associated with fewer pharmacy visits in rural areas. Higher mean travel time is also associated with a lower likelihood of initial entry into the health care system (Aday & Andersen, 1974); access inequality is correlated with long distances and long travel times (Williams, 1993). Pierce (2001), in a study of rural health, noted that distance is one of the barriers that residents face when trying to access care. While transportation, travel time, and distance problems can be partially alleviated by where facilities are located in a community (Lin et al., 2005), in rural areas where residents are scattered over long distances, geographic placement that is accessible to all residents is often impossible. Wallace and his colleagues (2005) found that although

public transit can be expensive, public transportation can help to remedy travel concerns, be a cost savings to the healthcare system, and net social benefits outweigh the extra cost.

Social Support

Social support is an important factor in coping and the management of stress such as that which accompanies illness (Vyavaharkar et al., 2007). As a construct, social support is multidimensional, complex, and difficult to define or measure (Hessler et al., 1995; Vyavaharkar et al., 2007). Unlike social networks, which include the social relations of an individual (Smith & Christakis, 2008), social support networks include those people who are able to provide support to an individual at the level of instrumental support (financial, tasks); informational support (giving advice, decision-making help, sharing knowledge, and evaluating options); and affective support (emotional support) (Hessler et al., 1995; Smith & Christakis, 2008). Social support also incudes "helpfulness," which is "the perceived extent to which the support needs of a person can be met by his/her social contacts" (Smith & Christakis, 2008) as well as a senior's satisfaction with the support that he or she receives (Vyavaharkar et al., 2007). Social support, however, can also work to the detriment of seniors as when there is a power struggle between caregivers or when the needs of the senior are contrary to those of the support persons (Chogahara, 1999). An example would be when the senior wants to stay in his or her home, but the caregivers can no longer care for the senior and want to institutionalize him or her. Another example is when a support person disagrees with the treatment plan that a provider has prescribed and works to convince the senior that the plan is not in his or her best interests.

The positive effects of social support are well documented in the literature, as are the negative effects of the absence of support (Vyavaharkar et al., 2007). In coping with stress, the literature has documented the positive effects of social support resources (Smith & Christakis, 2008; Vyavaharkar et al., 2007), although there is little agreement about how they work (Vyavaharkar et al., 2007). Social support requires social relationships that can be used to help seniors achieve positive health-related ends (Smith & Christakis, 2008) and take into account both vertical and horizontal ties (Derose & Varda, 2009). Vertical ties are those that link people across social or economic class while horizontal ties are those that link individuals to each other. Such relationships can help seniors manage emotional distress and manage the problems that lead to stress, thus increasing coping responses even in the most difficult situations, although the support network must match the needs of the senior to be effective (Vyavaharkar et al., 2007).

Through social networks, people who are part of a senior's social support system can affect health by providing access to resources, by providing social involvement, and by influencing a senior in how he or she makes decisions (Smith & Christakis, 2008). Derose and Varda (2009) showed that people who live in neighborhoods where neighbors are willing to help each other are more likely to have a regular source of health care. They also showed that support networks are positively correlated with people receiving financial support during an illness. Hessler and her colleagues (1995) suggest that the various sources of emotional support enhanced the well-being of rural seniors. Morbidity and mortality as well as medication adherence have also been shown to be influenced by the level of social support available to seniors (Smith & Christakis, 2008; Vyavaharkar et al., 2007). Furthermore, whether the social support is actual or perceived makes little

difference; well-being is positively affected (Hessler et al., 1995). Therefore, living in a supportive environment is important to the maintenance of health (Raffaelli & Wiley, 2012). Support is especially important for seniors as they face age-related changes to their health, including changes in their ability to perform activities of daily living (Hessler et al., 1995).

Factors That Affect Social Support

Isolation

The geography of rural areas often contributes to the isolation of seniors because of the long distances that people must travel to get to senior centers, providers, and friends and family (Clark & Leipert, 2007). Those who live in areas where inclement weather is a concern are even more at risk for social isolation because of the dangers of driving in poor visibility, on icy roads, or in mountainous areas (Clark & Leipert, 2007). Maintaining social support networks can be challenging when distance or transportation is a factor and seniors are unable to participate in activities at senior centers or other gathering places or when visitors are unable to easily get to the senior's home (Clark & Leipert, 2007; Goins et al., 2005; Youmans, 1977). Isolation contributes to functional decline, loneliness, decreased involvement in social activities, and decreased coping strategies (Averill, 2002; J. Johnson, 1998; Rosenthal & Fox, 2000; Youmans, 1977) resulting in risk for nonadherence to medication regimens and negative health outcomes (Balkrishnan, 1998; Smith & Christakis, 2008). Other factors that contribute to social isolation are the out migration of younger people, rural culture of self-reliance, and decreased income (Artnak et al., 2011; Clark & Leipert, 2007). As seniors age, they are often left with diminishing social support to help them with their health care needs

(Shenk, 1992) due to the death of friends and family members, which increases the need for outside help and formal support services (Shenk, 1992). Thus, seniors' pool of social support diminishes over time, and they must look outside of the family and close friends for assistance (Shenk, 1998).

Preferences

Smith and Christakis (2008) suggest that how people form ties is important to the effect of social networks on health. People tend to choose others who are similar to them when they form interpersonal bonds; thus, the creation of social networks is deliberate. Rural seniors typically prefer support networks that are informal and include family, friends, and neighbors rather than formal groups or providers (Clark & Leipert, 2007). Women tend to have larger support networks than men and report feeling greater life satisfaction within their networks (Hessler et al., 1995). Men tend to use their wives for support rather than establishing large networks (Clark & Leipert, 2007; Shenk, 1998). While very old rural women may have fewer support resources, old age does not necessarily prevent women from having support networks (Hessler et al., 1995). Men and women, however, view different sources of support as important (Hessler et al., 1995).

Agency

Lee and Winters (2004) identified agency as a theme in their study of rural seniors dealing with the concept of choice and social support. Family and friends, they found, significantly influence seniors' decisions, especially if they live close by; however, this influence is not always positive. While some researchers suggest that social support is crucial to difficult decision-making, it may also have a detrimental impact on seniors if advice is contrary to the senior's well-being (Johnson, 1998). Beliefs of the support

network can run contrary to the needs of the senior and can act as a facilitator or a deterrent to the use of health care services (Derose & Varda, 2009). Finally, negative outcomes may be associated with social support networks if the network members demand conformity, restrict the senior's freedom, or advise the senior based on faulty information (Derose & Varda, 2009).

Ben-Sira (1984) found that seniors who have increased contact with friends and family may see it as a sign of decreased independence. Thus, he found that formal networks provide more support for the chronically ill than informal support networks because formal networks usually involve professionals who have experience working with seniors and their illnesses. The literature suggests that social support networks are instrumental in helping seniors achieve better health outcomes but can also work against a senior's best interests if the members of the network are unable to provide the senior with proper guidance or if the senior perceives the support as decreasing his or her independence.

Indicators of Access to Prescription Medications

A national survey of rural health policymakers, community leaders and stakeholders ranked access to quality health care services as their top priority (Artnak et al., 2011). Combining Penchansky and Thomas (1981) and Norris et al.(2006), indicators of access help to clarify the definition of access to prescription medications. In order to realize access to medications, there are enabling resources that must be in place.

Availability

One of the unique challenges for seniors in rural areas is the lack of availability of pharmacies in many areas. Unfortunately, rural pharmacies have been closing due to

factors that include low Medicare and Medicaid reimbursements (Keast et al, 2010; Radford et al., 2009), retiring pharmacists who are unable to sell their practices (Traynor, Sorensen, & Larson, 2007), financial stress (Radford et al., 2009; Xu & Rojas-Fernandez, 2003), and not enough population to sustain a pharmacy. Since the distribution of health services, including pharmacies, has been primarily in urban centers (Youmans, 1977) many rural areas have gaps in the continuum of care as a result of the lack of availability (Goins et al., 2005). The availability of drugs, whose cost has increased, has declined when pharmacists can no longer afford to carry the drugs because of the reimbursement policies that do not compensate the pharmacy for the price paid to acquire the drug.

Another problem that has recently plagued both patients and providers is the shortage of certain drugs. The Food and Drug Administration provides a list of drugs that are currently in short supply. In 2011, there were 251 drugs in short supply, which included both oral and injectable drugs (Center for Drug Evaluation, 2013). Hospitals have scrambled to try to get these drugs or to find alternative drugs (Morrissey, 2012).

Accessibility

Seniors with chronic illness depend on accessibility to care and medications (Artnak et al., 2011). Accessibility is more than just the availability of services; it also includes the successful utilization of available services and resources (Aday & Andersen, 1974). Accessibility extends to the level, types, and patterns of seniors' actual use of health care (Aday & Andersen, 1974). In rural areas that are far from urban centers, accessibility becomes a bigger problem for seniors because of distance and travel time, complexity of the system, cost, and other barriers (Morton & Weng, 2013). Poor

accessibility influences healthy aging in a rural population (Lovett et al., 2002; Morton & Weng, 2013) and negatively impacts seniors.

Eligibility/Affordability

Whether or not seniors can afford their medications is an indicator of access. Seniors whose income and insurance coverage do not allow for either the purchase of medicine or the doctor visit to get a prescription in the first place will have difficulty adhering to a prescribed drug regimen (Goins et al., 2005; Jones et al., 2009). Rural seniors, as a group, tend to have lower incomes and lower levels of education that constrain their ability to benefit from health care services (Youmans, 1977) and are more likely to limit their medical care due to costs than are urban households (Jones et al., 2009). Thus eligibility is the ability to qualify for services as well as the ability to afford drugs. It makes intuitive sense that having the financial means to afford medication would enable access (Aday & Andersen, 1974; Balkrishnan, 1998; Lee & Winters, 2004; Murray et al., 2004).

Affordability, however, is not limited to the ability to pay for medications but also to the level of insurance coverage that seniors have as well as to the sources of income (Aday & Andersen, 1974). Financial means extends also to the ability to have transportation to get to a pharmacy or to a provider to get a prescription and the ability to afford an office visit or the ability to pay for prescriptions by mail (Aday & Andersen, 1974; Balkrishnan, 1998; Lee & Winters, 2004; Murray et al., 2004). The ability to pay for food, shelter, utilities, and transportation (Blankenau & Boye-Beaman, 2000; Morton & Weng, 2013; Quesada et al., 2011) affects seniors' health and well-being and is part of

their ability to manage their illnesses. Choosing between medicine and food does not make the medicine accessible.

Amenability

The health care system's complexities can be staggering to seniors who are sick, do not understand how the health system functions, and have fewer resources than if they were living in urban settings. Seniors' desires to use the medications that are available to them depend, in part, on whether they believe that they need care, they want care, they can get care, and the providers are competent and trustworthy (Norris & Aiken, 2006). Thus, trust and beliefs are the two major indicators of amenability; however, it should be kept in mind that amenability presupposes that seniors can get the medication that they need.

Trust refers to a senior's trust in those people who are acting in his or her behalf – – providers and/or "known insiders" (Lee & Winters, 2004). In the case of providers, Balkrishnan (1998) found that trusting their providers helped to mitigate any concerns that seniors might have about adverse effects of taking their prescribed medications. Thus, trust that the provider knows what he or she is doing with regards to the medications that they prescribe to the patient increases the patient's desire to try to obtain the medication. Trust also extends to what Lee and Winters (2004) called the "known insiders" — those individuals whom seniors trust to act in their best interests. These "known insiders" are not necessarily providers but individuals to whom seniors are apt to listen with regards to medication adherence, keeping medical appointments, and preventive care (Lee & Winters, 2004).

Beliefs are divided into two categories in the literature: beliefs about health status and self-efficacy. For seniors who believe that they have the illness for which they are prescribed medication, believe that the medication will be beneficial, and believe that their condition can be controlled and/or cured, adherence increases (Balkrishnan, 1998; Chia et al., 2006). Furthermore, if the senior is confident in his or her provider's knowledge, adherence is increased. Finally, those seniors who perceive fewer benefits from home remedies or alternative treatments are more likely to adhere to a medication regimen (Balkrishnan, 1998). The second category, self-efficacy, is defined by the belief that the senior has control over his or her health and has the ability to take the medications properly. Among the findings in the literature, self-reliance is most frequently mentioned. Lee and Winters (2004) found that self-reliance is a major source of self-efficacy — the idea that the senior can manage his or her illness. Independence is mentioned by Chia, Schlenk, and Dunbar-Jacobs (2006) and Clark and Leipert (2007) as contributing to self-efficacy, much like self-reliance. The idea that powerful others are not essential to the senior's maintenance of or being responsible for the senior's health also plays a role in self-efficacy (Chia et al., 2006; Clark & Leipert, 2007). Those seniors who have high self-efficacy are more likely to adhere to their medication regimens.

Acceptability

Acceptability means that the senior accepts the conditions under which he or she gets the medication. This includes agreeing that the prescription and the regimen are appropriate and that they perceive a culturally appropriate environment — one in which they can feel comfortable (Norris & Aiken, 2006). Such an environment may include having a family member present when the prescription is being written, a pharmacy

where the employees speak the senior's language or behave in a manner that is in keeping with the senior's values, or a health care professional who takes the time to answer the senior's concerns about side effects of the medication. There are cultural discrepancies that are specific to rural life that may affect whether seniors use available health resources (Chia et al., 2006). These cultural practices may affect the level of trust that seniors have in their providers, the medications, and the diagnoses.

Pharmacists and other Health Care Providers

Pharmacists, as primary care providers, are an integral part of a well-functioning health care system. When seniors are able to access their prescriptions and pharmacists, hospital admissions go down (Clark & Leipert, 2007; Hiscock et al., 2008). The lack of pharmacies in a town contributes to less utilization of pharmacists, thus decreasing their ability to manage and coordinate elderly patients' complex multi-drug regimens (Xu et al, 2003). Pharmacists are a "significant component of primary health care" (Hiscock et al., 2008). Straub and Holmes (1997) found that in rural areas, pharmacists are the most prevalent health care providers and that they engage in a significant amount of contact with seniors (Lin et al., 2005). The role that pharmacists play in the health of seniors is well documented; for example, pharmacists' direct involvement with seniors improves medication adherence and access to prescription drugs (Lin et al., 2005).

Pharmacists review patients' medications and provide counseling about adverse reactions, drug interactions, costs, and treatment concerns (Lin et al., 2005). Given that the elderly tend to have chronic diseases — often multiple diseases — and tend to take multiple medications, such counseling, monitoring, and patient education are particularly important (Lin et al., 2005). In fact, pharmacists are aware that their involvement in a

community may improve patient care (Murray et al., 2004). For example, pharmacists' involvement and their ability to get to know an elderly patient in their community have been found to reduce the rate of inappropriate prescriptions by primary care providers and also reduce the rates of adverse drug reactions from inappropriate prescriptions (Lin, 2004).

Inappropriate prescribing may be the result of a senior seeing multiple healthcare providers; thus, a pharmacist in the community has the ability to monitor and coordinate medications that are prescribed by multiple providers (Lin, 2004). Adding to the importance of community pharmacies are previous studies that suggest that "community pharmacies are the most accessible health resources to the general population, especially in rural areas" (Lin, 2004, p. 301). In fact, rural seniors are more dependent on community pharmacies for their medications than are urban seniors, and, in addition, are more likely to use the pharmacy than to use medical providers as a source of medication (Mueller & Schur, 2004). One important way that community pharmacists help seniors get medications is by connecting seniors with drug company programs for low-income patients. Many pharmaceutical companies now have such programs, including Astra Zeneca, Merck, and Pfizer.

CHAPTER III

METHODS

Historical Context of the San Luis Valley

The San Luis Valley of Colorado is one of the oldest settled areas of the state and one of the most isolated. The Valley is home to Colorado's largest population of Hispanic families, many of whom have lived in the area since the Spanish conquest (Tushar, 1975). Residents of the Valley are overwhelmingly poor and are aging, while many younger residents out-migrate for better jobs (Counihan, 2009; Magilvy et al., 2000).

The Valley has a long history of settlement by Native Americans, Spaniards, and Mexicans. The first known English description was written in 1807 by the explorer Zebulon Pike (Bean, 1964). However, previous to Pike's visit to the Valley, Native American tribes both lived and hunted in the area. The Utes, Tewas, and Uncompahgres all lived on the land, while Apaches, Comanches, Arapahos, Cheyennes, and Kiowas contested dominance of areas of the Valley for control of the rich hunting grounds. The Utes controlled the Valley for much of its early history. Because of their dark skin, other Native tribes called the Utes "blue" and the Valley "the land of the blue sky" (Bean, 1964).

The Spanish are believed to have first arrived in the Valley in the 1500s, travelling back and forth to Mexico via Medano Pass in the Sangre de Cristo Mountains, which frame the eastern edge. Due to the Native peoples' dominance of the region, coupled with a harsh climate, the first Western settlement did not appear until 1849. This first permanent settlement was in what is now the town of Guadalupe. Settlers were

primarily Spaniards who had bred with the Native population as well as with their slaves and servants. Many of their descendants live in the Valley today (Bean, 1964).

Given the long history of settlement, exploration, mining, Indian wars, the Civil War, and important treaties (Bean, 1964; Simmons, 1979), there is surprisingly little information on the Valley, its history, and its residents. Some of the families have written and published their genealogies, and there are locally published books that are valuable sources of information, but compared to other prominent areas of the United States, the research material available on the Valley is scant.

The San Luis Valley is the largest valley in the United States and one of the largest mountain basins in the world, comprised of approximately 8,000 square miles with an average elevation of 7,500 feet. The Valley is an elliptical-shaped land mass bounded on the east by the Sangre de Cristo Mountains and the San Juan Mountains on the west. The Rio Grande is the largest river that flows through the Valley with its headwaters at the Continental Divide. Various tributaries allow for irrigation, although there is little precipitation, and water is a scarce commodity due not only to the arid nature of the Valley but also to the numerous water contracts that exist that funnel water out of Colorado to the West.

The modern San Luis Valley is comprised of six counties: Alamosa, Conejos, Costilla, Mineral, Rio Grande, and Saguache. The Valley remains an agricultural region that employs many migrant farm workers and has the largest native Latino/Hispanic population in the state of Colorado — families who descended from the original Spanish, Mexican, and Native American settlers. Families with names like *Jaquez* and *Espinosa* still live and work in the area and maintain leadership roles in the communities. Family

traditions are important and are cherished, and food, social ties, healing, celebrations, and cultural practices have been cultivated and honed over generations (Tushar, 1975).

The people of the Valley have been resilient as newcomers have moved in and young people have moved out. Many, like Theresa Vigil, a local herbalist, left the Valley in their youth for a professional education only to be called back by the beauty and history of the place and their ties to family and tradition (Vigil, 2012). Others have remained in the Valley and carved out a leadership role in the communities as teachers, health care professionals, attorneys, farmers, and ranchers. While progress has certainly come to the Valley, residents still cling to "the old ways" that keep traditions alive.

While a romanticized version of the Valley and its residents is accurate in many ways, there are down sides. The Valley is a geographically large area that is distant from urban centers and the amenities that urban centers have. Like other rural areas, the relatively small and scattered population and high poverty rate do not support large, intricate health care systems. The folkways, rural culture, aging population and lack of urban amenities make establishing a career in health care less attractive for young health professionals like family practice physicians, nurses, and pharmacists. The lack of these practitioners has reached a crisis level in rural areas of the United States, and the Valley is no exception (Morton and Weng, 2013).

Rurality plays a key role in both the culture and the disparities that Valley residents experience. Employment primarily revolves around agriculture, construction, and service jobs, all of which are low paying ("Colorado — Kaiser State Health Facts," 2011). Towns in the Valley are far from each other, and roads are long and lonely. Winters can be difficult with sub-zero temperatures and heavy snowfall. A large

population of migrant workers comes each year, and some settle in the Valley; seniors from other parts of the United States come to retire, and still others come to get away from urban lifestyles. Tourists flock for the solitude, the Sand Dunes, the outdoor activities, and the art and often stop on their way to Taos or Santa Fe.

The San Luis Valley is at the same time economically depressed and culturally vibrant. Its large Hispanic population is the largest native Hispanic population in the state ("Colorado — Kaiser State Health Facts," 2011; U.S. Census Bureau, 2010a). Residents actively guard their history and culture and take pride in the lifestyle that their ancestors created (Counihan, 2009). Younger residents, however, often want the excitement and opportunities that an urban environment provides, so out migration is common. As a result, the population of the Valley is aging, which creates difficulties for those left with few resources. Yet, the people of the Valley have actively sought ways to make rural living more attractive to health care professionals, retirees, and college-age students. Adams State College is now Adams State University and has a thriving relationship with the University of Colorado Denver Anschutz Medical Campus. Its related institutes such as the Colorado Clinical and Translational Services Institute (CCTSI), which is funded by the National Institutes of Health, bring medical, nursing, dental, and other health professions students to the Valley to do portions of their residencies. Through these relationships, future health care providers are exposed to the culture and lifestyle of this historic and vibrant area in the hopes that some of them will want to settle there.

An active health research community also thrives in the San Luis Valley. Professionals in the clinical and social sciences actively work in the Valley, studying various aspects of health care in both academic and applied-research contexts.

Collaboration with local health facilities allows researchers to translate research into practice to create better services with the limited resources of rural communities. Thus, the San Luis Valley, while it has significant challenges, is a breeding ground for understanding both the plight and the abilities of rural seniors.

Data

Data for this study came from respondents from four separate groups: 19 seniors (aged 60-85) from five towns in the San Luis Valley, Colorado; members of two seniors' social support network (two daughters); primary care providers in five of the six Valley Wide Health Systems clinics as well as each of the four Rio Grande Health Systems clinics that serve the elderly; and seven pharmacists. The towns in which I interviewed seniors included Alamosa, Billington, Dagus, Tara, and Ravensport (except for Alamosa, which is easily identifiable as the hub of the Valley, the names of the towns have been changed). I chose these towns because of their diverse populations and distinct geographic placements. Seniors in these towns live varying distances from pharmacies and thus perceived distinct barriers and facilitators to access. The University of Colorado Denver COMIRB granted approval for this study (reference 11-1599).

Seniors

The criteria for selection of seniors were: at least 60 years old, at least one documented chronic health condition, take at least two prescription medications, and no more than 200% above the poverty line. Initially, I used purposive snowball sampling using key informants to try to answer the research questions and to have a population with which to start (Charmaz, 2006). Once categories began to emerge, I went to theoretical sampling to find participants who could contribute to the development of my

theory (Charmaz, 2006; Creswell, 2013). Through coding, field notes, memos, and follow up interviews, themes emerged that led to my findings. The senior sample was purposive in order to obtain the perceptions of seniors who fit the criteria for selection and who represented diverse sections of the Valley. Choosing respondents from different towns also helped to confirm the emerging theory because the respondents had heterogeneous backgrounds, based not only on their place of residence but also on their distinct distance from pharmacies and other healthcare amenities (Creswell, 2013).

Sixteen respondents were recruited primarily with the assistance of key informants from local senior centers; three other respondents were recruited through their caregivers. Each potential respondent was invited to participate in a study about how seniors cope with inconsistent access to prescription medication by the key informants. Each respondent who consented to be interviewed was asked to sign a consent form and told that they would remain confidential. Of the 19 seniors, seven were interviewed in Billington, five in Dagus, three in Ravensport, two in Tara, and two in Alamosa. Twelve seniors are Latino/Hispanic and seven are white. The ethnicity of respondents is close to mirroring the ethnic make up of the Valley: 63 percent of respondents are Hispanic, compared to 46.9 percent of Valley residents, and 37 percent are white, compared to 49.8 percent of Valley residents (See appendix H).

Social Support Network

Criteria for a social support network included anyone who provided instrumental support to the senior for the purpose of accessing their prescription medications. Thus, those whose support did not specifically help a senior get their medicine were not considered. Only two of the seniors had members of their social support network

available to be interviewed. Of the 19 seniors, most did not have a support network that provided instrumental support. Each respondent was an adult daughter who happened to be available to be interviewed, and each consented to be interviewed separately from her parent. They were consented and informed that their identity would remain confidential.

Pharmacists

I used theoretical sampling not only because a theory was emerging from the seniors' data, but also because the pharmacists are a homogeneous sample who share characteristics of their job. The sample was also a convenience sample because it was based on pharmacists who were available to be interviewed at the chain pharmacies. Through semi-structured, in-depth interviews they began to confirm my emerging theory. A pharmacist from each of the pharmacies in the Valley was recruited by telephone. I called several days in advance and made an appointment. Each pharmacist was told that I wanted to understand their perception of the barriers that seniors face in being able to purchase their prescriptions and that the interview would take approximately 45 minutes. The four chain pharmacies employ more than one pharmacist, so I interviewed the pharmacist who was working during the least busy time of the day or evening. At the independent pharmacies I interviewed the pharmacist, who is also the owner. Each participant was consented and told that his or her responses would be confidential.

Primary Care Providers

The primary care providers' sample was purposive and convenient. PCPs at each clinic were recruited by their clinic managers based on the patient load of seniors on the day that they chose to do the card study. Only those providers who were seeing seniors on that day participated. Neither the names nor the degree of the providers were

requested. Each patient card was filled out anonymously. Every clinic in the Valley Wide Health Systems and Rio Grande Health Systems initially agreed to participate, although, in the end, one of the Valley Wide clinics did not participate because the providers were too busy. Primary care providers were not consented because their participation was anonymous and I never knew who the providers were.

Data Collection

I collected data on four separate groups: seniors, seniors' social support network, primary care providers, and pharmacists. Seniors were interviewed using semi-structured, intensive interviews; only two seniors had members of their social support networks who were available to be interviewed, and those interviews were semi-structured. Pharmacists were interviewed using semi-structured interviews, and primary care providers' data was collected through the use of a card study.

With the exception of the card study, which did not require an interview, a general set of questions, including questions about demographics, were asked of all respondents in their categories, i.e. seniors, support persons, and pharmacists. Each group's general questions included guiding questions at the beginning of the interview (see Appendix F). As each interview progressed, I included questions that were specific to their barriers, medical conditions, or other circumstances. As respondents brought up new topics, I followed their lead and allowed them to expand on their topic of interest. Through the course of the interviews, new topics evolved from one interview to the next and each was systematically followed up with both the respondent and in subsequent interviews. Each respondent was forthcoming with answers to my questions. No respondent refused to answer any questions; in fact, each person was anxious to tell their story and almost every

respondent said that s/he hoped that my study would make it easier to access their medications.

Seniors' perceptions of barriers, coping strategies, and decision-making strategies were identified during memo writing and initial coding, which was done at the end of each interview, and presented to subsequent respondents for their comments and consideration after they had discussed their own perceptions. The same technique was applied to my interviews with pharmacists and the two seniors' daughters. An iterative approach to the interviews compared each respondent's comments with previous interviews to allow me to gauge commonalities within and across geographic areas of the Valley. Interviews with seniors were conducted until I reached the point of saturation where I was hearing the same answers to questions and the same comments about barriers. Each interview lasted from 45 minutes to two hours. I followed up with respondents when necessary for clarification of previous information or to check on my own understanding of something they had said. I also checked in by telephone, particularly with my key informants to follow up on the respondents' health.

All interviews were audio recorded and transcribed verbatim. All respondents except the PCPs were given a $10 gift card to Safeway to thank them for their participation.

Seniors

Intensive interviews delve deeply into the respondents' "stories" and elicit an understanding about the condition that is being discussed. The interviews that I conducted allowed respondents to elaborate on the process of obtaining their prescriptions, including decision-making, and included information about social support

networks, their primary care providers, and any barriers that they perceived that hindered their ability to access their medications. Getting the "story" directly from seniors is invaluable in understanding how their access can be increased through structural or community interventions. I was able to establish a trusting rapport with all the seniors and that rapport gave me a greater perspective on the cultural ties, practices, and beliefs that influence the perceptions of their own health and what influences their decisions.

These processes encompassed those categories that were most relevant to the seniors and illuminated relevant ways of decision-making, given their unique circumstances and cultural contexts. Those processes that were not immediately obvious were discerned through a more emic perspective, that is, understanding how seniors perceive and categorize their options, based on what has meaning for them. Using in-depth and intensive interviews allowed me to go beyond stereotypes and assumptions that are prominent in the literature and to understand where there is an intersection between emic — the seniors' perceptions and etic — the perception of previous researchers' perspectives.

I chose to interview seniors from different towns, which were, in turn, chosen for their geographic and demographic diversity. Dagus has a large migrant farmworker population, many of whom have retired in the town. There is a large percentage of Hispanics (87 percent), many of whom do not speak English. Forty percent of the jobs in Dagus are manual labor or agricultural. Tara has a population that is about 59 percent white and about 37 percent Hispanic. Ravensport has a Hispanic population of about 84 percent with 13 percent whites with little agricultural work; construction is the primary industry. Billington is one of the smallest towns in the Valley with just 784 residents.

Hispanics comprise 85 percent of the population and whites 12.5 percent. About 29 percent of the industry is in retail trade, with about 28 percent of the jobs in construction (U.S. Census Bureau, 2010a).

Social Support Network

I interviewed the two seniors' daughters using semi-structured interviews regarding the type of social support that they provide for their parent. Each interview lasted approximately 30 minutes and elicited information about the seniors' needs and how the daughter helped in meeting those needs. I also interviewed a nurse in one of the clinics in the outlying area of San Jacinto who provided instrumental support to some of the clinic's patients. This interview was spontaneous, as I had not intended to interview individuals in the clinics; however, as the opportunity presented itself and the nurse was eager to share stories about some of the clinic's patients, I took the opportunity to get a better understanding of another provider's perception of seniors' barriers.

Pharmacists

I interviewed pharmacists in Alamosa and the towns of Linda Vista and Venado, where two of the independent pharmacies are located. The interviews were semi-structured, in-depth interviews conducted at the pharmacies. In all but one case, I met privately with the pharmacist in a room separate from the customers and other staff. All interviews but one lasted about 45 minutes. In all cases, the pharmacists had carved out as much time as was necessary to complete the interview. In one case, while at first the pharmacist felt that he only wanted to spend a few minutes with me, his interview ended up being the longest one, at about 90 minutes.

Primary Care Providers — Card Study

I collected data from PCPs who see seniors on a purposely selected day at five of the six Valley Wide clinics and four Rio Grande Health Services clinic using a card study (Westfall et al., 2011). The card study is a short qualitative survey that providers fill out while they are seeing a qualifying patient and designed to elicit specific information about one aspect of medication access (see Appendix E for the instrument). Each clinic was given a packet that included the questionnaire cards, a return envelope, my business card, and detailed instructions for how to fill out the cards for each patient. I also went over the instructions with the clinic managers and checked understanding by asking that they repeat back the instructions to me. Each clinic manager obliged and demonstrated understanding of the procedure.

The clinic manager chose the date based on the number of elderly patients scheduled. Since each clinic has multiple providers, each provider who saw patients who met the criteria for inclusion filled out the card for that patient on the chosen date. Before each appointment, the medical assistant or scheduling clerk attached a card to the chart of each eligible patient so that the provider would have the card during the office visit and could fill it out immediately thereafter. Once a card was filled out and returned to the clerk, he or she put it back in the envelope that I supplied. I picked up the envelopes within a few days of the study.

Data Analysis

Data analysis proceeded in two phases: the analysis of interviews and the analysis of the card study. Interview transcripts, memos, and field notes were analyzed using a

grounded theory approach. Each interview was transcribed verbatim and then I used line-by-line coding to categorize the data. Once categorized, I used *in vivo* coding to look for individual perspectives and specific terms that might provide insight into respondents' meanings. Such terms as "milking the system," "scum of the earth," and "side effects" were used by several respondents and their meanings were important to unpack and understand.

Next, using focused coding, I looked for those initial codes that were most prevalent and conceptual. Such codes/themes as "out of their control" began to emerge and I began to construct a set of major categories. Finally, using theoretical coding, I began to put the most salient themes together to try to link what I felt were the major categories to see if I could find a relationship. Glaser (1978) discusses "how the substantive codes may relate to each other as hypotheses to be integrated into a theory" (p. 72) and so I looked for relationships in the data that might be so integrated.

Analysis of "the way things are" and "out of control" provided an analytic stepping-stone from which to explore respondents' actions in response to their frustrations. In this study, respondents' concepts of "the way things are" ultimately led to their acknowledgement that they did not know what to do to make their lives better; they felt "out of control." Lack of trust, frustration, and a feeling of helplessness are universal themes that take on different dimensions in the realm of medication access. By exploring versions of these themes, as related in the data, and consolidating them, there emerged a construct that could encompass the themes and provide a description of a larger theory.

Developed by Glaser and Strauss (1967), grounded theory is an inductive approach to data analysis that generates theory through an iterative process of comparison

of observations. Through the analysis of categories, themes, and patterns, Grounded theory uses empirical data, analyzed in a systematic way, to produce findings in qualitative research.

Strauss and Corbin (1990) suggest that grounded theory allows for the social scientist to also be creative if three guidelines are followed: (1) Keeping the data at the forefront by making sure that observations fit the reality of the data; (2) Maintaining skepticism or approaching all findings, observations, explanations, and questions about the data as provisional until they are aligned with the data; and (3) Following rigorous research procedures by using systematic coding to attain reliability and validity in the data analysis. Glaser and Strauss outline coding techniques that include initial coding, focused coding, and theoretical coding strategies in order to discern patterns from the data.

Grounded theory emerged partially in response to the positivist movement of the mid-1960s. Glaser and Strauss showed that qualitative research is empirical, systematic, and credible (Charmaz, 2006) and can produce middle-range theories as advocated by Merton (1968). Importantly for this project, Strauss injected his views on human agency into the grounded-theory method and concluded that social meaning develops through action (Charmaz, 2006). Charmaz (2006) encapsulates Strauss's ideas in her statement, "Strauss brought notions of human agency, emergent processes, social and subjective meanings, problem-solving practices, and the open-ended study of action to Grounded theory" (p. 7).

Charmaz (2006) proposes an "interpretive portrayal of the studied world" (p. 10) that constructs the participants' realities. In choosing grounded theory as a method of data

analysis, I was able to interpret the realities of the seniors and to construct a picture of how their realities affect their ability to stay healthy given the decisions that they make with respect to their medications. Grounded theory allowed me to fully investigate all aspects of my respondents' views and decisions as they work to construct their plans for how to cope with any perceived barriers to their medication access.

Theory is developed as a result of collecting, coding, and analyzing data acquired through selective sampling that occurs after the initial sample is interviewed (Charmaz, 2006; Glaser, 1992). Throughout the interview process, coding reveals new insights that are included in the subsequent interview questions. Respondents may be re-interviewed and new subjects added until saturation of information is reached.

Coding is the central part of data analysis in grounded theory. I coded interviews as prescribed by Glaser (1978), Glaser and Strauss (1967), and Charmaz (2006). Throughout my data collection, I took field notes and created memos as an intermediate step and prompt for data analysis. I sorted, catalogued, and analyzed the coded transcripts to determine themes. My unit of analysis was barriers that respondents described. I began with initial coding of interviews by moving quickly through the data. Next, I used focused coding to categorize the data in a more conceptual and selective way. Finally, I used theoretical coding to create categories that related the focused codes to each other around a central theoretical concept as it emerged from the data (Charmaz, 2006; Glaser, 1992).

Grounded theory's emphasis on induction works best in analyzing these data because there is no current theoretical framework that looks specifically at how the elderly cope with poor medication access. The use of inductive methods allowed me to

focus on emerging concepts in order to describe the ways in which seniors think about their medication access. Using grounded-theory coding, I was able to elicit preliminary themes that led to an iterative comparison with subsequent respondents and providers to get a better understanding of seniors' decision-making process and the barriers they navigate.

A card study is a qualitative survey (Fink, 2003) that is a robust method for describing primary care with minimal time requirements on the part of the provider (Westfall et al., 2011). Data was analyzed using simple cross-sectional, descriptive analysis to explore how PCPs deal with their patients' barriers based on the answers to the survey questions. However, due to the small number of respondents (56), neither statistical analysis nor generalization was feasible. The data elicited from the card study allowed me to get basic information from primary care providers whose schedules did not allow for in-depth interviewing. Minimizing time spent with providers is important because of the schedule to which they must adhere and because of the relative shortage of providers in the Valley. Because, in some clinics, providers were seeing in excess of 40 patients per day, using the card study method was the best way to honor their time and still get data about their experiences.

Using the grounded theory approach allowed me to discover the theme that runs through the data. The thematic process incorporates the basic social process of change through seniors' decision-making, while allowing for the multiple perspectives of seniors, pharmacists, PCPs, and those who provide instrumental social support. The use of the card study added a dimension that would have otherwise been unavailable. Together, the

interviews and the card study worked to provide a more complete picture of the barriers to medication access.

CHAPTER IV

PROVIDERS

Comprehensive health care requires the services of multiple providers, most of whom specialize in a certain area such as physical therapy, surgery, or mental health. Every patient with chronic diseases will use providers from different specialties who work together and, hopefully, coordinate care so that care is not duplicated and the patient receives optimal benefit from each provider (Artnak et al., 2011). For this study, I have concentrated on only two types of providers: primary care providers (PCP) who include physicians, physician assistants, and nurse practitioners, each of whom has prescriptive authority, and pharmacists. Seniors' care is impacted by their structural health literacy, which, in turn, impacts some of the interactions that providers have with them in clinics or in pharmacies. For example, seniors' ability to take some medications and not others (because of cost, side effects, or regimen) can alter the way that a provider prescribes medication. A new medication that may be more efficacious is useless if the senior cannot buy it because the insurance does not cover it. Thus, providers, in order to ensure that their patients have the best chance of adherence, are admonished to learn about each patient's potential barriers to access (Medina, 2015).

Primary Care Providers

Since this study is about access to medications, my concern with primary care providers is primarily about their understanding of seniors' ability to access the drugs that they are prescribed. Because of the large volume of patients whom each provider sees, as well as the shortage of PCPs in the Valley, interviewing PCPs was not possible. A card study (Westfall et al., 2011) was conducted in nine clinics of the Valley Wide Health

Systems and the Rio Grande Health Systems in order to gauge PCPs' understanding of whether their senior patients have trouble purchasing their medications.

The card study is a short, targeted survey that is similar to a rapid-response survey and is administered over one day (Westfall et al., 2011). The benefit of using a card study in this project included the PCP's ability to provide data within his or her clinical time constraints, the ability to target the specific population of interest, i.e. seniors, and the ability to get a snapshot of providers' understanding of seniors' medication access barriers. Of the nine public clinics that serve the poor, eight responded. One clinic did not respond because its manager (who also manages two other clinics participating in the survey) stated that the PCPs did not have time to fill out surveys because the clinic is understaffed, and PCPs were seeing 50 percent more patients than normal. This inability to take approximately 15 to 30 minutes to fill out the survey suggests that PCPs in the San Luis Valley do not have time to ensure that patients have access to the prescribed treatments. PCP shortages in rural areas are well documented (Artnak et al., 2011; Carlton, Simmons, & Simmons, 2011), and the ability to ensure that patients can get their medications is key to therapeutic treatments (Osterberg & Blaschke, 2005).

Providers documented visits for 52 seniors. Fifty-nine percent received a prescription that day. Of those, 56 percent were for new prescriptions, and 47 percent were for refills. One card did not state the nature of the prescription. Sixty-three percent of the prescriptions written were for acute conditions, and 44 percent were for chronic conditions. Relative to barriers to medication access, 54 percent of providers were not aware of any barriers that their patients had to access, and 27 percent did not respond; only 19 percent were aware of at least one barrier. The main barrier that PCPs

acknowledged was cost (n=7), followed by "other" (n=4), and distance to a pharmacy (n=3). When asked if the PCP discussed potential barriers to prescriptions, 31 percent said "yes," 42 percent said "no," and 27 percent did not answer. Asked if the provider were aware of anyone who helped the patient get their medications, 27 percent said that they were, 41 percent said "no," 19 percent did not know, and 17 percent did not answer.

The results of the card study suggest that PCPs in the Valley are prescribing medications without knowing whether the patient will be able to follow the treatment plan. Just writing a prescription does not ensure that the patient can get the medicine or that the patient can continue a course of treatment over time. Thus, patients are often accused of being irresponsible for not adhering to medication regimens when, in fact, adherence is impossible without access (Osterberg & Blaschke, 2005). This lack of understanding underscores concerns about quality of care, which directly impact the ability of patients to overcome or live with their disease. The results of the card study helped to inform the questions that I asked seniors about any barriers that they face (see Appendix E).

While collecting the cards at the clinics, I was able to interview some of the nurses and other ancillary clinic personnel. Valencia, a nurse in one of the clinics, discussed her frustration with the way the PCP in her clinic relates to some of the elderly patients. She told a story of an elderly man who was seen for a routine check for his chronic disease. The physician said after the visit that he wondered whether the patient spoke English because he did not seem to understand what the physician was telling him. The nurse, who knew the patient, told the physician that the man spoke English perfectly but was hard of hearing; perhaps the patient was unable to hear the physician's

instructions. I asked the nurse if the physician were new, and she said that he had practiced at this clinic for many years. Why did the doctor not know that his patient was hard of hearing? Valencia said that the man was a relatively new patient – he had only been to the clinic a few times.

Bob, another patient of this clinic, is a man in his early 90s with good health insurance and prescription-drug coverage. He has trouble getting his prescriptions because of his lack of understanding of the automated ordering system that his mail order pharmacy uses. Valencia often orders his medications for him because he also has poor eyesight and has trouble seeing the keys on his phone, a requirement when making the selections for the order. The clinic in which Valencia works is in an outlying area that is sparsely populated, so she has some time available to help patients like Bob. Valencia's ability and willingness to help Bob is helping him adhere to his treatment plan; however, Valencia's ability to find the time to help her patients is not typical, especially in rural areas where healthcare personnel shortages are widespread. Yet, this type of interaction and intervention could make a difference in access for many elderly patients.

Valencia's efforts point to an informal service that works on behalf of seniors and helps some people with access issues. Formal networks such as Affordable Care Act navigators can help seniors make choices about what Medicare plan to choose once a senior is connected to a navigator, but informal ancillary services such as Valencia provides can be a vital link to medication access. Unfortunately, informal services are hit and miss; that is, if the circumstances are right, a senior may be fortunate enough to find help with an access problem; however, the senior cannot always count on that help being available.

PCPs who spoke to me separately about this project, particularly physicians, expressed that they do not believe it is their job to query patients about medication barriers. MaryAnn said, "It's not my job to hold their [patients'] hands and make sure they take their meds. I'm not a social worker." She goes on to say that "[spending more] time with patients can get me fired [from her job as a physician in a corporate-run clinic], so no, I don't take the time to ask."

PCPs' awareness of access barriers does not necessarily lead to better access for seniors because, ultimately, it is up to the patients to find a way to get their medications. If PCPs do ask about barriers to medication access, however, there is a chance that they may not know how to help patients who have barriers, aside from stocking samples of some of the medications or giving out discount cards provided by pharmaceutical companies. For example, several seniors in my sample said that their PCPs were not aware of policies that govern entitlement programs or the local agencies that can help seniors pay for food. The rules that govern entitlement programs like Medicare and food stamps are complicated and often dynamic. Changes in entitlement programs may improve access overall but create a learning curve for both patients and practitioners that can impede access, at least in the short run. Thus, PCPs' structural health literacy may also be poor given the workload in many rural areas that keep them from taking the time to find out that if Fred owns property, he may be ineligible for food-stamp assistance, thereby forcing him to cut back on his medication in order to eat, as is the case with two seniors I interviewed.

Even in the course of PCPs' daily routines, they must be aware of the structures that govern things like the writing of prescriptions. As will be explained below, errors in

writing prescriptions are often caught by pharmacists, who must return the prescription to the PCP because Medicare or insurance companies will not pay for the medication unless the prescription is written in a specific way. Thus, the PCPs' knowledge of the policies that govern their own practices is sometime lacking, resulting in access problems for seniors.

Still, the results of this card study suggest that PCPs are not aware of barriers that many of their patients experience in trying to purchase their medicine and, therefore, they are not able to structure their patients' therapies in the most effective way. Furthermore, these results are corroborated by interviews with patients and members of the clinic staffs. The effect of poor access is that if seniors cannot purchase their medicines, then they cannot adhere to their PCPs' recommendations.

Pharmacists

Pharmacists are the most accessible healthcare providers (Sunderland et al., 2006); patients can walk into or call any pharmacy and get advice about their medications. Pharmacists can provide many services beyond the mere filling and dispensing of prescriptions; for example, many pharmacies provide immunizations; monitor blood pressure; fill medication boxes; monitor medication adherence; monitor narcotics addiction; provide assistance with the use of medical equipment; educate seniors about their medicines; and, most important, safeguard against medication errors that stem from PCPs' inaccurately written prescriptions (Berbatis, Sunderland, Joyce, Bulsara, & Mills, 2007; Sunderland et al., 2006).

The pharmacists I interviewed noted that barriers to consistent access to medications goes beyond just transportation, cost, and other barriers reported in the

literature. While the barriers that are mentioned in the bulk of the literature on access certainly play a role, structural forces outside of seniors' control have even more impact on the availability of medications to seniors. The wholesale cost of drugs, insurance policies, and seniors' knowledge of the healthcare system drive both the availability of medicines and the seniors' ability to buy them.

There are four chain pharmacies and now three independent pharmacies that serve the 8,000 square-mile area and 47,000 residents of the Valley. Five of the pharmacies are located in Alamosa, and the others are within 20 miles of Alamosa, leaving residents who live in other towns at a disadvantage; some areas of the Valley are 60 miles or more from Alamosa. I interviewed seven pharmacists in the Valley. Mike, Rachelle, Anita, and Luis work at the chain pharmacies; Paul, Antonio, and Hannah own small, independent pharmacies.

None of the chain store pharmacists is a Valley native; each came from other areas, primarily urban areas in other states. Luis has been in the area only a few years. He lives outside of town with his family and rarely interacts with the community outside of his job. He enjoys outdoor activities and finds ways to get out of the Valley when he can. Mike has been in the Valley for a number of years and spends much of his time trying to decipher insurance benefits for his patients. Talking to him, one can see the frustration on his face as he describes how many seniors do not understand how the Medicare system works. Rachelle is the manager of her chain pharmacy. She is young but she seems to have the pulse of the community. Her frustration is with the PCPs who, she believes, do not pay enough attention to their patients' prescriptions. She says that she catches many prescription errors each week, and she would like to meet with PCPs to "teach" them how

to write prescriptions properly. Anita works at the fourth chain pharmacy. She is concerned that she spends too much time educating patients about things that she feels should have been discussed by PCPs.

Hannah, Paul, and Antonio are independent pharmacists. Their stores are fairly close to each other, within a 20-minute drive. Hannah is active in her community, and she tries to keep in touch with her customers by offering delivery within a small radius of her store. She is a Valley native who raised her family in the area. Antonio's pharmacy is a small independent pharmacy. He is also active in the community, often participating in health fairs and other health-related events; however, he does not keep up with much of the news about what the independent pharmacy owners are doing to safeguard their businesses. Antonio, while not a native of the Valley, has lived there for many years. Finally, Paul's pharmacy closed during this research project. Paul tried different ways to stay in business while offering services to communities far from his store. His story is highlighted at the end of this chapter. Paul's concern is with insurance companies and the way that they reimburse pharmacies. Paul and his family are Valley natives.

The differences in each pharmacist's origin does not predispose them to be more or less involved in the community or to try to make access easier for seniors. Rachelle, for example, does not have the constraints of pricing and profit margins, so she is able to spend more time with seniors who have questions or concerns, and she knows that she can stock any medications that her customers need. Paul, an independent pharmacist and Valley native, tried many different strategies to stay in business over the years, including not stocking drugs that were too expensive, at the expense of his customers' needs; yet, he felt he had no choice. Thus, while all of the pharmacists are concerned about their

patients, the chain pharmacists are just employees in a large corporate structure that can withstand and often dictate pricing policies. The independent pharmacists must safeguard their bottom line at the same time that they work with patients. Chain pharmacists are unlikely to lose their jobs and do not have to worry about cost, supply, or other aspects of the business, while independent pharmacists must possess a complex set of skills that include taxes, insurance, marketing, promotion, negotiation, law, and management and go beyond the knowledge of drug interactions and Medicare plans.

One important function that pharmacists provide is working with insurance companies, including Medicaid and Medicare, to ensure that prescriptions are covered (Radford et al., 2009). Often the pharmacist is the one who discovers that a patient has inadequate drug coverage or that a prescription does not contain the required information and is, therefore, not covered by the insurance (Radford et al., 2009). Rachelle, a pharmacy manager, says, "Sometimes seniors come in with a prescription for their diabetic supplies, or whatever it is, and because the prescription has not been written correctly, I can't fill it, so the people get mad at me."

According to pharmacists in the Valley, they and their staff spend between 10 and 40 percent of their time fixing insurance problems, including sending incorrect prescriptions back to PCPs' offices because the prescriptions have missing information. Anita says, "That's a great part of our job, unfortunately, [we spend] at least 30 or 40 percent of our time on missing information." Pharmacists also catch medication prescription errors regularly. According to Rachelle,

> I catch maybe 10 [errors] a month. Mostly the mistakes are made by the EMR [electronic medical records] systems, where the docs have these automated systems that spit out the script. For example, just yesterday I caught one where the prescription was for an extended-release version of the drug when the patient

> needed the immediate-release version. I asked her what this drug was for and when she told me, I had to send it [prescription] back to the doctor. It happens all the time.

Part of the reason that pharmacists in the Valley believe that they spend so much time fixing problems is because in the Valley, pharmacists and PCPs do not communicate. There are rarely meetings or conferences where providers and pharmacists talk about their concerns together. In fact, one community group in the Valley recently received a grant from a large Colorado nonprofit funder to hold such a meeting. George, the coordinator and facilitator, explained, "I had to set ground rules so that the meeting would be civilized, and people wouldn't call each other names. They [doctors and pharmacists] just don't get along. I don't know why, but they don't."

Pharmacists' Perception of Seniors' Medication Barriers

In my interviews with the pharmacists, I noted two themes that explain concerns pharmacists have regarding seniors' ability to access their medications: the cost of drugs (COD) and reimbursement to pharmacies, and seniors' structural health literacy. These two general themes encompass barriers that both directly and indirectly hinder medication access for seniors and also affect the ability of local, independent pharmacies to stay in business.[3] COD and reimbursements influence three categories: financial concerns, availability of medicines, and morbidity, while structural health literacy influences financial concerns and morbidity; in turn, each theme is influenced by government and corporate policy (see figure 4).

[3] Two weeks prior to this writing, one of the remaining four independent pharmacies closed.

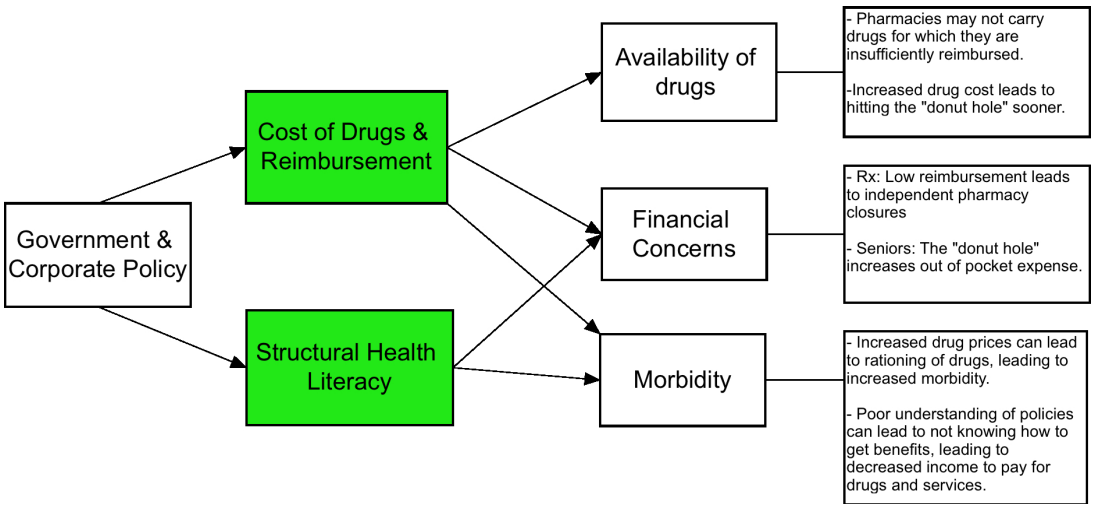

Figure 2: Pharmacy themes and how they impact pharmacists' concerns.

Cost of Drugs and Reimbursements

The cost of drugs and reimbursements affect both pharmacies and seniors. For pharmacies, especially independent pharmacies, reimbursements that are less than the acquisition cost of a drug create a revenue loss that is often unsustainable. If pharmacies lose enough money on certain drugs, they may choose to stop carrying those drugs, which leads to a senior's inability to purchase the drug from that pharmacy. Another implication of the cost of drugs for seniors is that the retail price of a drug, regardless of the senior's co-pay, counts against the Medicare gap ("donut hole") ceiling. Finally, increased morbidity is a factor when a senior in unable to afford the cost of a drug. As will be seen, seniors often ration their medications by taking less, altering the recommended schedule, or not purchasing the drugs. Each of these choices can result in increased morbidity because the treatment plan is not being followed.

What follows is an explanation of how drugs are priced in the marketplace. An understanding of the pricing and reimbursement structure is necessary in order to get a complete picture of pharmacies' financial constraints, which can lead to going out of business, and why independent pharmacies stop carrying some drugs. In rural areas,

where one independent pharmacy may serve a large geographic area, seniors are at risk of losing not only access to their medications but also to a provider.

The price of drugs is set both by the pharmaceutical manufacturing companies and by the Pharmacy Benefit Managers (PBM), based on their corporate policies (Eberle & Van Amber, 2008; Hoey, 2012). PBMs are third-party administrators for prescription drug plans. Currently, all mail-order pharmacies like ExpressScript are PBMs. PBMs are also embedded in some healthcare plans like Kaiser and the Veterans Administration and within some health-insurance companies (see Figure 3); some PBMs are independent. PBMs process and pay prescription drug claims to pharmacies and create formularies that list which drugs they will pay for and the Maximum Allowable Cost (MAC) for each drug (Eberle & Van Amber, 2008; Hoey, 2012). The MAC defines the price that the PBM will reimburse a pharmacy for each drug that the pharmacy sells (Eberle & Van Amber, 2008). The reimbursement amount is disconnected from the price that a pharmacy pays to purchase a drug from a wholesaler (Wilson, 2012). If a PBM increases the cost of a drug, the MAC price is what the PBM will reimburse the pharmacy, regardless of the price that the pharmacy paid to acquire the drug. MAC prices are set arbitrarily by each PBM, which can increase drug prices at any time for any reason; there is no regulation (Wilson, 2012).

Over the last several years, PBMs have increased the cost of some drugs over 2,000 percent. These drugs include not only expensive cancer drugs but also more common drugs such as antibiotics and insulin. For example, many ointments and creams such as Lotrimin have increased by 1,000 percent, and digoxin, a staple for patients with heart disease, increased from about $1.15 for a three-month supply to $30 for the same

supply, which equates to an increase of over 2,600 percent (E. Rosenthal, 2014). Pharmacies are not reimbursed at the acquisition price but at the MAC price, which may be below the cost that the pharmacy paid to purchase the drug (Choudhry & Shrank, 2010; Eberle & Van Amber, 2008; Hoey, 2012; Wilson, 2012).

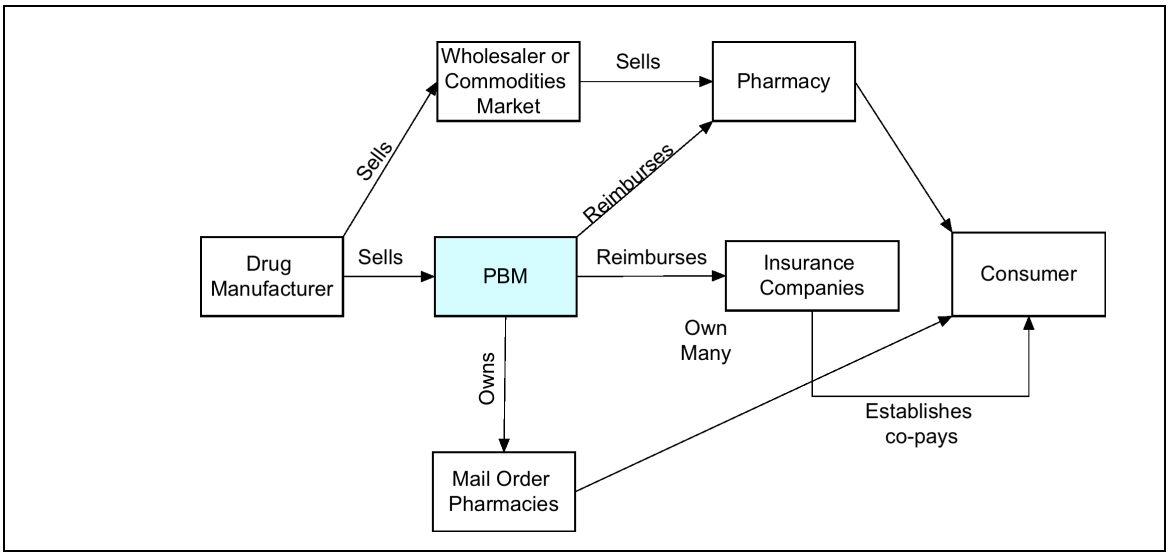

Figure 3 Flow chart of how PBMs are connected in the prescription drug markets.

The amount that a PBM charges for a drug impacts both the patient and the pharmacy in the ways noted in Figure 3. As noted in Figure 3, reimbursements do not flow to the consumer because the consumer either pays a co-pay or the full price; typically, neither PBMs nor insurance companies reimburse consumers for drug purchases. Organizations that lobby for independent pharmacies have helped state legislators pass bills to regulate the PBMs, but the laws are difficult to enforce (Hoey, 2012; Wilson, 2012). In my interview with Brad Young, Director of Government Affairs for RxPlus Pharmacies, a consortium of independent pharmacies that lobbies for favorable state and national legislation, he stated that PBMs have a financial incentive to close independent pharmacies because they will save money on administrative costs; therefore, increasing the cost of drugs to independent pharmacies is in keeping with their

corporate policies of cost containment. RxPlus successfully lobbied lawmakers to pass a bill in the Colorado legislature in 2014 that deals with MAC pricing and requires PBMs to disclose the source of MAC prices as well as allowing pharmacists to appeal below-cost reimbursements. Young said that he believes the law will be difficult to enforce, but it sets a precedent for stronger legislation in the future. Unfortunately, not all pharmacists are active in the consortium and are not knowledgeable about what the consortium is doing. For example, Antonio said,

> I know there was some legislation introduced into the state legislature. I don't know where it went or if it's been killed by now, but there was something being introduced into the state legislature to require third parties to be more responsive to drug price increases, that they would have to check what the AWP (Average Wholesale Prices) was at least on a monthly basis. I don't remember how the whole legislation was written. I'm sure third parties were opposed to it because it would drive their costs up if they had to be verifying the AWP on everything weekly.

The CODs, and, by extension, the MAC price, impact the finances of seniors and pharmacies, primarily independent pharmacies. For seniors on Medicare, increasing the COD decreases the amount of time before they hit the "donut hole."

How fast a senior reaches the "donut hole" is partially based on the MAC price of the medication (Dismuke & Egede, 2013). According to Medicare Interactive ("Medicare Interactive — The doughnut hole," n.d.),

> The coverage gap starts when your total drug costs—including what you *and your plan have paid for drugs*—reaches a certain amount since the start of the calendar year. In 2014, this amount is generally $2,850. When you reach this amount, you hit the coverage gap. As a result of health reform, you get discounts to help you pay for your drugs during the coverage gap. In 2014, there is a 52.5 percent manufacturer's discount on most brand-name drugs. This means you pay 47.5 percent for brand-name drugs listed on your Part D plan's formulary, and the manufacturer plus the federal government together pay 52.5 percent. For generic drugs, the government provides a 28 percent discount in 2014. You pay the remaining 72 percent of the cost. These discounts will gradually increase each year until 2020. Starting in 2020, you will typically pay no more than 25 percent

> of the cost of your drug at any point during the year *after you've met your deductible* (italics mine).

"Your plan" in the above passage refers to the amount that the insurance pays, which is the MAC price of a drug for that plan. If the MAC price of a medication increases, then the senior has fewer dollars to spend before he or she reaches the "donut hole." The "donut hole" can have serious consequences for low-income seniors whose medications may cost hundreds of dollars. Having to pay a high percentage of the retail price for their medicines often forces seniors to go without their full therapeutic dose or even without the medicine altogether. In cases where the medicine is necessary for life, such as insulin, the results can be catastrophic. Thus, the COD affects seniors' morbidity by increasing the cost of drugs that can lead to seniors' inability to afford the medications once they reach the "donut hole" and cannot get therapeutic doses of their medicines because they are rationing medication or cannot afford to buy them at all (Choudhry & Shrank, 2010).

Finally, the COD affects availability of drugs for seniors and has a consequence for pharmacies as well. Often, when a drug's cost goes up, the pharmacy is only reimbursed by the PBMs at the old, lower cost (Hoey, 2012; Wilson, 2012). The difference between the new cost and the reimbursement amount results in a loss of revenue to the pharmacy. Since many of the small, independent pharmacies run on a thin profit margin and make most of their money on prescriptions, any loss becomes painful (Radford et al., 2009). In the San Luis Valley, the independent pharmacies have stopped stocking some of the medicines whose prices have increased. Antonio, one of the independent pharmacists said,

> Unfortunately what's happening now is that mostly the independents, they're starting to lose that money, and they're starting to not fill the scripts and send them [patients] to [the chain pharmacies] because they don't seem to care [about the cost]. But then again, that creates the access issue for the patient because that means to get them filled, the only place they can go is Alamosa. But that is beginning to be the scene, that when they [independent pharmacies] start seeing, relatively speaking, a large amount of money, they're not even getting their drug cost at all. They're literally losing money on it. They can't afford to do that.

In the last month, one of the four remaining independent pharmacies has closed because the owner could no longer sustain the losses (see Paul's Story below).

The effect on seniors is that they can no longer buy some of their medications at the local pharmacy and must go to the chain pharmacies. In the San Luis Valley, there are four chain pharmacies, all of which are located in Alamosa within walking distance of each other; therefore, they are not convenient for the majority of seniors who live outside of Alamosa. The chain pharmacies have many other products and services on which they make a profit, and these other products make up for the loss of drug revenue (Choudhry & Shrank, 2010). The unintended consequences of seniors having to go to the chain pharmacies for certain drugs is that it often becomes more convenient to just buy all their prescriptions in one place, so the independent pharmacies lose customers, which makes them more vulnerable to closing.

Like the cost of drugs, insurance premiums and payments are influenced by policy, and insurance company policies influence seniors' finances, morbidity, and the availability of drugs, as will be described below. While not all insurance plans cover prescription drugs, those that do pay for drugs at different rates, have different formularies, and have different rules about brand-name versus generic drugs (Eberle & Van Amber, 2008). Seniors may obtain drug coverage from public insurers — Medicare

(and Medicaid, if they qualify) — from private insurance companies, or from a combination of public and private insurers.

Insurers set the amounts that they charge patients for co-pays (a fixed amount that a patient pays for a covered health service) and deductibles (an amount a patient owes for a covered health service before the insurance begins to pay) and reimburse providers for drugs through their PBMs. The drugs that are covered are those that are listed on the insurer's formulary (Eberle & Van Amber, 2008). The formulary lists every drug that the insurer will cover and the amount that the insurer's PBM will pay for that drug. Typically, insurance plans are renewed every year, so the formulary is valid for the year. Drugs are frequently dropped or added to the formulary each year, and the amount that the insurer's PBM will pay may also change each year (Choudhry & Shrank, 2010). If a pharmaceutical company changes the price of a drug, the new price does not necessarily affect the amount of reimbursement detailed in a formulary; therefore, pharmacies that buy drugs at the new, higher rate will not always be reimbursed by the insurer's PBM at that higher rate, creating a loss for the pharmacy. As Paul explained,

> I'm losing my butt! And the third parties are not responding to the price increases [of drugs by the pharmaceutical companies and PBMs]. Third parties are the insurance companies. The third parties are [paying] the price of $15 for 100 [pills]. They don't care that you're paying $250 for it. But the insurance companies aren't going to be losing. I mean, they're the ones that are a pain in the butt because the insurance companies, even if they increase [the price of drugs], they're still paying us the same amount as they were a year or two years ago. They're supposed to adjust, but they don't.

Antonio stated, "Unfortunately quite a few [drugs have gone up in price], particularly — and much more so — some of the generics. Prices of generics have increased up to 2,000 percent in that last nine months. There is an antibiotic that is out — tigecycline — [that] used to cost $10-12 for 100, and suddenly the price jumped up to

$350 for the same 100." Finally, in the case of Medicare, the insurer (Medicare) sets the threshold for the "donut hole" and the criteria for who is or is not eligible for services and how much seniors pay (Dismuke & Egede, 2013).

Morbidity is affected by insurance-company policies on reimbursements, copays, deductibles, and brand-name versus generic medications. Insurers try to keep their costs down by advocating for doctors to prescribe generic drugs that cost less than name-brand drugs (Choudhry & Shrank, 2010). Sometimes, however, a generic medication does not work for a patient. Insurance-company policies usually require that PCPs request an authorization to prescribe the name-brand drug for such a patient. If the insurer does not authorize the brand name drug, then the patient must pay out of pocket if he or she chooses to use that drug. Rachelle says, "I also sees a lot of patients for whom the generics don't work, and, in that case, my hands are tied because I can't give them the brand name and often times they're on generics because their insurance doesn't cover the brand name." In a follow-up telephone interview Rachelle explained that typically seniors who want brand-name drugs settle for generics. She says that she rarely sees a patient whose reaction to a generic is severe enough to warrant the insurance company agreeing to pay for the brand name drug. The decision to push for the brand-name drug, however, falls to the physician.

Availability is affected by insurers through their payment policies. If the full price of drugs is not reimbursed to pharmacies, then pharmacies may stop carrying any drugs on which they lose money. If a drug is dropped from an insurer's formulary, then patients cannot access that drug unless they pay out of pocket. Paul says, "They [some drugs] went up 200 fold. They weren't paying us for this, so I quit carrying the product;

therefore, I wasn't filling it. As long as I don't have the product, I don't have to fill it. Therefore, I would stop ordering it until I deplete what I have and I just can't do it. In fact, there are still a few of them that I won't order because it's just too expensive."

Structural Health Literacy and Providers

The health care system, especially insurance, is dynamic; new regulations, programs, costs, and formularies can change every year (Kaplan & Zhang, 2013). For seniors who may be isolated, low income, poorly educated, cognitively impaired, or who do not have or do not know how to use computers and the Internet, getting updated information about the services to which they are entitled is complicated at best. Anita says, "That's the job [of the pharmacist], dealing with all the insurances. But even for us it's complicated. There are just so many — Medicaid, Colorado Access — it's just all confusing. I mean if it's confusing to us, it's confusing to them [seniors]. They get really upset because they're sick, and they want their medicine right away." The lack of information and understanding of the healthcare system policies creates numerous problems for seniors as well as for the pharmacy staff, who often are the ones who disentangle seniors' complicated insurance policies and payment systems.

For example, if a senior only has enough money to purchase one of her two medications, then one of the ailments for which she takes medicine will go untreated. The patient will choose which medication to purchase without necessarily being aware of the consequences of not taking the other medication. Morbidity may also be affected when the choice is between medication and food. For example, Anita explained that a patient

> was unaware of when she was supposed to enroll in Medicare, so she missed it [the enrollment deadline], and it's like a whole year she's going to have to pay a bunch of money. She was talking with her husband, "Oh, we're gonna not eat out as often and stock up on Ramen." It was an older couple who, you know, they just

> missed the enrollments and weren't aware, and so that was a kind of sad situation for them.

Finally, poor structural health literacy can affect seniors' ability to purchase medications if they do not remember which pharmacy has the prescription or do not know which insurance pays the medication. Several pharmacists mentioned the problem of "the little blue pill." Patients often call the pharmacy for refills of medications whose names or other identifying information they do not know. The patient, who asks for a refill of "the little blue pill," sometimes does not know what the medication is for or even whether the particular pharmacy is the one that has the original prescription. Mike said that patients come in and ask for "the small blue pills. My doctor gave them to me, and now I'm out and I need a refill." Once at the pharmacy to pick up a prescription, seniors may empty their wallets of multiple cards, not knowing which one, if any, is the correct insurance card. Often, there are cards that have long since expired, but the senior is unaware of what insurance pays for the drugs or which card has the current information.

Rachelle says, "Patients don't know which insurance card works for any given transaction; they just pull out their whole stack, and the pharmacist has to figure out which one is which." Sometimes, none of the cards is valid, so the patient is unable to pay for the medication. In Rachelle's pharmacy, she keeps a telephone for patient use. She has a book with the phone numbers of the common insurance carriers and government agencies so that patients who do not have their card or have multiple cards can call and try to figure out how to pay for their medications. Rachelle says that having the telephone available for patients saves her and her staff time, but sometimes patients will be on the phone for an hour or more trying to decipher the information. Poor structural health literacy is implicated in a senior's inability to produce the right

insurance card and to be able to straighten out any problems such as those that Rachelle describes.

Paul's Story: The Demise Of Yet Another Independent Pharmacy

Paul has been in the pharmacy business for 13 years. His pharmacy has been located in the center of Alamosa, the hub of the San Luis Valley, where he has watched his patients grow old and develop chronic diseases for which they need their medicine. He has also watched as the small town has grown and incorporated more and more chain businesses. His pharmacy was the only independent pharmacy left in Alamosa, but now, even Paul's pharmacy is history.

When I first visited Paul for this project in February 2014, he was busily filling prescriptions behind a big glass wall. I had made an appointment over the phone the day before, but when I arrived, he sent his assistant to tell me that he was busy and that I could come back tomorrow if I still wanted to talk to him. "I don't really have much to tell you," he commented, "but if you still want to talk, I can give you five minutes. Come back around 1:00." I did.

Before I could turn on my recorder or even sit down, Paul started listing the barriers he thought that seniors experienced. "Distance, money, travel . . . but I don't see that many people that are elderly that have problems with their money." He was clearly in a hurry to get rid of me. Then I asked him about regulations. Paul started talking and didn't stop for over an hour.

Medicare Part B, Obamacare, and the price of drugs — each topic brought a barrage of criticism and a clear indication that he was afraid for his business. "I don't do Part B. The reason for that is that the government wanted $15,000 to $20,000, and I

didn't have $15,000 to $20,000, and I just won't recover that, so I just don't do the Part B. About Obamacare, "it's like with this Obamacare, everybody got put on Medicaid, so, therefore, there's more Medicaid people coming in, whereas last year we had problems with Medicaid paying us because they ran out of money. So I don't know what's going to happen this year when everybody's put on Medicaid and you have a lot more [Medicaid eligible customers]." According to the Health and Human Services web site, the official web site for the Affordable Care Act, Colorado's Medicaid-eligible population increased by 314,436 people (Assistant Secretary of Public Affairs, 2013).

But the increasing price of drugs sent Paul on a tirade about not only the increasing prices but also about how the chain stores do business and treat their pharmacists:

> These insurance companies are not paying us for the increases [in drug prices] . . . I'm losing my butt! When I asked which drugs went up in price, Paul responded: Well, Percocet, the oxycodone. They all basically went up. The others, the name brands, are the ones we really have trouble with because those are very expensive and we don't have that much of a lead way to work with. So if they do go up $10 or $13, we tend to lose but there's not much I can do. They're my customers, so I tend to lose. So I'm not making as much as if I were working for a chain store.

Speaking of chain stores, Paul recognizes that selling drugs is not the only source of income for large retailers, so losing money on a few prescriptions can be made up through the sale of other products like food and housewares.

> It's just a situation that working for a chain store you really don't give a shit (laughs); therefore, you know, you're just running everything through there [the store]. And they're making more money [on] over the counter [medicines] than we are because, the thing is, a prescription department and over-the-counter department are two separate things but if one's not making it, they'll make it with the other one.

Since the chain pharmacies have the power of a large corporate network and multiple lines of profit behind them, Paul believes that the independent pharmacists cannot make the kind of money that they made in the past, thus putting them at risk for closing.

> I know that we're having a hard time staying alive and, you know, there's thoughts in your mind, you know, "The hell with this shit. I'll just go work for the dark side, and not worry about anything," you know. I have to take care of myself, too, because even right now, with my accountant, we went through my taxes and everything else. Shit. If I were working for a chain store, I'm sure I'd be making $110,00 a year. And then my wife is helping, so she doesn't get paid. You work for a chain store . . . I worked for all three, four of them, and they'd kill you. They don't care. It's just volume, volume, volume.

He also believes that he is more capable of giving good service to his customers than a chain; however, there is a cost that comes with trying to keep the "small town feel" of his store. "The customers that I do have, they are spoiled, and I need to [spoil them] because I care about them and there's just not a situation where I can throw them away. So if I do have to close or something, it will hurt."

On the other hand, Paul has tried to reach out to other communities that are far from Alamosa by setting up a system where people can pick up their prescriptions like they pick up their mail.

> OK, [the town of] Dagus: I went through a bunch of red tape, a lot of work and I have mailboxes at a grocery store — just the same thing as a mail system, you know, where we deliver. I take [narcotics] personally and have the people meet me there in the store and hand it to them, and they just sign the paper saying they did receive it. I got over 200 boxes over there, and we advertised and everything else, but not many people take advantage of this situation or this benefit to them. Why? I don't know. So, what does that tell you? Maybe they don't really need a delivery system. Maybe they don't really need anything.

The lack of buy-in at the Dagus location was, perhaps, an indication that other forces are working against independent pharmacies or that people did not know about the mailboxes.

One day I was on my way home from the Valley and decided to stop by Paul's pharmacy to let him know that I had been in Dagus talking about his delivery service. I walked into the store and was surprised to see much of the inside being taken apart by workmen. I thought that Paul was remodeling until I saw his wife Jean. She told me the story of the buyout. Paul was not able to save his pharmacy; he was bought out by one of the chain stores. It offered to take on his debt and his customers, and it even offered him a job, which he accepted. "I guess it's really not so bad; Paul works so hard, and he never gets any time off. Now he'll at least get off days."

"What about your customers?" I asked.

"We put a sign on the door. See? They'll know where to find him."

Providers' perceptions of seniors' barriers to medication access shed light on structural issues that are different than what seniors articulate. Since providers see a different side of poor and inconsistent access, their perceptions help to give a more rounded picture of what barriers prevent access to medications and how those barriers work. In the case of physicians and pharmacists, there is little communication in the Valley, and that leads to delays in getting seniors their drugs. Policies, both governmental and corporate, also impede access for seniors, both directly and indirectly. Overall, providers perceive that the biggest barrier that seniors face in getting their medications is the seniors' inability to navigate the structures that pay for their medications and the constraints that are put on providers by government and corporate policy makers.

CHAPTER V

SENIORS

Seniors in the San Luis Valley are vulnerable to a myriad of health and healthcare disparities. Based on their income, education level, place of residence, and ethnicity, Valley seniors fall into the demographic profile of people who historically have less than optimal health and poorer access to healthcare. In this study, I went beyond the identified barriers and delved into how seniors perceive barriers and how these identified barriers are symptoms of a greater problem, one over which seniors have little control — the structures that lead to access of health care. My data suggest that structural health literacy is the common thread between barriers and access.

I discuss these data about medication access from two standpoints: the structural impact on seniors, which includes structural determinants such as transportation and entitlement policies, and individual determinants of SHL such as knowledge and decision-making. I include a section on social support networks where I explore how these networks play a part in the interviewees' ability to access their medications.

The group of 19 seniors whom I interviewed has a number of challenges that directly affect their access to medications. In particular, all but two seniors live at or below the poverty line. The two seniors who are above the poverty line are still considered low income. All but five of the seniors have adult children, but in most cases, the grown children do not provide instrumental social support to their parent, either because the children are themselves low income or because they are estranged. In a few cases, the senior is caring for the adult child. Most of the seniors have friends and neighbors with whom they socialize but, other than friendship and emotional support,

they do not provide help with medication access because the friends and neighbors are in the same financial situation as the senior.

The seniors are in different stages of their lives. A few are considered "old-old," that is, they are over 80 years old; several still work or volunteer; some are home-bound; others are active in the community through their churches or senior centers. There are differences in the way that the seniors view their lives, from optimistic — they are enjoying their lives, to very pessimistic — they are miserable and have little hope that their lives will improve before they die. No senior, regardless of his or her outlook on life, however, expressed a wish to die. A common outlook on medication access is the idea that "the government" makes life harder for seniors than is necessary; however, as we shall see throughout this chapter, there is little consensus about specifically why their medication access is difficult and how it could be made better. There is also an indication that, in their later years, seniors lose social support when they most need it, which forces them to rely on their structural health literacy to help them get the services that they need.

Impact of Structures

The literature discusses many of the barriers that make medication access difficult for rural seniors (see Appendix C). Barriers such as distance, transportation, and cost have been well documented for many years. The seniors who I interviewed mentioned that some of these barriers create problems in their attempts to get medications; however, not only do the types of barriers differ amongst individual seniors, but the level of each barrier differs. I found that there are differences within barriers and also between barriers. For example, within transportation barriers, some seniors have no car, while others have transportation barriers because, even though they have a car, they have no gas money or

can no longer drive. Another example involves barriers within the cost of drugs. For some seniors the co-pay is difficult, while others can afford the co-pay but because the cost of their drugs is high, they hit the "donut hole" and then have to ration their drugs at the end of the year.

Access is also impacted by the differences between barriers. For example, Dominica has distance barriers because the pharmacy is 54 miles from her home, but her co-pays are low, at about a dollar. Penny and Roberto do not own cars, so they must rely on others to take them to the pharmacy, but Roberto needs nutritional supplements that are not covered by Medicare. Narda and Darla have no income and cannot afford any co-pay at all. Kate and Anna choose to take natural products like herbs, but their doctors know nothing about how the herbs might interact with their prescriptions. Rosa needs more medication, but she can't remember to talk to her doctor about it, and Alphonso received a letter telling him that the medication he is on is not recommended for seniors, yet his doctor will not discuss a change with him and his daughter. Multiple seniors discussed their low tolerance to generic medications, and almost all of the seniors mentioned problems with their drug insurance plans. These barriers, as perceived and discussed, have different levels of impact on the seniors. Of those seniors I interviewed, all feel that they have at least one problem, even when they have transportation and the money to buy the medications. There is no consensus among all the seniors about which barrier is worse.

As mentioned previously, government and corporate policies play a substantial role in seniors' access to medications because policies set the criteria for entitlement eligibility, insurance co-pays and deductibles, physical structures like public

transportation, and the price of drugs. Policies also dictate what constitutes "need" in terms of a senior's income and assets and how care is distributed. Fear of government retaliation for "breaking the rules" often leads to social suffering (Tim Rhodes et al., 2005), even when the rules/policies are unclear, uncodified, or create unintended consequences for seniors. Examples of these issues and the concomitant social suffering emerged throughout my interviews.

Selected Policies and Rules

In this section I discuss the four main policy barriers that seniors mentioned: entitlements, narcotics, transportation, and insurance coverage. Seniors are affected differently by these policies, depending on their needs, state of health, nature of their disease, and where they live.

Entitlements and Means-tested Programs

Seniors who receive benefits that are based on their low-income status like Supplemental Security Income (SSI), food stamps, or Medicaid — have few resources for increasing their income without losing some or all of their benefits. For those seniors who could make a little money to help cover their co-pays, telephone and utility bills, gas, and, perhaps, afford them a modicum of entertainment, making that money is nearly impossible. Recipients must report all income, regardless of its origin, to the Social Services office. Any income may be deducted from a senior's allotment and is counted against his/her eligibility for services (U.S. Department of Health & Human Services, 2014). Thus, a senior who could bring in income from such sources as getting a roommate, house sitting, or gifts from family or friends (including food) to help with expenses, could be in danger of losing his or her benefits altogether. Therefore, many

seniors are afraid to look for ways to increase their incomes, even if they cannot make ends meet with the government income, for fear of losing everything.

Dominica's financial situation is poor. Her $700 per month SSI and $140 in food stamps leaves her little disposable income for her medications despite her co-pays being only one dollar. Her good friend, who is also her caregiver and also a senior, is in a similar situation. Her caregiver qualifies for food stamps and Medicaid. Neither woman is making ends meet. Asked if Dominica and her caregiver could be roommates in Dominica's two-bedroom trailer, she replied,

> No, I'd lose all my benefits. If I get caught I'm in big trouble. I asked them [Social Services], "Can I get a roommate to at least help?" Yeah, when you get a roommate, you lose this, you lose your food stamps, you lose your Medicaid. Man, Social Security says you can get a roommate but then they cut you whatever your roommate is paying. See, she [her caregiver] had a friend, when was it, two years ago? Three years ago? He came back from Montana and needed a place to stay so she let him stay there [her home]. Well, then she talked to Social Services, and they said, "No, we'll charge you." You'll lose your food stamps and as soon as you lose your food stamps you'll lose your Medicaid, and it's all over, and I cannot do without Medicaid.

So Dominica tries to scrape by with what she gets from Social Services. She says,

> I can't stay afloat here and my rent is only $175 a month plus utilities. It's $20 every time you go to Alamosa. I try and lump it all in one day, go to the pharmacy, go to the doctor, go grocery shopping and whatever else I need, in one day, and it's not possible because I can't afford to go back. And they need to relook at their damn food stamp program too — the price of groceries and crap, they're giving me $140 a month, and the rest has to come out of my pocket. Buying beans and cornbread and bread and milk, you can't live off that for $140 a month. I go to the store and spend $140 and still have to come up with $50 to $100 of my own money to cover the rest of the groceries, and you know, I live off sandwiches and TV dinners and soup and Ramen and crap because I'd love to eat healthier, but I can't afford to.
>
> They have got you in a — in a hole — and each time you get your fingers to the top they stomp on them. I actually had people treat me like I'm scum. "You're milking it, you're just another one of "those," but most of the people in this town have raised their kids off welfare, but yet they have a county job. And I get penalized if I get one dollar over what I'm supposed to have in this house. I have

> to report it and I get penalized. I had a retirement I forgot all about from K Mart, where I worked years ago. It was a lousy $2,000 dollars. And I called them and told them I had it and that it was coming and what do I need to do? They took away my Medicaid, they took away my food stamps; they shut it all down after they told me, "Well call when it all gets here. You have to spend it down right now." I wouldn't want to keep one damn penny of it, and they took everything away anyway, and I had to fight to get it put back in place.

Before receiving income from government programs, seniors have to go through the qualification process, which can take a long time; furthermore, each type of government has its own process. In Narda's case, she has qualified for food stamps but not for SSI. As a result, her income is not enough even to afford the most minimal rent or other living expenses. Narda is a 60-year-old woman who has no income to speak of: "I still have food stamps but other than that, I just survive on what I have and what everybody can give me." She did not work long enough to qualify for Social Security benefits, and she is too young for Medicare; she has Medicaid.

> I can't get Social Security [SSI] yet because I haven't worked in a long time, but I've been trying for over – since 2000 to get it. He [her husband] kept moving me around, so I couldn't get it, moving from state to state for jobs. He didn't leave me in one place to get Social Security. And I could have got it back then on my own job work. Now I can't get it, except I have to try to get it. This really sucks (laughs), cause I can't work anymore.

Narda receives "$150 or $160" per month from the Aid to the Needy Disabled (AND) program, which she will have to pay back if she can qualify for Supplemental Security Income (SSI). AND is a state-administered program that "provides a small cash assistance benefit to low-income Colorado residents age 18 – 59 who have at least a six-month total disability that precludes them from working while waiting for SSI approval " ("Aid to the Needy Disabled," 2014). Narda is no longer eligible for AND because she turned 60; however, she will continue to receive benefits until a determination is made on her SSI.

Currently, Narda lives in a 15-foot travel trailer that she is squatting on someone's vacant land in one of the small towns in the Valley. She has no electricity, running water, or heat in her trailer because there are no utilities on the land. Her days are spent at the local senior center, which sends a van to pick up the elderly residents who live out on the prairies and do not have transportation.

Using a walker, Narda told me that her health is "lousy"; she has been diagnosed with multiple sclerosis and has trouble walking. She also has heart problems, sleep apnea, and severe asthma, which she has had since she was a child. Narda has a general idea of her health problems, but her understanding of her diseases is poor.

> I fall all the time . . . I have MS. I got two black spots on my head; one is MS. The two black spots are growths or whatever. It causes blindness and causes paralyzation (sic) in that part of your brain. They said I had a heart attack. They said I have EKG (sic) but I think it was from carbon dioxide (sic) poisoning. I think I'm losing my sight. I wake up in the morning and I'm paralyzed from the waist down or the neck down, and I start crying. And then I suddenly go blind for half an hour to a couple hours, so I just sit there. They say I have tennisitis (sic); I can't play tennis either.

Because Narda is ineligible for Social Security benefits and her wait for SSI has been so long, she has no choice but to live without any amenities. Narda is self-reliant, however, and she takes advantage of many of the amenities offered by the senior center, like the shower and the free breakfast and lunch served during the week. During winter and on cold nights, Narda sleeps with the five cats that she allows into her trailer. "The cats sleep under the covers with me. They love it there, and it keeps me warm."

Narcotics

Another policy that has lately received much attention from policy makers and community leaders concerns the prescribing of narcotics for pain. The Valley, like many other areas, has a problem with narcotic addiction, yet many seniors whose chronic

diseases have advanced, suffer constant pain and rely on their narcotics to be comfortable and even to function. While some seniors have developed a tolerance for narcotic pain relievers and require increased doses from time to time, they are not necessarily addicted and they do not abuse their drugs. Most seniors who I interviewed, who have narcotics prescribed, told the same story: whether they take one pill or two or none depends on how they are feeling that day.

Only one senior, Rosa, takes her narcotics "as prescribed"; that is, her physician prescribed one pill three times per day, and that is what she takes, regardless of her level of pain. I asked Rosa whether her pain required that she take the exact dosage and she said, "no, but that's what he [the doctor] ordered, so that's what I take." However, her prescription is for 60 pills, which does not equate to the 90 pills that she needs to follow her doctor's order. I asked her whether she has spoken to her doctor about the difference in the pill count, and she said that she has not. She was told by her pharmacist the she could only get 60 pills at a time and she can only get a refill once a month, within two days of day 30. When she runs out of pills, she is in pain until she can get a refill. She has not asked under what circumstances she might be able to get the 90 pills she needs.

Rosa's problem stems partly from a fairly new narcotics policy, Policy for Prescribing and Dispensing Opioids (Colorado Department of Regulatory Agencies, 2014) that tries to stem the outflow of narcotics into the illicit market. Throughout Colorado, local task forces are looking for ways to stem the abuse of narcotics by curbing prescribing and dispensing and putting strict controls on when and how narcotics can be dispensed. There are two major unintended consequences to the way that the policy is written in the Valley. First, seniors are required to undergo random urine tests to check

for levels of their narcotics. For seniors who take pain medicine according to their level of pain, test results can be misleading. For example, a senior whose pain is under control may not take their pills on a set schedule. If a urine test shows low levels of the drug on a given day, the provider may lower the amount of narcotics that they prescribe, leaving the senior with too few drugs for when their pain flares up. Conversely, if a senior's pain has increased and he has taken more pain medicine, the urine test may show a higher level of the drug, prompting the provider to decide that the senior is addicted and cutting off the access altogether.

The second major unintended consequence is that providers at all levels have been alerted to the abuse of narcotics, and they have been admonished to be aware of signs of addiction and abuse. Seniors who go to their providers' offices to ask for refills (seniors must get refills in person) are often scrutinized by the staff and treated poorly. Dominica explains,

> I don't have too much trouble with the scripts other than the pain medications. I understand they have a tremendous problem going on with all these creepy doctors writing scripts and these pill mills in Florida and all that, but it doesn't take an Einstein to figure out, if you look at somebody's chart, that they get one script a month, and they don't come in early and ask for their script or anything else like that. They're taking it for a reason and they're taking their dosage. But to be treated like you're a street drug corner dealer, and treated like trash and it's a round and round deal, and they have to be hand carried. I know there's an epidemic. But instead of going after the people they need to go after, they're throwing the legitimate patients right in with the rest of them and making it virtually impossible for us to get what we need, and now Medicare has refused to pay for Oxycontin, and now we've got patients with cancer who cannot get their pain meds. It's wrong.
>
> I got grilled by a nurse two weeks ago, when I went down to see [my doctor]. She wanted to know what meds I was on, so I gave her the list, and she didn't pay attention to anything on the list, other than the fact that I was taking a pain medication and the dosage, and the first thing out of her mouth, "Can you function on this? How can you function on this?" Lady, I know people who take my daily dosage in one tablet. And that's all she was grilling me about is, "How

> can you function on this?" But if I don't need it, I don't take it, but she had me on the ringer "How can you function on 5mg of Percocet a day?" I don't take it all every day if I don't need it, and that's all she was concerned about. She could care less about why you need medication for blood pressure in your legs. Why are you on this? Why are you on that? All she could focus on was, I was taking that pain med.

Narcotics policies, while meant to help curb the increasing abuse, create a great deal of social suffering, in terms of both physical and emotional pain, for seniors who need pain relief. Not only are seniors at risk of losing their access to pain medication, they are also treated disrespectfully, adding to their suffering.

Transportation

Transportation is a problem in the Valley, where there is no public transit, the only private transportation company is unreliable and expensive, and the distance to a pharmacy can be more than 60 miles. Seniors who have chronic diseases are often impaired and cannot drive the long distances or cannot drive at all. Weather further complicates driving in the winter when snow and ice cover the isolated roads of the Valley. Thus, regardless of whether a senior has a car and the money for gas, he or she may not be able to drive to a pharmacy.

Few of the seniors I interviewed are able to drive themselves to a pharmacy, even if they have a car. Their age, disease, and the cost of gas are reasons why they do not drive. In some cases, their driver's licenses allow them to drive within a small radius of their home, but the radius does not encompass the location of a pharmacy. Furthermore, most of the seniors who do drive expressed fear of driving in winter weather conditions, and said that they try to avoid driving in such conditions. For those seniors whose diseases are more debilitating, driving is not only uncomfortable but can be a hazard, yet they drive anyway because they have no other way to get their medicines. Dominica says,

> When it's 7 degrees below up here in the winter time, and the roads are iced over and that thing [her truck] doesn't do well on ice, or I'm having a bad day and can't hardly stand or lie down and then have to drive down there [Alamosa] and it's taking three or four hours — an hour down there and gotta fight with them [doctors] and go to the pharmacy and then it's an hour drive back, so you're gone three to four hours, it about kills me.

Eight of the 19 seniors own cars. Alphonso, Jacqueline, Darla, Dominica, and Nancy are consistently able and willing to drive, but Darla, Dominica, and Nancy have little money for gas, so they try not to drive unless they have to. Maria and Kate have restricted licenses and can only drive within a 20-mile radius. Viviana has a car but is unable to drive at all.

The only community transportation option for seniors is the private company, Red Willow SLV Transportation, which serves the Valley. Red Willow gets mixed reviews from the seniors. Nancy, who lives in Tara, over 50 miles from Alamosa, says,

> You have to call weeks in advance for the Red Willow. Well, sometimes you don't have weeks' notification, and we're not down there in Alamosa; I understand that, and we're not down in Monte Vista. They've got to drive 52 miles to pick us up and take us wherever they're going with it. So who is the easiest to cancel? The one that lives that far away, and we get cancelled out a lot. I got signed up for it and took five months to get one ride. It's that bad. There's a huge need for it but they won't hire more drivers. They won't get more cars so it's a battle. As soon as you get your doctor's appointment, if you have a cell phone, you run outside and call Red Willow and see if you can get a ride.

On the other hand, Penny, who lives in Dagus, much closer to Alamosa, does not have trouble getting Red Willow to pick her up; however, she has to time her trips to coincide with another senior who is on dialysis because of the cost of the ride:

> I take SLV Transportation. I have to go in with the dialysis person and pick up my meds and stuff and then I have to wait til they go home at 2:30. That takes the whole day. I get my groceries and stuff to eat. I look around at the other stores and stuff like that, but still. I have to go with the dialysis person cause Medicaid don't — only covers the ride for $12 and that's it. So that's why everybody who has that $12 thing has to go with the dialysis person, to help out the price of the trip. It's 40-some dollars privately – about $42, I think, but Medicaid only pays

> $12 and that's why they had to put people in with the dialysis people to help with the transportation – you know, the price of gas and everything. Some days I just don't want to stay there for 5 hours. That's the way it is. They pick up the dialysis people on Saturday, but I can't go in with them. That's a no no. Can't use it for weekends, just Monday through Friday — not even for emergencies.

Occasionally, there is a neighbor or a family member who can drive a senior to the pharmacy, and one of the outlying senior centers has a van. None of the other seniors whom I interviewed relies on others to take them places except Viviana. Each person said that sometimes he or she might hitch a ride with someone, if it is convenient for the driver to take a passenger. In the case where the senior has an emergent situation that requires transportation but not necessarily an ambulance, then, and only then, will he or she aggressively look for someone to drive. While no one could think of such a situation recently, several seniors said that, in such a case, they believe they could find someone to help them.

Some senior centers provide limited transportation that is dependent on their funding. In the town of Ravensport, for example, the senior center has a van that takes seniors into Alamosa each Tuesday for several hours. Other senior centers, however, do not get enough funding to have a vehicle and hire a driver. Furthermore, the van only operates one day a week, so seniors who need to go into Alamosa on other days have to find their own ways.

For those who have trouble getting to a pharmacy, there are mail order pharmacies and limited delivery services available in some areas of the Valley. None of the seniors I interviewed use mail order pharmacies except Carlos, who is a veteran. Carlos gets his healthcare from the Veterans Administration, which mails his medications to him. Seniors said that they do not like using mail order pharmacies because they are

afraid that they will get the wrong drugs and then have to wait until another shipment comes. The independent pharmacies will mail some drugs, although not narcotics. They also have limited delivery service. For example, Hannah's pharmacy will deliver drugs within a three-mile radius from the store. Before his pharmacy closed, Paul delivered prescriptions to another town and would leave them in mailboxes that were set up in the local market. Patients could request a private locked box, and Paul would set up a delivery schedule. He would also deliver narcotics — meeting seniors and having them sign a delivery receipt.

As helpful as delivery and mail services are, not everyone takes advantage of them. The services also cover a small area of the Valley, so only select communities can benefit. These services, while convenient for some seniors, do not help seniors get to the provider to get their narcotics prescription refilled or to deal with acute illness or injury. The lack of transportation and public infrastructure leaves many seniors without the mobility they need to adequately care for themselves. While entitlement programs like Medicaid will pay a small amount for transportation, the payment is only for some seniors with certain medical conditions. The payments are inadequate to allow other seniors to use what few services are available. Neither private nor public entities are willing to take on the challenge of providing seniors with transportation regardless of where they live.

Insurance Coverage

The seniors I interviewed who are at least 65 years old are enrolled in Medicare. Those younger than 65 have Medicaid, and some seniors have both. The difference between the two programs is that Medicare is federal government-sponsored health

insurance specifically for seniors who are 65 or older. Medicaid is federal and state government-sponsored health insurance for the poor. Seniors who get SSI or who meet the income criteria are eligible for Medicaid. Medicaid-eligible seniors pay a small amount for each provider visit and each prescription, and sometimes, pay nothing at all. Both Medicaid and Medicare have multiple formularies, depending on the PBM and the plan in which a senior is enrolled. Neither insurance typically covers brand-name drugs, nor do they cover most nutritional supplements. Seniors who have trouble with generic medications have a difficult time getting brand-name drugs because the insurance is reluctant to pay for them. While often the generic medication's side effects are mild, occasionally a senior does need the brand-name drug. For example, Nancy says,

> If you're suffering from severe arthritis and this drug might help where you don't have to take all these pain meds, give it to them! Cymbalta was one of them. There was a couple of different inhalers they refused, and I can't remember what the others were, but I've been denied four or five different medications the doctors wrote the scripts for. The name brand I can take, but the generic makes me sicker. I've gone days without taking my diabetes medicine because I'm tired of puking my guts up, and yet they won't let me have the name brand. They want [you to have] the generic. If you can't take it, let the patient have the name brand. [Asked if Medicare has ever paid for the name-brand] Straight across the board, no. You get the generic or nothing, and it's wrong! I'm lucky enough at this point, I can control my diabetes with food and pills, but if they're going to force me to take a medication I can't take, I'm going to end up on insulin, and that's not right. That's not fair.

Nutrition is also an on-going problem for low-income seniors who have conditions that require increased calories. For example, Roberto, a 67-year-old ex-paramedic, has Graves disease; heart valve problems resulting from rheumatic fever; angina; and ankylosing spondylitis, a severe form of arthritis that affects the base of the spine, eventually causing the vertebrae to fuse. Roberto has problems maintaining his

weight, so his doctor prescribed Ensure, a high-calorie dietary supplement, to help him maintain a healthy weight.

> The insurance doesn't want to pay for my Ensure, and I need it terribly bad because I lose weight like that. No matter how much I eat, it's hard to keep it on, so the thing is to gain weight. I was doing real well until the insurance stopped [paying for it]. [I just] eat the best I can and try to eat high protein foods like beans and legumes. I always have a pot of beans on the stove. It's the cheapest and best meal I can eat.

Other seniors, like Alphonso and Maria, have similar problems with their insurance coverage. Alphonso received a letter from Medicare explaining that the anxiety medication that he takes is contraindicated for seniors, but his physician will not prescribe a different medication. Speaking to him and his daughter, it became apparent that they had both tried to discuss the medication with the doctor without success. Once the letter was sent, Medicare stopped paying for the drug. Alphonso says that he has tried three times to stop taking it, but he is unable to sleep, so he pays for the medication out of pocket.

Drug coverage varies with the insurance plan and the formulary for each plan. Getting a brand-name drug covered is difficult and requires that the provider spend time making a case for why a patient needs it. Other items, like nutritional supplements, may be covered with the more expensive insurance plans, but often low-income seniors cannot afford the premiums for those plans. The lack of coverage can lead to increased morbidity for seniors like Roberto, who need more than just a pill to stay healthy. The payment policies shift the responsibility for health to the insurance companies, yet patients are often blamed for their inability to maintain their health.

Structural Health Literacy and Seniors

Structural health literacy (SHL), as described in chapter three, is a construct that draws from and is embedded in health literacy and is a major contributor to access. For seniors, SHL helps explain how access is more complicated than a list of barriers suggests. Seniors' access to their medications is hindered when they do not understand how to navigate the various structures that make up the healthcare system and those policies that affect it. While most of the seniors I interviewed have a basic understanding of their insurance — usually Medicare and/or Medicaid — some of them do not know what Medicare plan they have, what their plan does or does not pay for, whether they are eligible for some types of government assistance, and what resources they could use to help with their healthcare expenses. How these seniors cope with barriers varies according to their circumstances. Each person deals with his or her situation according to their level of understanding of the healthcare and entitlement systems, the policies, and their ability to participate in the system. Discussions with seniors elicited three levels of understanding of healthcare and entitlement structures that helped or hindered their ability to access medications.

Level I involves prior knowledge of the structures that guide access to the system of care. Guiding questions are: What do seniors know? Do they understand how the system works generally? Level II includes how seniors apply their knowledge to deal with barriers. For example, do seniors know the deadline for applying for Medicare? Are they aware of an underground economy? Do they know what questions to ask about their entitlements or their care? Level III encompasses decisions and actions about what to do to cope with poor or inconsistent access given what they know.

Level I: All of the seniors I interviewed have some knowledge of the system of healthcare. They understand the basic information that they need to know to keep the entitlements that they currently have, like Medicare. They know that there are enrollment dates and co-pays, that there are eligibility criteria, and that there are rules that govern how their benefits are calculated. Their experiences with the system have given seniors a frame of reference from which they can gauge what their future benefits may be. Some, however, do not know of other programs or benefits that could help them maximize their assets or cash flow.

Level II: Seniors understand some aspects of Level II; for example, all respondents know the Medicare enrollment dates, and they know whether Medicare will pay for their current medications. They also know the co-pays for their current medicine and provider visit. The knowledge that seniors lack is knowledge about policies and their implications and, in some cases, the type of insurance plans they have. Few seniors understand, for example, how narcotics policies could negatively impact their access to their pain medicine. They understand that there are eligibility requirements for entitlements, but they often do not know what those requirements are, and they do not know how to find loopholes or services that will afford them more benefits. For example, as I mentioned earlier, Viviana does not know that she can turn some of her assets into cash to pay for her healthcare and medicine. Narda does not think about asking whether she might be eligible for dental care, and Kate does not ask about mental health services at the clinic where she gets care.

Carlos, a 67-year-old veteran, developed muscle spasms in his legs at around age 30, which, he believes, were a result of severe sciatica. His doctor began prescribing

narcotics for the pain. As a result of the prescriptions, Carlos became addicted to narcotics:

> In those years I would have muscle spasms and I'd have to go to the doctor for something and he'd give me this medication and I didn't know what the hell it was. He'd give me an opiate — vicodin — or I'd take a Percocet, you know. I had that sciatica, I had a severe type of sciatica in my early thirties, and they put me on that and I didn't know what that was. Here I am taking that big 10 milligrams of Percocet, and if I didn't realize what it was, I'd just take it. I didn't know then what I know now. If I take one and a half [pills] I'm going to feel way better than just taking one. I know how to abuse them. I didn't then. Before, when I was getting the opiates, I didn't realize what they really were. I thought it was just a medication that I had to take, like a dumb hillbilly. But then in my fifties, I thought, "This is good." It would've been nice if he gave me a good rundown on what I'm taking, you know? I don't feel it's up to me to find out all the stuff that's involved in this medication. The doctor should sit down and say, "This is this and this, and blah, blah, you know this, that, and the other thing." I don't think it's being done. I know in my case it's not being done.

Today, Carlos is "clean"; he no longer abuses drugs, although he continues to have pain on occasion from his restless leg syndrome and arthritis. He says that he needs to be careful with the amount of physical activity in which he participates because he will get "sore":

> The last time I took opiates — about two months ago — he [his doctor] prescribed them because I had helped my daughter move a bunch of furniture and it just got to me. And I told the doctor, "You know, man, I worked this weekend and this and that." And he says, "Oh I wrote you a script for Vicodin." I didn't even ask for them. I just made the comment to "how are you feeling today." I took them exactly according to the dosage. Had it been a couple years before, shit, I'd be popping maybe 2 or 3 an hour and be zipping. Nothing matters; the world is beautiful when you're on those things. He gave me a 10 days supply; that's all they're allowed to give you here and, if you need more, it's sent to Denver [Veterans Administration pharmacy]. Denver fills the prescription and you get the pills in the mail. They'll mail opiates in the mail.

An underground economy helps some seniors get benefits that they might not otherwise get. Sharing drugs is one way that seniors can bypass having to pay co-pays for doctor visits or for medications. Of the seniors I interviewed who have dealt with an

underground economy, only those who have adult children with whom they have a relationship said that they have shared drugs. Seniors only share drugs that they believe they know about, such as antibiotics and pain medication. One senior said that she shared narcotics with her daughter after her daughter had surgery. Another senior said that she received "mild" antibiotics from her son for "bronchitis." Asked why they shared their drugs, both seniors said that sharing saved money on co-pays and time because they both felt that they knew what the problem was and did not want to "waste" time on a provider visit. Other respondents alluded to sharing drugs but did not openly admit that they did.

Within Level II, some of the stories that I highlighted earlier apply, such as finding ways to get rides by tagging along with other seniors. Sharing resources is one way to apply one's knowledge about how the system works. Of course, sharing resources like medications is not a good idea, yet seniors who have needs that go unmet must find ways to compensate for their lack of individual resources. In Level III, we see how seniors make decisions about what to do to cope with their inconsistent access to medications.

Level III is about decision making: what criteria seniors use to decide how to handle poor and inconsistent medication access. My data suggest that decisions about medication are situational and event-centered; that is, seniors do not often have preconceived plans about what to do in the event that they cannot get all their medicines. One exception to this is seniors who know that they are getting close to the "donut hole" may consciously hoard medication or save money to cover the cost. However, studies have shown that low-income seniors often do not plan for the "donut hole" (Kaplan & Zhang, 2013). While seniors in my study sometimes have a general plan or hierarchy of

expenses, individual drug decisions are subject to the senior's state of health at the time that a purchase must be made or the dose of a drug taken. In other words, seniors make decisions when there is a problem.

There is a network and social component (Pescosolido, 1992) that connects seniors to their decisions. Thus, decisions about medications, while situational, are embedded in social processes like norms, and in networks, both social and structural, as well as event-centered. Events such as a change in severity of the illness, a new illness, advice from the social network, or a new treatment plan from a provider will trigger an adjustment in the decision making process by either elevating a condition to a more prominent position or by decreasing the perceived need for a given medication relative to other medications.

Decisions about medication access, however, are not necessarily rationally based; that is, there is not a preponderance of utility maximization (which drug is most needed) or purposive rational action (the end justifies the means). Rather, seniors often use a heuristic model (focus on a single aspect of a complex problem while ignoring other aspects) in a given decision stream (Pescosolido, 1992). There are social components that affect agency that "shift the focus from individual 'choice' to socially constructed patterns of decisions, including consultation with others" (Pescosolido, 1992, p. 1096). These "others" may be a PCP, a friend or family member, an informational pamphlet, media program, or even someone that the senior overhears in a conversation. In this type of heuristic decision making, seniors tend to focus on how they feel today in deciding which medication they will purchase, if they cannot purchase all of them. For example,

pain may trump heart disease when choosing which medication to buy, even though physiologically, pain may cause less damage than heart disease.

The seniors deal with their perceived barrier(s) by making decisions that they believe mitigate the effects of the barriers. The decisions they make are an attempt to get the most therapeutic value from their medicines, given their circumstances; however, seniors, regardless of their level of education and income, do not always use the resources that are available to them because they are unaware that the resources exist, they do not trust the resources or the people that run them, they feel a stigma attached to the use of a resource, or they do not understand how to use the resource.

Darla is a 67-year-old divorced woman who lives in the small restaurant that she owns in Ravensport. Her restaurant used to be open every day, but she fell and tore ligaments in her knee and sprained her back, which closed the restaurant for eight weeks. Since the accident, her restaurant is open when she feels that she can work and typically only for a few hours. She has lost most of what little business she had. Darla also has fibromyalgia and unstable angina. Her physician prescribed Flexaril, a muscle relaxant; a narcotic pain reliever; and a heart medicine that she cannot name.

Darla cannot afford any of her medications because she lives on about $300 per month in Social Security income, and she feels a stigma about getting government assistance. Asked if she has considered applying for food stamps or SSI, she says, “I can just be drugged, and have a totally controlled life by outside, and then I can go get my food stamps, and my disability and get stoned all day long. What do I have to give to the world and to my grandchildren? It hasn’t been easy, but it is getting better.” Darla’s living conditions are less than optimal. Her restaurant is large enough to accommodate

some furniture, but it lacks a full bathroom. To compensate, Darla purchased a large horse trough for bathing, which she put in the kitchen area next to the floor drain. Her ex-husband attached a spigot to one end so that she could drain the water after her bath. She boils water on the stove and slowly fills the tub.

She tries to save her money to buy the Flexaril because it helps her sleep by relieving the muscle spasms in her back. She is supposed to take the Flexaril three times a day, but she only takes it at bedtime when she is having severe spasms. Darla has not purchased any of her other medications because she cannot afford them, and it is the spasms that concern her. For her fibromyalgia, she takes over-the-counter pain medication like ibuprofen and for her heart she just watches her diet.

Similarly, Narda is a 60-year-old divorced woman with virtually no income. A big, ripped-up purse holds Narda's various medicine bottles along with a small plastic container of loose tobacco. As she pulls out each bottle, she tries to pronounce the generic names of the drugs. "I try to make my medicines last longer just in case I don't get no money. The doctors don't want to see me, like one told me that I have to have an MRI on my brain. I had one once but I can't get another one. I just hoard the drugs." "Hoarding" entails taking some of the medicines only when she feels that she absolutely needs to, and trying other remedies like over-the-counter drugs.

> I just don't take it. Like my asthma medicine, I should have it two or three times a day and I don't, cause I can't. I have to use the inhaler out at the house, and when it's cold, the inhalers don't work, and the machine I have needs electricity so I just don't bring it in [to her trailer]. I do bring it [into town], like I got it over at the neighbor's house where I'm staying at [house sitting]. I take it at least once every other day or something. Then the inhalers I try to only use for emergencies, which is what an inhaler is for anyway. Since I'm out in the prairie without electricity, I have to use it in the morning or in the evenings. If I use it in the evening I won't use it in the morning.

Narda has her financial priorities worked out, which helps her make decisions about how to spend her money. “My cats come first when I have money. After that, household products: toilet paper, basic survival stuff and depending on what food stamps will pay for. I borrowed $10 from my aunt [and] I borrowed $26 from a friend here to get my medicine, so I had to pay that back first. Tobacco is the last on the totem pole.

At the time of our interview, Narda had fallen and hurt her ankle and her hip. She did not have the money to go to the doctor or even to buy an Ace bandage to wrap her ankle. Because Narda considers herself self-sufficient, she made the decision to “tough it out” and keep going. When we spoke, her ankle was swollen, and she was in pain. When I asked her if she planned to go to the doctor, she replied that she was going to call the next day. In the meantime, she was using “ladacaine patches” that she uses for her back pain, in hopes that they would work on her ankle, and she had iced it and had it elevated.

In another example of a heuristic type of decision-making, Dominica is explicit about the way that she makes decisions about her drugs. Our conversation went as follows:

> CS: So if you can’t get your drugs . . .
> Dominica: You go without.
> CS**:** How do you make decisions about which drug you buy and which one you don’t?
> Dominica: It depends on what’s left over after I get the bills paid.
> CS: But let’s say you have three meds coming up but you can only afford to buy two, how do you decide which one to not buy?
> Dominica: It depends. I look at what the drug is and what it does. And if it’s a toss up between my pain medication and my antidepressant and the one for the blood pressure in my legs, I get the pain meds and the antidepressant, and the blood pressure sits until I can pay for it. It’s eenie meenie miney mo.

All of these seniors have made decisions about how to spend their money and about which drugs are more important to them. In each case, medications that treat the

most potentially deadly disease have been overlooked in favor of medications that are palliative when only one or two medications are affordable. Ultimately, the most severe of each senior's diseases may get worse and shorten his/her life because of the lack of treatment, but in the short run, the decisions that each makes reflects their desire to be as comfortable as possible.

Social Support

As I began this project, I expected to interview members of the seniors' social support network. I discovered that few seniors have such a network. I defined social support as someone who helps a senior acquire his or her prescriptions in some tangible way such as providing transportation, money, or by picking up the medicine. While a few seniors have adult children who live in the area or friends from their church or neighborhood, most of the seniors are unable to rely on their social networks for instrumental support. In some cases, such as Dominica's, the children are estranged. Some adult children are supported by the senior, as is the case with Nancy and Dolores, and, in Linda's case, her daughter is disabled. Friends and neighbors tend to have similar financial and transportation constraints and need help themselves; thus, they are not able to provide instrumental support.

The social support of elders has consequences for both seniors and the community. As individuals age and become infirmed, they tend to need assistance with activities of daily living that can include getting to the doctor and the pharmacy. Without that support from friends or family, many seniors must rely on government or private agencies to provide the support. Groups such as Meals on Wheels and Amistad Senior Center help seniors in the Valley, but the services tend to be specialized, necessitating multiple

agencies to cover the full gamut of needs. With limited funding, providing all the services that seniors need is prohibitive for these communities. Also, as seniors age, they begin to lose friends and family to death, which can lead to social isolation. As social isolation increases, there is less chance that seniors will have support networks outside of their children or institutions.

Seniors who have instrumental social support networks include Viviana, Carlos, and Alphonso. Each has at least one child who lives in the Valley and is willing and able to help the parent, primarily with transportation or running errands. While each senior receives a little money from time to time, none of the adult children is well off financially. Other seniors like Anna, Betty, Roberto, and Darla have children who live either in different parts of the state or in other states. While the relationship with their children is good — they speak by telephone frequently and enjoy the interaction — only Darla and Anna receive money from their children, and, in Darla's case, the money comes infrequently and is rarely much more than $100.

Most of the seniors I interviewed interact frequently with their social networks, primarily neighbors and people from their churches and senior centers. They lead active social lives in their communities through their church, senior centers, and neighborhoods, but the social interaction does not often translate to instrumental support. Instrumental support outside of family is often found through community organizations like Meals on Wheels, which brings prepared meals to seniors' homes or home health aides who are paid for by Medicare or other entitlement programs.

Seniors in the San Luis Valley face multiple obstacles to consistent medication access, which are exacerbated by the structural barriers that are difficult to navigate and

almost impossible to change. These structural barriers include government and corporate policies like insurance co-pays, eligibility criteria for entitlements, and formularies. While some seniors, like Penny, have figured out how to make the system work for them, others, like Narda and Viviana, do not even ask questions about what services might be available to them. Even seniors like Jacqueline, who are managing within the system because they are still healthy enough to drive and have enough money to pay for their basic necessities, are at risk for negative consequences if they should become disabled or if they have a major life event that drains her finances. What seniors know, how they use their knowledge, and on what basis they make decisions about their medications are crucial to their level of access. However, the interrelationship among structural, social, political, and economic factors creates a situation whereby seniors are left to their own devices to try to figure out how to make the system work for them so that they can take care of themselves. Yet, seniors are often blamed when they are not able to navigate these structures and end up unable to adhere to treatment plans or to access the care that they need.

CHAPTER VI

STRUCTURAL HEALTH LITERACY

The field of public health has always focused on prevention rather than treatment. Over the last few decades, health literacy has emerged as a public health construct that, when used, can empower people to have better health outcomes (Pleasant, 2014). However, while health literacy is basically a behavioral tool, there is a level of bias toward personal responsibility that is inherent in the construct of health literacy that is rarely questioned by those working to eradicate health disparities. Clinicians and scholars have discussed the ways in which health literacy constitutes a social determinant of health, they have consolidated multiple areas of literacy into a single construct of health literacy, and they have created an umbrella term that tries to cover all the ways in which a patient should be informed about their care. In other words, anyone has been able to "identify nearly whatever they want as health literacy" (Pleasant, 2014, p. 1489).

Different versions of health literacy imply that the patient, the clinician, or both must take personal responsibility for the patient's medical outcomes and that patients have access to the medical services in the first place. The term "health literacy" is a cumbersome construct that has little meaning because it is too broad and can mean different things to different people, decreasing its overall effectiveness in helping patients and clinicians work together to provide competent, value-free care. Yet, scholars explicitly argue that if only patients can understand medical terms, disease processes, and treatment options, and if clinicians can take more time with patients, use less jargon, and present a more caring attitude, health literacy and patient outcomes can be improved (Nielsen-Bohlman et al., 2004; Paasche-Orlow & Wolf, 2007; Speros, 2005).

The purpose of this chapter is to propose and describe a new construct — Structural Health Literacy (SHL) — that either can stand alone from or be an adjunct to the general construct "health literacy" and focuses attention on the ways structures that guide or influence healthcare and healthcare access can be understood by patients at all levels of education, income, health status, race, and culture. I define SHL and its components, discuss the implications of using SHL as an adjunct to health literacy, and end with an example of how a lack of SHL contributes to one patient's difficulty in accessing healthcare.

Health Literacy as a Construct

To understand the construct of structural health literacy, one must begin by understanding health literacy and its basis in healthcare and public health. While health literacy is emerging as its own field, to date there is no theoretical basis on which health literacy rests nor have any fully testable hypotheses or adequate methods of measurement emerged from the available definitions (Berkman, Davis, & McCormack, 2010; Pleasant, 2014). The definition that comes closest to creating a testable hypothesis comes from the Calgary Charter on Health Literacy (Coleman et al., 2009), whose definition reads,

> Health literacy allows the public and personnel working in all health-related contexts to find, understand, evaluate, communicate, and use information. Health literacy is the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills. (p. 1)

According to its authors, "health literacy . . . [is a] behavior. Thus, behavior change is a valid outcome of improved health literacy" (Pleasant, 2014, p. 1486). Therefore, if patients' health improve as a result of their use of health literacy skills, Pleasant (2014) suggests that the construct has been tested.

Few studies on health literacy have been qualitative, and have actually interviewed patients; most definitions of health literacy have emerged from the field of health promotion, which is based on behavioral theories used in public health (Edwards, Wood, Davies, & Edwards, 2012). While some definitions, models, and frameworks incorporate patient empowerment, most task the acquisition of information, acquisition of literacy skills, and informed decision-making to the patient and the primary care provider. As Squires and her colleagues (2012) point out, "In terms of interpersonal communication (e.g. between a doctor and patient) the communication skills of the messenger are critical to an individual's skill in interpreting the message being delivered" (p.49). Furthermore, Passche-Orlow and Wolf (2010) comment that health literacy:

> takes into account the contextual demand placed on the individual by (a) their specific clinical condition and associated health care decisions, (b) the communication characteristics of the dominant medical culture, (c) the structure and function of clinical services that assume adequate health literacy proficiency and require self-advocacy and vigilance, and (d) the emphasis that society places on individual, rather than ecological, determinants of health. (p. 35)

While health literacy does take contextual demand into account, it assumes that the context is behavioral (Pleasant, 2014) as in the four points in the quote above. For providers and the community at large to expect patients to have a working grasp of health literacy — a "functional" health literacy (Nutbeam, 2000) — is to downplay the idea that health literacy is complicated, multidimensional, and requires that patients be well educated in matters of health, medicine, and healthcare. While education programs for specific health-related concerns from diabetes to childbirth are widely available in many communities, providers often do not have time during office visits to be teachers. As a result, patients who, for whatever reason, do not participate in educational programs are often stigmatized as non-compliant or unconcerned about their health.

From the mid-1970s, scholars began thinking about the connection between literacy and health. In 1991, Weiss and his colleagues described the idea that general literacy could be related to health outcomes (Weiss, Hart, & Pust, 1991). A patient's inability to read and understand complicated medical information could hinder his or her ability to manage disease, adhere to treatment plans, and advocate for appropriate care. Beginning in 1999 with a report from the American Medical Association (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs & American Medical Association, 1999), a series of seminal reports on health literacy emerged from commissions, professional associations, and scholars. Included in the list were Nutbeam (2000), Agency for Healthcare Research and Quality (Berkman et al., 2004), and the Institute of Medicine (IOM) (Nielsen-Bohlman et al., 2004), whose definition of health literacy is most often cited as the standard definition. The IOM's definition is, "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Before and after the IOM definition, many definitions of health literacy have been proposed with varying degrees of emphasis on personal responsibility, cognitive capacity, communication, social influences, and health outcomes (see Appendix D) (Sørensen et al., 2012).

The definitions of health literacy often put a level of personal responsibility on patients with which they are not always able to comply and either leave out or diminish the external factors that influence behavior in favor of individual factors like self-efficacy. In the case where patients are educated about medical jargon or how a disease progresses, one can assume that some of the clinical information given out by providers will be

understood by patients. In cases of cognitive dysfunction, very low education level, or language/cultural barriers where there is no cultural concept of what is being discussed, patients may not understand Western concepts, how or why prescribed treatments work, or what is expected of them (see, for example, Fadiman, 1998). How much a patient should know is beyond the scope of this discussion, save the vague notion that a patient should know something about his/her disease and treatment. The assumption by many scholars is that clinicians or other healthcare workers will teach patients about disease processes, treatment modalities, how to ask good questions of their practitioner, how to advocate for treatment plans that patients want, how to read a consent form and a drug information sheet, and medical jargon (see for example, Paasche-Orlow and his colleagues, 2007). If these lessons are well learned by patients, the literature implies that patients will get better faster, will have less morbidity and lower mortality, and will use fewer healthcare dollars; patients will adhere to their medications, keep their appointments, change their lifestyles, advocate for themselves, and have a list of concerns ready to present to their provider so as to use the provider's time most efficiently.

Indeed, understanding the concepts above can help a patient be healthier and manage his/her disease but first, a patient must be able to access healthcare. Access, while implied in health literacy, is not explicitly discussed nor are methods of access anywhere explicated. Thus, health literacy in general can only go so far in helping patients achieve the kinds of outcomes that transcend race, class, and socioeconomic status; in other words, health disparities are subject to other barriers that are not addressed by the umbrella term "health literacy."

Structural Health Literacy as a Construct

I propose Structural Health Literacy (SHL) as a construct that compliments health literacy but deals exclusively with the problems inherent in the structures that form and compliment the healthcare system, which are significant barriers to healthcare access: SHL increases the possibility of access to the healthcare system. As an antecedent to health literacy, SHL shifts the emphasis from patient personal responsibility — in the neoliberal sense (Harvey, 2005) — for understanding the complexities of the healthcare system to policy makers, organizations, and professional educators whose job it should be to ensure that patients have the information they need to get access to the healthcare system. Given the lack of a theoretical basis for health literacy, the theoretical relationship of structural health literacy to health literacy cannot be determined without further research.

Personal responsibility, while an important part of health, is often conceived of as a patient that is compliant with medical treatment plans and has a positive health outcome. Squires and her colleagues (2012) comment that, "Although it is tempting to . . . identify someone as 'health literate' if they demonstrate a desired behavior (e.g. quitting smoking), there are far too many mediating factors that influence whether or not an individual engages in a behavior or has a positive health outcome to be able to make this direct association" (p. 50).

Before patients can adhere to medication, discuss treatment options with their providers, or advocate for themselves in the healthcare system, they must get into the system; that is, they must be able to get an appointment and get to the appointment and then they must be able to purchase their medications, medical supplies and equipment,

nutritious food, and any other items that increase their health and ability to deal with disease or injury. Getting into the healthcare system is not always easy for patients who are poor, live in rural communities, or are homebound. Once in the system, patients must be able to stay in the system during the course of their disease process; that is, they must be able to refill prescriptions, keep follow up appointments, get to rehabilitation appointments, see specialist providers, and maintain living arrangements. In some cases, staying in the system is even difficult for patients who have money and are of the dominant population because of the complexities of the structures that form the American healthcare system, which I discuss later in the chapter.

The American healthcare system includes private and government health insurance plans, corporate policies that guide the price of drugs and insurance company formularies (the list of drugs that the company will pay for), and government policies that dictate eligibility requirements for services. Outside of the healthcare system, but an important aspect of access to healthcare, are government entitlement and means-tested programs like food stamps. SHL is focused on what patients know about these structures and their ability to navigate them so that they can get the resources to pay for provider visits, drugs, and other care. I suggest SHL has three components — 1) knowledge of the way that structures function, 2) how to find resources to help navigate the structures, and 3) asking the right questions.

The first component, knowledge of how structures function, is the most important and undergirds the other two components. SHL seeks to create awareness about the specific ways in which structures and their policies affect patients' ability to access care and allow for educating people about the structures that are pertinent to their access (see

logic model below). In many cases, patients do not have the ability to change government or corporate policies or the way in which structures function; however, in order to navigate through the structures to get benefits that equate to access, patients should have some understanding of how the structures work. Knowledge of structures and their policies is on a continuum from the most basic understanding to a complex understanding of the intricate dealings of government and corporate policies. Structures and the policies that govern them, in this case, include private and government-sponsored health insurance such as Medicare or Blue Cross insurance; means-tested programs such as food stamps, Temporary Assistance for Needy Families (TANF), or subsidized housing; and corporate policies that affect, either directly or indirectly, access to drugs and care, such as the retail price of drugs.

Finding and using resources is the second component of SHL. Strong SHL implies that patients have the tools and information to not only navigate the structures but also to get the services they need to access healthcare. To understand how structures and the policies that drive them function is complicated. While many resources exist in the community and on the Internet that can help patients understand how to navigate the structures to get the resources that they need, these resources can be hard to find and difficult to understand. Trying to read and understand the website about Medicare, for example, can be daunting because of its many pages and links and an uncertainty about which sections pertain to a patient's concern. In most cases, however, there is a resource that can help patients find the information that they need to make decisions, enroll for a service, or verify information about a service. Patients who are structurally health literate know how to find a resource to answer questions or help with filling out forms and

understand the basics of the structure with which they are working. Whether the resource is a person, the Internet, a pamphlet, or a book, structurally health literate persons have a good idea of where to find the information that they need.

Asking the right questions is the third component of SHL that a patient needs to navigate structures. SHL considers the need for patients to ask questions that will give them answers that are useful for managing their health. The right questions can save time, money, and suffering. Part of patients' ability to get answers is to ask questions that are pertinent to their needs. Asking a provider for a diagnosis does not explain the disease process, and a search for "coughing" on the Internet will bring up every reason for coughing from postnasal drip to lung cancer. Therefore, knowing what information is pertinent is critical to getting answers that help patients make decisions about their health and healthcare. The right questions need not be complicated; "why," "how," "when," "who," or "what does this mean" can begin a conversation about a patient's needs and understanding; however, structurally health literate individuals will be able to ask follow-up questions that narrow the scope of answers until they have the specific answer that they need.

While basic health literacy remains essential to patients' ability to manage their disease or injury, structural health literacy describes a different dimension of understanding, one that does not necessarily have to do with a person's specific disease and treatment but one that can directly impact a person's ability to access care at any level — an "upstream" model. As an upstream model, SHL increases access to healthcare, allowing seniors to stem the negative effects of poor access. Currently, navigating the structural components of healthcare is embedded in health literacy but only to the extent

that navigation directly affects healthcare — for example, understanding consents for treatment, reading medication labels, or filling out forms. Yet, other structures play a role in whether a person can access care. Individuals who are poor often do not access means-tested programs such as food stamps or Supplemental Security Income (SSI) because they may own property and have been told that they do not qualify for these benefits. In some cases, these people do not know the rules that govern eligibility; they just take a clerk's word that they are not eligible. Yet, there are instances where owning property will not keep a person from getting benefits, but it is incumbent on the benefit seeker to come up with the documentation required to prove eligibility. Before benefit seekers can contest the determination, however, they must think to question whether their circumstances warrant another look at the asset.

Structural health literacy, as an antecedent of health literacy, aims to facilitate access to healthcare rather than to increase an understanding of a patient's health or healthcare options. By advocating for community-wide involvement in not only educating seniors but also providing comprehensive resources that are specific to helping seniors get the financial and community resources to which they are entitled, SHL reduces the burden of personal responsibility from the shoulders of seniors and their individual providers and places some of the responsibility on the community (geographic as well as government and corporate entities) to ensure that all seniors have those resources.

I do not suggest that a patient must have SHL to access care. I do suggest that people with strong SHL will have an easier time navigating the structures that give them access to care and will have an easier time navigating the healthcare system itself. Strong

SHL will help patients have sufficient resources to follow their treatment plans, get to their provider appointments, and manage their health. SHL also does not delve into the area of motivation, as some definitions and frameworks of health literacy strive to do. Once patients understand how the structures that affect their healthcare access function, the motivation to act on that knowledge is outside the realm of SHL. Motivation should not be coupled with SHL because the goal of SHL is to ensure that patients have the information, education, and resources that give them the choice of whether or not to pursue access. People also become aware of what resources are available to them so that they can make decisions about which resources they want to use. For example, in interviews, one woman felt that she did not want to apply for food stamps because of a perceived stigma; however, after discussing the idea of food stamps further, she said that IF she needed them, she now knew that she would be able to get them. She put the decision about whether to apply for food stamps on hold pending her assessment of her financial situation and perceived stigmatization.

Definition

Structural health literacy proposes that there is a knowledge gap between how healthcare structures work and what patients understand about how the structures work, and this gap creates barriers to healthcare access. Structures like Medicare are governed by policies like eligibility criteria that are impossible for patients to change. SHL can be defined as the extent to which an individual understands, can navigate, and use to his or her advantage the structures and policies that influence access to healthcare, as evidenced by the level of access that the individual achieves. SHL posits that unless people understand how policies that govern structures apply to them, they will have a difficult

time getting their needs met. I add a caveat here: No one can know every policy, nor does a senior need to know every policy. The goal of SHL is to ensure continued access to care. As such, "the level of access" should be taken to mean that the senior has all the care that s/he needs without the need to sacrifice basic daily needs like food and housing. Therefore, the evidence that a person has strong SHL is situated in each senior's level of need and can be discerned by a logic model (See Table 2).

If patients cannot navigate the structures within institutions successfully, the consequences can be dire, especially for the frail, elderly, and the poor. SHL supposes that people do not have a knowledge gap just because they are uneducated or otherwise incompetent but because policies keep changing and become increasingly complicated. Whether new policies are better or worse is not at issue here. If people are not informed of changes, navigating the system becomes difficult. Government and corporate policies and procedures guide how structures function, which benefits are available, and to whom; and they have a direct impact on a patient's ability to access the system. Corporate and government policy is generally defined as,

> a documented set of broad guidelines, formulated after an analysis of all internal and external factors that can affect a organization's objectives, operations, and plans. Formulated by the organization's directors, corporate [and government] policy lays down the organization's response to known and knowable situations and circumstances. It also determines the formulation and implementation of strategy, and directs and restricts the plans, decisions, and actions of the organization's officers in achievement of its objectives. ("Corporate policy?," n.d.).

Examples of benefits that are created by policies that directly affect patients include infrastructure such as public transportation — are buses available, what are the routes, timetables, and fares; the way that community organizations that serve patients function — are meals provided, hours of operation, social vs. educational setting, age

requirements; and means-tested programs like food stamps — eligibility criteria, monthly allotments, what can be purchased, documents required to prove status. Examples of policies that indirectly affect patients include those that govern public service agencies such as health departments — level of funding, departmental priorities, types of employees (e.g. nurses, case managers, navigators, researchers), areas served; drug cost reimbursement to pharmacies — amount of reimbursement versus the amount paid for drugs, timeframe for payments, formularies; rules crafted by organizations that employ physicians — number of patients s/he must see, types of drugs that can be prescribed, tests that can be run, whether a prior authorization is needed to see a patient (in the case of specialists).

Policies such as some narcotics policies that require patients to physically be present in their providers' offices to get a prescription for their narcotics refill, create unintended consequences for people who may live 50 miles or more from the doctor's office and/or the pharmacy. The result is that many people have to live in pain until they can get to the doctor and the pharmacy. Another example is the change in policies at home health agencies. Because of liability concerns, many home health agencies have stopped allowing their workers to transport seniors or to pick up prescriptions for them. While the issue of the company's liability is an important one, the policy leaves seniors who used to rely on their home health aide to take them shopping or to the doctor in the lurch. Thus, seniors now have to find other ways to get transportation.

Individuals at all levels of income and education as well as individuals of all races, ethnicities, cultures, and languages have a need to understand the workings of the structures that affect their daily lives. In the case of health and healthcare, policies that

govern structures such as those mentioned above have an impact on how patients access healthcare. Using health literacy alone to address a patient's ability to function in the healthcare setting does not cover all the avenues that lead to good care. Structures, policies, and their effect on healthcare access are not clearly embedded in health literacy. Thus, even if patients can read at a high level and can discuss their conditions with a provider and advocate for the type of care that is desired, they still have to deal with structures and their policies in order to pay for the services.

Sample Logic Model

Table 2

INPUT/RESOURCES	ACTIVITIES	OUTPUTS/OBJECTIVES	OUTCOME	IMPACT
Community educators, e.g. nurses, Medicare experts, Patient navigators	Information seminars, one-on-one assistance, trainings	Monthly meetings at senior centers, Specific education given to individuals	Seniors learn specific information about one or more structures or policies, e.g. Medicare supplement plans	Seniors can demonstrate knowledge presented in trainings. Can articulate how they might be able to use the information. Support networks are included when available
Non-profit organizations, e.g. Meals on Wheels	Distribute reference/resource lists	Organizations distribute resource guides to individuals through organization and at locations where seniors gather.	Resource guides are used to call for information or help with a concern	Seniors keep the guide in a convenient location for use when they need information. Support networks are included when available
Community Meetings, e.g. health fairs	Distribute information, sign up for trainings, seminars	Coordinate with educators to deliver information sessions and trainings to seniors who signed up	Seniors sign up for seminars or information sessions	Seniors who are mobile attend seminars; non-mobile seniors request in-home. Support networks are included when available training.

Table 2: Sample logic model for testing SHL

Implications of SHL

Policies dictate enrollment dates, co-pays, discounts, penalties, reimbursements, eligibility, and availability of services. All individuals who have health insurance, whether public or private, need to know the enrollment periods for their particular insurance or they run the risk of being without insurance if they miss enrolling during the open dates. Those who are turning 65 years old and who are no longer in the workforce need to know about the different Medicare plans, co-pays, supplement policies, and what each Medicare part covers so that they can enroll in the appropriate plans. Those who have private insurance through their employer should know the difference between the plans that the employer offers, including what services are covered, co-pays, and whether the employer covers dental care, vision, and behavioral health. Does the employer offer a flexible spending account (FSA) plan, where a portion of the employee's wages are set aside, pre-tax, to cover co-pays and out-of-pocket medical expenses? Does the employee understand how to estimate expenses so that, at the end of the year, there is no unused money that reverts to the government? If patients are on Medicare, do they know how to estimate when they might reach the "donut hole" that will then require them to pay out-of-pocket for drugs? Figure 3 outlines the implications of SHL.

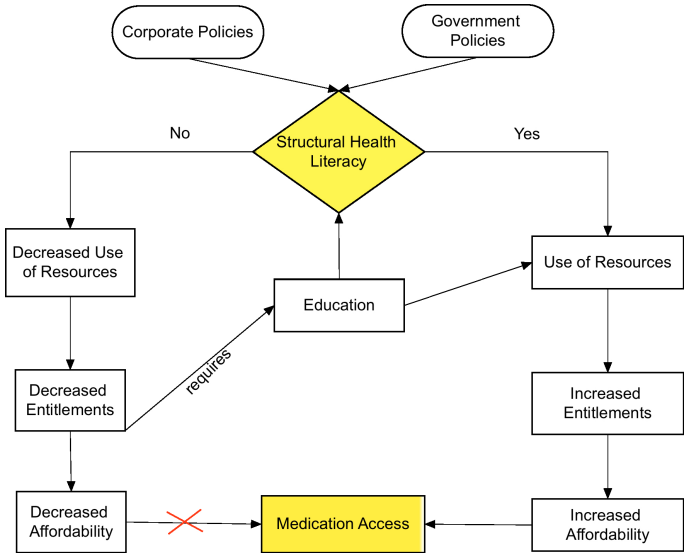

Figure 3 Implications of Structural Health Literacy

The Affordable Care Act (ACA) exemplifies the complexity of the healthcare system and its changing policies. Even as the ACA aims to cover more people, particularly those who have been left out of the health insurance system, the act creates unintended consequences for providers like independent pharmacists, such as increasing Medicaid coverage that results in lower reimbursement for drugs and lowers the pharmacy's profit margin. The ACA also adds a new learning curve that can be confusing to those who are trying to get insurance through the various marketplaces. For example, some states, such as Colorado, have their own marketplaces, and others do not; some states are expanding Medicaid, and others are not. In some cases, the federal government will impose a fine for people who choose not to buy insurance but, in other cases, the fines may be waived. Understanding how to determine what parts of the Act pertains to an individual patient and how to get the correct information requires a level of cognitive capacity, the ability to ask the right questions (e.g., do I qualify for a waiver?) and, if the patient cannot find the answer on his/her own, to know whom to call to get help (for example, a patient navigator or the 211 system of information run by the United Way).

Patients who do not have enough income to pay for both their drugs and their living expenses are often eligible for government assistance. But many other low-income people own property and are not eligible for some government assistance programs, even though their assets are small and are tied up in illiquid instruments like real estate or livestock. Does someone who owns property know the guidelines for getting assistance under these circumstances? If individuals who are receiving assistance get a chance to make a little money by doing some small job such as babysitting a neighbor's child, do they need to report that income? Do they know how much income a person can make and not have it affect their benefit?

These questions are asked by people of all ages and socioeconomic status who either find themselves in a state of transition like moving into retirement or by those who are struggling to make ends meet with the income they have. For example, young people who are turning 26 years old and moving off of their parents' health insurance often do not understand how to navigate the insurance exchanges and do not know how to find out if they qualify for government subsidies. A student of mine who is in a pre-med program and is clearly a well educated and intelligent young woman has been without health insurance for nearly a year because she cannot figure out how to sign up for insurance and how to get subsidies. She believes that because her parents are well off, she does not qualify for Medicaid, despite the fact that she is a full-time student and lives on student loans and has a minimum wage, part-time job. She does not know where to find answers to her questions.

Others question whether having a roommate might make them ineligible for SSI or food stamps so they neglect to find ways to increase their disposable income and end

up having to choose between buying medicine and having a telephone or buying food. Individuals who have the means to afford their healthcare but have retired away from family can be challenged with diminishing physical health such as poor eyesight or shaking hands that preclude them from renewing their mail order drugs because they cannot see the numbers on the medicine label or they cannot push the right buttons on their telephone. Perhaps these individuals do not need outside care, but they do need occasional help with these small but important tasks. If they have sufficient SHL, they will know where to find this assistance if or when friends or family are not available to help them; they can ask the right questions of the right individuals in their community.

Decisions such as whether to buy a medicine, cut a pill in half, buy food, pay rent, or save up for the "donut hole" are often dependent on what the patient knows about the structures. For example, if patients know the retail cost of their drugs, they can determine when they will reach the "donut hole," and they can make arrangements to save money or start rationing their existing medication. They can also get advice from their pharmacists if they know about the "donut hole" and understand that what they pay for their medication will potentially increase at some point in the year.

SHL also affects ancillary services that contribute to healthcare access such as transportation. In urban areas, cities often have transportation services available for seniors and the disabled. Younger people and families can sometimes get vouchers for public transportation. In rural areas, however, public transportation is often nonexistent. Medicaid and Medicare may offer vouchers for private transportation companies or taxis for certain patients who need life-saving treatment such as dialysis. Others who do not need these types of treatments, however, are left to their own devices. For those

individuals who either cannot drive, do not have a vehicle, or cannot afford the gas, transportation can limit access to healthcare. Understanding that there are vouchers available or that a senior center or other community agency provides transportation for people going to medical appointments can be life saving. But how does one find these services? A person with strong SHL will know whom to call and will be able to find services such as transportation, if such services are available in the community.

Filling out forms for entitlement programs like Medicare or filing claims for behavioral health care are examples of tasks that patients must perform in order to pay for healthcare services. The forms can be confusing and time consuming to fill out and submit to the insurance company. Many people who are educated and who are financially stable have trouble with these tasks because of the policies that govern insurance claims, yet pharmacists will often perform this task for a patient if the patient requests it.

Illustrations

While Medicaid has recently approved coverage for dentistry in Colorado, only some procedures are covered. However, there currently are no private dentists in Colorado who take Medicaid (Kessler, 2104). In the San Luis Valley, there are dental clinics that are part of the community health system, but some people do not realize that they can use the clinics even if they are poor.

Narda, who has only five or six teeth and no dentures, spends most of her days just a few steps away from a community dental clinic at a senior center; yet, she has not sought services despite her occasional pain and inability to eat some foods because she believes that she needs “at least $100” to pay for dental care; yet, services are billed on a sliding scale and Narda, given her lack of income, would be able to get care for free.

Narda believes that she cannot go to the dental clinic because in her past experience with other providers she has either been refused an appointment or has been denied some services because she did not have the co-pay; however, what is clear is that Narda's poor SHL results in her not even asking the question about eligibility.

Behavioral health is another service that patients often have trouble accessing. For example, in the San Luis Valley there are no in-patient substance abuse treatment facilities, so patients must find other avenues for treatment; this is where asking the right questions becomes important: What treatment options are available? How does a patient pay for services? How can one gain access to the few treatment beds available in other areas? Are there support groups for outpatient treatment? What types of treatments are covered by the patient's insurance?

Kate, a 68-year-old woman who has a history of bipolar disorder and depression, is interested in getting counseling for her depression because she would like to try to get off her antidepressants, if possible. While she is a patient of the community health system that operates multiple clinics, she is not aware that there are psychologists and therapists on staff. Kate used to see a private therapist in her town, but she can no longer afford him. Her therapist, like many private therapists, does not take insurance, so Kate must pay for the visit and then bill insurance herself. Because she is unaware of all the services that the community health system provides, she has not seen a therapist, nor did she think to ask if there are therapists on staff. After our interview, Kate said that she would call the health-system office to find out whether there is a clinician whom she can see about her antidepressant medication.

Viviana[4], a native of Billington, is a 79-year-old widow who suffers from numerous chronic diseases, including diabetes, high blood pressure, end stage kidney disease, thyroid disease, and congestive heart failure. Lately, Viviana has had problems with her eyesight and hearing, and she has trouble walking as a result of her diabetes and congestive heart failure. Medications, including insulin, two heart medications, a diuretic, thyroid medicine, and blood-pressure medicine cost about $130 per month, and her co-pays for doctor visits, which are at least monthly, are $40 per visit. While insulin is necessary for Viviana to live, she cuts her heart pills in half in order to save money. Due to her kidney disease, Viviana's doctor told her that she would most likely have to have dialysis; her test results will be back any day. She anticipates that she will need to be dialyzed three times per week; however, she does not have the money for the co-pays or the gas to get to Alamosa, the closest dialysis location.

Viviana's husband, who passed away 19 years ago, left her with a small home that is paid off and some livestock meant to ensure Viviana would be taken care of in her old age. Her total income includes Social Security income of $383 plus up to about $6,000 per year from her livestock, resulting in a net monthly income of about $883 per month. Making ends meet is a constant worry because she is not eligible for any government assistance due to her two assets, so she saves "every little penny . . . because you don't know what's going to hit you next." Viviana eats on about $10 per week, plus a lunch and dinner provided by Meals on Wheels Monday through Friday in order to have enough money to buy her medicine. She laments,

[4] Approximately eight months after this interview, Viviana died. She was not able to pay for her dialysis without significantly decreasing her other medical bills, so she began further rationing her medications, which led to further complicating her medical condition. In the end, she felt that she was a "burden" on her family and gave up the will to live. She died with thousands of dollars of medical bills.

> There isn't enough money to buy the medicine even if you aren't eating. It's awful. I never had experienced that before. I didn't even know it existed. It just took one time to go to the hospital to find out . . . God only knows what I'm coming into now.

In order to survive, Viviana relies on her children's assistance for transportation, caring for the livestock, and, on occasion, a little extra money. One of her daughters, Beth, lives next door with her children and provides some assistance with everyday chores and picking up groceries. Beth shares driving Viviana to doctor appointments with one of Viviana's sons. Viviana's other children pay Beth $50 per month to care for her.

Viviana has Medicare and a supplement plan through Colorado Access, for which she pays $29.90 per month. "It used to be $30, but they brought it down, thank God. But, I gotta pay that every month." She is not eligible for food stamps or Medicaid because of her assets. She says, "I have never have had food stamps or nothing like that. The only thing I've ever had is what I get today. [T]hey [food stamp eligibility clerk] said because of the livestock, they don't think that I'm eligible for it." Viviana is in a considerable amount of consumer debt, which she attributes to "never-ending copays" and medication bills that she cannot pay; the bills fill drawers in two small dressers in her living room. "I get a doctor bill every day! If I don't get a bill in the mail I get sad — what happened today? I get bills from all doctors that I don't even know. These medicine and doctor bills are killing me."

Viviana has equity in her house and livestock that could help her financially. Were she to avail herself of one of the financial programs for seniors who own their homes like a reverse mortgage, a home-equity loan, or an equity line of credit, she could consolidate many, if not all of her bills and make one smaller monthly payment. The result would be that she might have extra cash for food, utility bills, and other living

expenses. When I asked her whether she was aware that there might be programs to help her use her assets to pay for her healthcare and living expenses, she said:

> Oh, no, I don't want to do nothing like that cause I don't want to die. I probably have a few years to go . . . maybe two or who knows, I don't want my kids to go through no problems because my husband and I worked so hard to get things going and to build this house and all that and then finally he passed away and I've tried to keep it going for my kids' sakes. I don't want to lose what my husband and I work so hard either.

Her poor SHL keeps Viviana from having healthy food, from adhering to her treatment regimen, and from spending her later years free from anxiety over her financial situation. Most important, however, her poor SHL may kill her because, in her current situation, she has no money for dialysis and without it, she may die prematurely. In order to be able to pay the extra expense of her dialysis, she will have to shift money from an existing expense; get money from her children, who have families and are low income themselves; ration her medications even further or stop some of them altogether. While Viviana may have other alternatives than to mortgage her home and livestock, she is not aware of any. Neither she nor her children have ever heard of any financial programs that could help her leverage her assets, and one of her daughters, who was present during our interview, explicitly told me that she "don't trust the government to not take my mother's house in one of those schemes." Furthermore, neither Viviana nor her children know whether there is a way to exempt her assets from eligibility requirements so that she might be able to get some assistance with utilities, food, co-pays, or other bills so that she could increase her cash flow.

Poor structural health literacy is not limited to people who are undereducated and poor; nor is it a rural problem or a problem of low-income urban neighborhoods. Any person, of any age, education level, socioeconomic status, or geographic residence can

have poor SHL. Those people who have the means to hire experts or who have the advantage of human resources departments at their place of employment, who have friends or family who understand structures, or who take the time to learn about how the structures that affect them function, are in the advantageous position of making structures work for them; they are able to find ways to maximize entitlements, negotiate with insurance companies, and find resources to help them when they do not know the answer. They are also able to ask the questions that give them access to healthcare, such as, "What do I need to do to be eligible for ___?" and "How do I do that?" They are also able to find resources because they have some idea of where to look. For example, perhaps a social worker at the local hospital will know who in the community can help with Medicare enrollment questions. Perhaps the local health department or senior center will know who delivers food to homebound seniors. Maybe the pharmacist will be able to explain what the "donut hole" is.

Structural health literacy, while related to health literacy, is a distinct construct that is a precursor to health literacy and a necessary first step to access healthcare. SHL as a micro construct focuses on the individual to understand how structures function and how each person can use the structures to his or her advantage. As a macro construct, SHL focuses on how structures function within the healthcare system so that education programs can be tailored to various populations. SHL further points out that having good health literacy is not enough; patients first need to get into the healthcare system, and strong SHL increases the chance that people will get access.

CHAPTER VII

CONCLUSION

In 2010, I spent a week in the San Luis Valley, a remote, rural area in Southern Colorado, with a group from the University of Colorado High Plains Research Network and the Colorado Clinical and Translational Sciences Institute. The goal of the trip was to understand some of the health disparities experienced by residents of the Valley, who are overwhelmingly Hispanic and poor, by meeting with primary health care providers, residents, health administrators, and community leaders. During a session with a provider at an outlying clinic, she mentioned that one of the concerns that she had was the inability of many of her patients, particularly the elderly, to get their prescription medications because of the long distance to the closest pharmacy. While her clinic stocked a few antibiotics and topical medications, most of the drugs that her chronically ill patients needed had to be purchased elsewhere. She was concerned that patients were unable to adhere to their medication regimens and, as a result, their chronic conditions were worsening.

At the time, I thought that a service delivering prescriptions from the pharmacies might help to solve the access problem, but after doing some research, I discovered that merely delivering medications to the clinic was a simplistic solution and there is much more to the problem of access than just long travel distance. As I asked people who work with rural seniors about the problem of seniors accessing their medications, I discovered that this is a problem in other rural areas of Colorado and, to date, little attention has been paid to the problem by researchers. Yet, many providers are concerned about their patients. The idea of understanding the access problem received an overwhelmingly

positive response from both providers and community leaders, who stepped forward to offer their help and support for the project.

I conceived this study whose purpose was to understand what barriers seniors face to accessing their medication and how they make decisions about how to cope with inconsistent medication access. A secondary purpose of this study was to compare providers' perception of barriers to seniors' perception of barriers. The study sought to answer these questions:

1. What barriers prevent seniors living in rural areas from having consistent medication access?
    a. How do seniors cope with barriers?
2. What do providers perceive are barriers to rural seniors' ability to access prescription medication?

I used the grounded theory method of analysis to answer my research questions because it allows for multiple perspectives in the analysis of interview data and is useful in understanding patterns of process and change. In reviewing the literature, I realized that there is scant information on seniors' medication access. Grounded theory allows the researcher to inductively identify themes that emerge from interviews; therefore, in speaking with seniors throughout the Valley there was the possibility that a major theme would emerge that could explain why seniors have access problems beyond the obvious barriers of distance and cost. I was also interested in knowing whether providers like physicians and pharmacists agreed that there were barriers and if their perceptions of barriers agreed with seniors' perceptions of barriers. Grounded theory was the best

method to tie all of the different perceptions and accounts of coping with barriers as well as analyzing how seniors made decisions about what to do if their access was inconsistent.

To get a complete picture of medication access, barriers, and decision-making strategies, I interviewed seniors from five different towns in the Valley that were various distance from the hub of the Valley, where most of the services are located. Each of the five towns also has a different demographic picture, thereby allowing me to assess whether there is any difference in how seniors access their medicines, given the distance from pharmacies. I was hoping to interview members of the seniors' social support network — those people who provide instrumental support to help seniors access their medications. Unfortunately, only two seniors had people available to interview; however, only eight seniors had someone who provided some level of instrumental social support.

I interviewed pharmacists from each of the pharmacies in the Valley to get their perspectives on barriers and to learn whether there are differences in how the pharmacists interact with seniors that could influence how seniors responded to barriers. Finally, I wanted to get information from primary care providers about their perceptions and knowledge about potential barriers that their patients have. It became clear early on, that due to the shortage of PCPs in the Valley and their tight schedules, it would be impossible to interview them in enough depth to get meaningful information because of their time constraints. Instead, I used a card study to elicit the information that I needed. Filling out the card for qualifying patients takes only about 30 seconds and was accepted by both PCPs and the clinic managers whose cooperation was necessary for the success of collection.

My findings indicate that seniors do experience barriers to medication access when they live in remote areas; however, while barriers such as transportation, distance, and cost do hinder medication access, a bigger barrier is a low level of understanding and knowledge about how the structures that govern healthcare and health care access function — structural health literacy. A result of low structural health literacy is that seniors, regardless of the level and type of barriers they encounter to access, have trouble navigating the structures that increase access, including policies like those that govern access to entitlements like Medicare, funds for housing or food, and the more commonly cited barriers like cost and transportation. Furthermore, PCPs often do not ask seniors about medication barriers so they are unable to help seniors in cases where the office does not stock a medicine or if there is not a staff member whose job it is to guide seniors. Pharmacists bridge the gap between providers and seniors, and seniors and their insurance companies. Interviews with pharmacists suggest that they are aware of barriers that even seniors do not identify specifically. These barriers point to many seniors' low structural health literacy and the concern that there are barriers over which seniors have little control.

Interpretation of Findings

The impact of understanding one's health and healthcare, as well as the structures that contribute to healthcare access, cannot be overstated. It is unrealistic to think that merely knowing about one's health status, bodily functions, and treatment options is sufficient to keep people healthy and adherent to their medications. It is also unrealistic to imply that seniors always have access to healthcare and to their medications. Such suppositions are the root of a "blame the victim" mentality that assumes seniors who do

not adhere to their medication regimens are somehow behaving badly or do not care about their health. Debates in the literature about why seniors have trouble adhering to their medication have raged for over 50 years with no resolution.

While theories of public health have attempted to explain the reasons why people behave the way they do in relation to their health, e.g. the Health Belief model (Becker, 1974), few researchers have directly spoken with seniors about the barriers that prevent them from accessing their medications and thus, their ability to adhere to medication regimens. In this study, through personal interviews with seniors and pharmacists, a new construct emerged from the data that helps inform the understanding of medication access and, secondarily, adherence. Structural health literacy describes a major theme that cuts across and underscores data about barriers to medication access. In this qualitative study, I filled in some of the gaps in the research on rural seniors' access to their medications, what effect access has on their ability to adhere, and what mechanisms and processes they use to compensate for barriers. I also compared what seniors believe to be barriers to what providers believe are seniors' barriers, and I explored the role that social support networks play in seniors' ability to compensate for inconsistent access to their medications.

The findings from this study indicate that structural factors play the major role in the creation of barriers to medication access for rural seniors. Structural factors are defined as government and corporate policies that govern the access to medications. These policies, which drive the structures such as Medicare, food stamps, public transportation, and other entitlements are often outside of the control of seniors because they are either created by boards of directors of private corporations or by legislators and

bureaucrats and are not subject to voter approval. Seniors are not in a position to challenge or change these policies and thus, must find ways to make the policies work to their advantage by either being able to navigate the structures that the policies create or by finding ways around the policies so that barriers are minimized.

In my interviews seniors identified three main barriers to medication access: cost, distance, and transportation. Cost has two major components — the retail price of drugs (set by corporate policies) and the co-pay that seniors pay to the pharmacist (set by government policies in the case of Medicare and Medicaid). The retail price of drugs directly reduces the senior's allotment of money allowed by Medicare for drugs. Once seniors use up the Medicare allotment, they hit the Medicare gap or "donut hole," and they must pay a much higher amount for their drugs until they reach the payment threshold, where Medicare again pays the major portion of the drugs. During this time, those who cannot afford the full (or even subsidized) price of their medications are left scrambling to decide which medicine they can afford to buy, how they will ration the drugs they have left, or how they will cope with not having any drugs at all. While the government will subsidize drugs during the Medicare gap period, the amount of the subsidy varies and, in any case, will not bring the out-of-pocket cost down to the co-pay amount; the co-pay is based partially on the senior's income and what type of prescription drug plan he or she has. Furthermore, seniors pay a deductible, again tied to the particular plan that they can afford, as well as their income. The retail price of drugs is set by corporate policies; the deductibles, co-pays, Medicare allotment, Medicare gap threshold, subsidies, sliding income scale for premiums, and all other Medicare charges

and services are set by government policies through Congress and the bureaucrats in the Health and Human Services agency.

Seniors identified distance to pharmacies as a second major barrier. Specifically, seniors described the problems that distance created for them: driving in inclement weather is hazardous and scary; when the senior is feeling badly, driving long distances is painful and unpleasant; distance makes it hard to find someone to take them or to pick up medication for them; driving long distances is expensive; seniors fear that their vehicle will not make the drive without breaking down; older seniors who still drive have limited licenses and can only drive short distances. Even when seniors own a car, long distances are often unmanageable, so they will try to find another way to get to the pharmacy.

The third barrier, transportation, is difficult for seniors to manage; the Valley has no public transit in any town. Local policies have not made public transportation a priority; therefore, Valley seniors have to rely on friends, family, neighbors, or community organizations to help them get to the pharmacy. The only transportation service is a privately held company, SLV Transportation, which is expensive and unreliable. Seniors who live close to Alamosa, the hub of the Valley, can sometimes use SLV if they can pay the fee — upwards of $40 round trip — or if they can partner with other seniors and share the cost of the ride. Seniors who live far from Alamosa often cannot get SLV to pick them up because the company's policy does not allow their cars to be dispatched to the farther areas of the Valley. Thus, seniors who live in the more remote towns are left without any means of transportation if they do not own a car or have someone who is willing to drive them. Some senior centers have a vehicle and will

transport seniors, but the centers have a set schedule, so seniors have to plan their activities around the center's schedule.

Pharmacists identified cost and SHL as barriers. In discussing the cost of drugs, each pharmacist mentioned the complexity of the insurance payment systems — both private and public — and gave examples of how structural factors create access problems; for example, insurers have their own formularies and cover drugs at different rates. The pharmacists pointed to examples of seniors who do not know which insurance pays for their drugs, do not know what insurance plans they have, or what benefits they are eligible for. The lack of structural health literacy often leaves seniors waiting to get their medications because they have to be able to provide the pharmacist with a vehicle for payment or pay for the drugs out of pocket.

If the co-pay has gone up — which lately has happened because of the increase in drug prices — seniors may not realize that they need more money and may not have the extra money to pay the co-pay. When the price of a drug increases from one month to the next, many seniors are not prepared for the extra cost and end up without the medication because they cannot afford the new co-pay. A number of seniors in my sample mentioned the increase in drugs prices, often by 100 percent or more. Pharmacists substantiated these claims. The increase in drug prices is set by corporate policies and there is no regulation that forces public disclosure. Pharmacists were quick to point out that even they have barriers that create problems when trying to fill prescriptions for seniors. While pharmacists deal with a different set of structural issues, like how a prescription is written by the PCP or the billing practices of a particular insurance provider, these maters directly affect a senior's ability to purchase their medicines.

PCPs' involvement in seniors' access is less direct. While PCPs write the prescriptions, they are not involved directly in either helping or hindering access for seniors. Once the course of treatment is determined and the prescription is written, access is out of the PCP's hands. In the card study, PCPs indicated that they do not really know what barriers their senior patients have and, in many cases, do not even ask if patients have any barriers to getting their medications. Some physicians feel that it is not their job to ensure that patients can get their drugs, while others are part of a system that employs social workers and other personnel who could help seniors if they were aware of problems. Whether seniors volunteer information to their providers about access barriers is outside the scope of this study, but after interviewing seniors who said that they do not ask their providers about their medication, it is not unreasonable to suggest that seniors do not often reveal barriers either out of embarrassment, because they do not think about it during a visit, or because at the time of the visit they do not envision having a barrier. Yet, if providers do not ask about barriers, there will be missed opportunities to help seniors get their medicines and adhere to their treatment plans.

Social support networks, where individuals provide instrumental support to seniors such as money, transportation, or pick up and delivery services could help seniors with access. Many seniors in this study have no instrumental social support systems, partially because the people in their social networks have the same problems and need instrumental support themselves. The two seniors who had someone to whom I could speak were unique amongst the respondents. Their daughters indicated barriers to access of healthcare generally and alluded to the structural problems inherent in their parent getting their medications. In both cases, the daughters also struggled with some aspects of

the health system because either they did not understand aspects of entitlement eligibility and were operating on false information, or they had time constraints that were barriers to their involvement with the PCP. While each provides some money to help their parent pay for medications, the amount of money that they can afford is not sufficient to ensure that the parent can buy all the drugs that they need. Those seniors who have little or no instrumental support have to figure out how to get their needs met by talking to their friends, trying to find local resources to help them, or making decisions based on how they feel on the day the decision about a medication purchase needs to be made.

The barriers that keep seniors from consistent access to their medications have their roots in corporate and government policies — structures. While many seniors have become adept at managing some of these barriers and are able to get along, the level to which they can negotiate barriers is not optimal. Furthermore, some seniors have gaps in their ability to manage barriers to the extent that they are left without medications for at least some portion of the time that they need them. I propose the construct of structural health literacy as an adjunct to the construct of health literacy, which has received a large amount of interest and has spawned numerous studies.

Structural health literacy works in concert with health literacy but does not make assumptions about self-efficacy, cognitive function, or health literacy and it also does not specify that the individual patient should be responsible for understanding all the intricacies of the healthcare system, the entitlement system, and the policies that govern access. SHL posits that access requires some level of knowledge about how the healthcare system works, the ability to ask questions in order to get more information, and the ability to find resources to help with access issues; the community is responsible

for providing education to patients about the policies and how the system works in their area. There is some level of personal responsibility and agency that is implicit in SHL; however, the complicated nature of policies and the structures that they create does not allow for any one person to know everything there is to know about every policy and structure. SHL advocates for a collective effort to establish information groups into which seniors can tap to get the specific information they need. SHL further advocates for seniors to learn what they do not know and to allow that lack of knowledge to prompt them to request more information from the community.

The following conceptual model illustrates the basic idea of SHL.

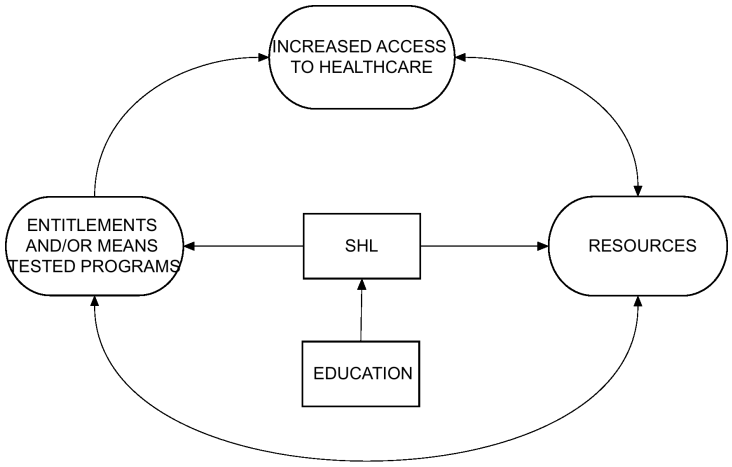

Figure 5: SHL conceptual model

As shown in figure 5, education is necessary for strong SHL, which allows patients to utilize available resources and have a better chance at securing benefits from entitlement and means-tested programs. The use of resources and the benefits afforded by programs increases the likelihood of healthcare access.

When seniors are sick, access to a medical provider, i.e. entry into the healthcare system, is the first step in their ability to care for themselves; access to medications is the second step. Currently, when a senior has access to a provider, he or she can begin the

healing process through the recommended treatment plan, which often includes medication. Once a provider, with the input of the patient, has recommended a treatment plan that includes medications, the burden is put on the patient to acquire the medicine and to take it as prescribed for the duration of the course of treatment, which may be for the rest of the patient's life. Depending on the complexity of the treatment regimen and the number of medications that are prescribed, the patient may or may not be able to adhere exactly to the plan. While adherence has been the subject of intense study because some seniors have complicated drug regimens and other problems that keep them from taking their medicines as prescribed, there can be no adherence without access. Thus, structural health literacy, by improving access to medications, improves adherence. This improvement in adherence, as a result of improved access, is the major contribution to health of SHL. The second contribution of structural health literacy is that it can be generalized not only to medication access but to healthcare access in all populations. Patients and their families in all populations must deal with paying for their care and for the supplies, equipment, and medications that they need to overcome their diseases. At all levels of income and education, patients face potential barriers to access, whether the access involves a new cancer drug, prosthetics for world-class athletes, or an MRI scan. Every population needs structural health literacy. Thus, this construct is a major contribution to public health.

Limitations

The limitations of this study stem primarily from the fact that this is the first study to look at barriers to medication access as a structural health literacy problem. As a result, the construct has not been vetted and there is more work to do to understand how

structural health literacy impacts seniors' access to medication, and in fact, the access of all populations. Another limitation is the small sample size of seniors — 19, of pharmacists — seven, and of primary care providers — 10. While this sample was large enough to get an understanding of how seniors deal with the barriers that they face and how providers work with the entities that provide drugs, a larger sample in multiple areas, that include urban areas, would help to clarify and explain differences in the ways that seniors cope with access problems. Doing this study in a remote, rural area is a third limitation. Whether seniors who live in urban areas or less remote rural areas will have different barriers is not known; nor do we know whether these findings can be generalized to other rural areas. A fourth limitation relates to the lack of information from seniors' social support networks. Because the seniors in this study often had no instrumental social support, I was unable to gauge how networks work to help seniors who have instrumental social support. Finally, a fifth limitation was that I was not able to interview primary care providers because of their time constraints. While the card study provided insight into PCPs' actions on behalf of seniors' medication access, having the chance to interview PCPs would have provided a better frame of reference, particularly because there may be differences in the ways that practices are run and staffed.

Recommendations

First and foremost, this study should be replicated in other populations and in other areas, including urban and suburban areas, with people from varying socioeconomic status. Public health officials, nurses, PCPs, pharmacists and others who work with chronically ill patients should ask whether their patients have barriers that keep them from accessing their medications. Information about barriers should be part of

the medical record so that providers at all levels can ask whether previous barriers have been resolved.

Community

The community of individuals and organizations that work with health and entitlement programs should compile simple, yet comprehensive information about any program that is available to help seniors with food, transportation, insurance, rent money, and other resources that seniors need to be able to afford their medications (see Table 2). The information should be put together with information from other agencies and should connect seniors with local resources that can answer questions and provide guidance given each senior's particular needs. Organizations that visit seniors in their homes, like Meals on Wheels, should be enlisted to help distribute information to homebound seniors who might be isolated from community resources. Furthermore, community agencies should take on the task of educating seniors about their options through community meetings, programs at senior centers, or by partnering with providers who see many seniors. The construct of health literacy puts the onus on providers to teach seniors about their health, but I believe that the responsibility for education should fall on the entire community in coordination so that all aspects of available options are covered and no one person or group has to take personal responsibility for the welfare of seniors.

Pharmacists and PCPs should meet regularly to discuss the requirements of third party payers relative to how prescriptions are written and the requirements the pharmacists must fulfill to get insurers to cover a patient's medication without the need to send prescriptions back to the PCP for revision. PCPs should explain to pharmacists their constraints given the type of electronic medical records or other concerns that they have

in prescribing medications. While these types of meetings are held periodically in other areas around the country, in the San Luis Valley there should be regular meetings where providers discuss new information and work to solve problems and concerns around medication access.

Policy

Legislation to stop the indiscriminate increase in drug prices should be passed and enforced. Providers, especially pharmacists, and patients should know what their drugs cost so that they can make informed decisions about their exposure to the Medicare gap amount. PBMs should be forced to disclose the price they charge for drugs so that consumers can shop and get the best prices by purchasing insurance plans that cover the drugs they take. PCPs should also be aware of drug prices so that they can prescribe drugs that they are relatively certain their patients can afford.

Communities where transportation is a problem should look for ways to earmark money to provide at least minimal medical transportation for seniors and others who require maintenance health care by negotiating with local cab companies or other private entities or providing special vehicles for medical transportation. With funding scarcities, partnerships with other communities who have successful models of medical transportation could provide insight into ways to structure such programs.

Those empaneled to assess narcotics policies should speak with seniors about their need for pain medicine and devise policies that do not deny pain drugs to those who need them in order to stem the abuse and illegal sale. While some seniors are dependent or addicted to painkillers, PCPs should assess the level of dependence versus the need.

Seniors who need their narcotics should not be treated like criminals or made to feel embarrassment because they are on narcotics for legitimate reasons.

Entitlements and Means-tested Programs

Seniors should have information on all entitlement and means-tested programs as well as programs that can help them maximize their income and assets; they should have the ability to speak to a local representative when possible. Programs that are government-sponsored such as food stamps or SSI are crucial to low-income seniors' ability to pay for housing, food, and medicine; however, some seniors also have property and equity that they can tap to help them meet their medical needs. Seniors should have access to programs that can help them tap the equity in their home or other potential income without fear of losing their assets. Reputable businesses that specialize in helping seniors should also be part of the information that seniors get as they work to pay their medical expenses.

Despite the limitations of this study and the newness of the SHL construct, SHL has the potential to increase access to both medications and healthcare. With the help of clinicians and public health professionals, SHL could be implemented in the San Luis Valley and tested with the numerous residents who currently have trouble accessing their medications. Understand how SHL can be useful can lead to educational interventions that can easily be tailored to the needs of communities throughout the United States. This study makes a significant contribution to the literature about access to medications and healthcare in rural communities.

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APPENDIX A

Theoretical Frameworks

Theoretical Frameworks	Author	How used	Desired Outcome
Cognitive and Behavioral Theory	Murray et al.	Aging affects memory, comprehension. Low health literacy. Cues to remember to take meds, cues to remember that the dose has been taken,	Help seniors learn to remember to take meds. Address the barriers related to aging.
Cognitive aging	Murray et al.	To create handouts with large print, simple language, and icon-based information	Improve comprehension and communication of instruction about how and why to adhere to a medication regimen with the help of pharmacists
Behavior care utilization model	Murray et al.	Relates environment and population characteristics to health behavior and choices	Ascertain the effects of age-related factors on adherence
Health Belief	Johnson et al.	Patients must believe that they need their medication in order to be adherent	Nurses can develop strategies to help their patients adhere if they understand whether a patient has a medication-taking routine.
Clinical model - unnamed	Chesney	A model to tailor materials to different cultural contexts and distinguishes between research and clinical practice	Guide the selection of assessment and intervention strategies for research and clinical practice
Health Belief Model	Balkrishnan	Predictor of adherence	None – meta analysis
Self-efficacy	Osterberg et al.	Means to get patients to adhere	Full adherence, understanding nonadherence, use of technology to increase adherence
Health Belief Model, Theory of Planned Behaviors, Transtheoretical Model	DiMatteo	Analysis of how researchers see adherence	Understanding of the reasons for nonadherence
Theory of Reasoned Action, Health Belief Model, Health Locus of Control Model, Health Decision Model, Rotters Social Learning Theory	McElany	To produce regression models for patient compliance	None – meta analysis

APPENDIX B

Reasons For Nonadherence Cited In The Literature

Author	Reasons For Nonadherence	Proposed Solutions
Murray et al (2003)	Forgetfulness	• Pharmacists should provide patient education, monitor medication use, communicate with other providers about patients' drug experiences. • Medication use should be monitored and carefully supervised. • Instruct patients on how to adhere and why adherence is important. • Pharmaceutical care strategies that are sensitive to health literacy.
	Cognitive impairment	
	Lack of understanding of the role of medications, including OTC and CAM	
	Inability to manage and reliably self-administer multiple medications	
	Attitudes	
	Beliefs	
	Limited access	
	Inadequate infrastructure for communicating information pertaining to medications among patients and providers	
	Inaccurate patient drug histories	
	Vague or incomplete documentation of adverse drug effects or interactions	
	Antiquated drug delivery and monitoring processes	
Johnson, Williams, & Marshall (1999)	Perceived medications are unnecessary	• Nurses should determine the likelihood of adherent behavior by asking patients questions that reveal behaviors and/or barriers to adherence. • Provide information to patients so that they can make educated choices about whether to adhere. • Recognize patient involvement in their own care • Create individualized dosing schedules • Use reminders such as pill boxes
	Perceived medications are not effective	
	Perceived medications are not safe	
	Access	
	Forgetfulness	
	Interruption of routine	
	Lack of reminders	
Chesney (2006)		• Adherence counseling visits • Individual & group counseling • Structural interventions
Balkrishnan (1998)	Demographic variables (age, sex, race, income, occupation, education, social class, marital status)	• The elderly non-white population should be targeted by patient education programs
	Medical variables (severity & duration of illness, comorbid conditions, frequency of use of medical services, patient satisfaction with providers, quality of care)	
	Medication variables (type of medication, drug-delivery system, regimen, adverse effects)	
	Economic variables (type of insurance, cost of drugs and medical care)	
	Behavioral variables (physician-patient interaction, knowledge of medical condition, compliance, attitudes and beliefs about health)	

APPENDIX C

Barriers to Access

Barriers to access mentioned in the literature by general category. These barriers are primarily mentioned relative to health care, but many, if not all, may also be barriers to medication access.

PERSONAL	**PHYSICAL**
	Activities of Daily Living – inability to perform Cognitive function Hearing Memory Vision
	SUBJECTIVE
	Atmosphere of pharmacy Attitudes (of patients) Choice of provider – few choices Convenience – business hours, location Fear of adverse events – of medication Fear of tolerance – of medication Fear of addiction Familiarity – unfamiliar with process or system, settings Number of medications – inability to manage multiple medicines Quality of care Security of provider location – is it safe? Self-reliance
CULTURAL	**SOCIAL**
	Informal networks – may hinder access Interpersonal dynamics – with both formal and informal networks Isolation
	CULTURAL
	Attitudes (of patients) – toward providers, facilities, and/or drugs Beliefs Choice of provider – provider's cultural competence Cultural differences – between senior and providers Familiarity – with system, processes, and or/ settings Quality of care Provider communication – ability to communicate with senior Impersonal services Race – of provider Security of provider location Self-reliance
STRUCTURAL	**FINANCIAL**
	Cost of care Cost of medications Insurance Socio-economic status
	KNOWLEDGE/LITERACY
	Is the required medication carried by the pharmacy? Complex medication regimen Lack of information about services Role of medications in illness
	ORGANIZATIONAL
	Antiquated drug delivery system

	Antiquated monitoring process Choice of provider Distance Fragmented services Inadequate infrastructure Inappropriate hours Limited health care supply Location of facilities No follow-up No outreach No quality health care available Opening hours Quality of care is poor Transportation Travel time
OTHER	**OTHER**
	Environmental “Not related to density or location”

APPENDIX D

Health Literacy Models

NAME	How model defines health literacy	Key concepts included	Key contributions and strengths/limitations of model	Key concepts retained in RTI HLSCM
1. Baker (2006) Individual-level model Dynamic	Presents Institute of Medicine's (IOM) and *Healthy People's 2010* definition: "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. "States that this definition is static and presents framework that is dynamic (individual and health care encounter). Components of HL: ▪ Print (ability to understand written health information).▪ Oral (ability to orally communicate about health).	Individual capacity (defined as reading fluency).Prior knowledge (includes *vocabulary* and *conceptual knowledge* of health and health care) affects capacity and health literacy. Potential mediators/moderators: culture and norms, barriers to change (new knowledge, positive attitudes, greater self-efficacy, behavior change). Outcomes: improved health outcomes.	Views underlying prior knowledge as a resource that affects HL, not as part of the definition. Strengths:▪ Identifies mediators/ moderators that may influence outcomes.▪ Emphasizes the role of prior knowledge and recognizes conceptual knowledge as well as vocabulary. Limitations:▪ Does not identify specific health outcomes.	▪ Prior knowledge.▪ Communication as component of HL.▪ Culture and social norms (from family, community, media, etc.) as factors that influence the relationship between health literacy and health outcomes.▪ Individual-level mediators: attitude, self-efficacy.
2 Lee, Arozullah, & Cho (2004) Individual-level model Dynamic	IOM definition: "the capacity of individuals to obtain, process, and understand basic health information and services needed to make appropriate health decisions."	Theoretical framework of how HL affects outcome—through intermediate factors: depicts "net" effects of HL and intermediate variables. Mechanisms or intermediate factors linking HL to health outcomes (considered intercorrelated): ▪ Disease & self-care knowledge.▪ Health risk behavior.▪ Preventive care & physician visits.▪ Compliance with medications. Outcomes:▪ Health status.▪ Emergency care.▪ Hospitalization. Moderators/control variables:▪ SES.▪ Gender.▪ Ethnicity.▪ Health insurance coverage.▪ Disease severity.▪ Income discrepancy. Ethnic composition of community	Strengths: Presents testable relationships based on framework. Limitations:▪ Does not directly consider individual's motivation, self-efficacy, or attitude.▪ Does not consider provider-level, system-level, or societal-level factors.▪ While acknowledging its importance, does not include social support as a potential mediator of the relationship between HL and health outcomes.	Differences between Lee et al. framework and RTI framework: Lee: knowledge of health and disease is a mediator between HL on health outcomes; RTI: knowledge contributes to one's HL level and is a result of applying HL skills to stimuli. Health outcomes also influence control variables. Describes environmental variables as influencing health literacy skills development, mediators, and health outcomes.

3. Mancuso (2008) Individual-level model Dynamic	Reviews and critiques various definitions of HL but does not totally adopt any.	Six dimensions of competence that are antecedents of HL:1. Operational.2. Interactive.3. Autonomous.4. Informational.5. Contextual.6. Cultural. Attributes of HL:▪ Capacity: individual skills in information processing, oral language, social skills, and others.▪ Comprehension: understanding information.▪ Communication: reading, writing, speaking, understanding, listening, and observing. Consequences of poor HL: increased costs, less knowledge of diseases and treatments, fewer self-management skills, poorer compliance, more errors, poor ability to negotiate and access the health care system, poorer health outcomes.	Uses concept/dimensional analysis to conceptualize the antecedents, attributes, and consequences of HL. Positions HL within the context of individual and society and identifies the interaction between the six competencies and the three attributes. Limitations: does not identify the pathway between antecedents/attributes and outcomes; does not distinguish between long term and short term outcomes; does not identify potential mediators between HL and health outcomes.	▪ Communication as a component of health literacy.
4. Manganello (2008) Individual-level model Static	Refers to IOM definition: "the capacity of individuals to obtain, process, and understand basic health information and services needed to make appropriate health decisions. "Framework specifies skills related to HL: Levels from Nutbeam (2000):▪ Functional.▪ Interactive.▪ Critical. Adds:▪ Media literacy.	Conceptual framework of adolescent HL. Individual traits (affect HL):▪ Age, race, gender, language, culture, education.▪ Social skills.▪ Cognitive skills.▪ Physical abilities.▪ Media use.HL (affect health outcomes):▪ Functional.▪ Interactive.▪ Critical.▪ Media literacy. Mediators:▪ Family and peer influences.▪ Mass media.▪ Education system.▪ Health system. Health outcomes▪ Health behavior.▪ Health costs.▪ Health-service use.	Strengths:▪ Considers HL based on the ecological model: incorporates both individual and environmental influences on HL and health outcomes.▪ Explains relationship between HL and health outcomes in specific subpopulation (adolescents), and recognizes that the structure of a framework explaining the relationship may vary by population. Limitations:▪ Does not address motivation, physician-patient interaction, and other psychological	Individual traits:▪ Culture.▪ Cognitive skills.▪ Physical abilities. Mediators:▪ Family.▪ Mass media.▪ Health care system. The influence of societal-level variables on all sections of the model.

			considerations.	
5. Nutbeam (2000) Individual-level model, but identifies social and political goals Dynamic: HL can be improved through educationa l programs	World Health Organization's definition (Nutbeam, 1998): "The personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health."	Identifies 3 progressive levels of HL (from Freebody & Luke, 1990):1. *Basic/Functional:* suf ficient basic skills in reading and writing to be able to function effectively in everyday situations. Interventions should focus on the educational goal of communicating information.2.*Communicative/ Interactive:* more advanced cognitive, literacy, and social skills used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances. Interventions should focus on the educational goal of developing personal skills.3. *Critical literacy:* more advanced cognitive skills which, together with social skills, can be applied to critically analyze information, and to use this information to exert greater control over life events and situations. Interventions should focus on the educational goal of personal and community empowerment. Outcome model categorization (model includes measures for each category):*Health promotion actions*: education, social mobilization, advocacy *Health promotion outcomes* (intervention impact measures): health literacy, social action and influence, healthy public policy and organizational practice *Intermediate health outcomes* (modifiable determinant of health): healthy lifestyle, effective health services, healthy environment *Health and social outcomes*	Strengths:▪ Create s a multidimensional conceptualization of HL, goes beyond functional literacy to Integrate concepts of interactive and critical literacy into HL.▪ Places health education and communication into the wider context of health promotion, and highlights HL as a key *outcome* from health education.▪ Recog nizes how social context and environment influence health behaviors, which in turn, affect health outcomes.▪ Identif ies both individual and community/social benefit outcomes from each of the three HL levels. Limitations:▪ Doe s not cleanly and separately distinguish concepts of knowledge, skills, motivation, and access (empowerment).▪ Limited consideration of other individual-level factors.	▪ Influence of environmental factors on health outcomes.▪ Health behaviors related to lifestyle, but considered an outcome rather than a mediator in RTI's framework.▪ Morbi dity and mortality as health outcomes.

6. Paasche-Orlow & Wolf (2007) Individual-level model and identifies system-level factors Static in model, but authors discuss HL as dynamic (changes over time, depends on context: complexity of tasks, attributes of health care system)	IOM definition but adds the emphasis that HL must be examined in the context of the specific tasks that need to be accomplished (context specific.)	Influences on individual's HL: sociodemographic variables (race, ethnicity, education, age, occupation, employment, income, social support, culture, language), capabilities (vision, hearing, verbal ability, memory, reasoning). Mediator/moderators presented as falling into three domains: ▪ Access and utilization of health care (patient factors including navigation skills, self-efficacy, perceived barriers & system factors (complexity, acute care orientation, tiered delivery model).▪ Provider-patient interaction (patient factors including knowledge, beliefs, participation in decision making & provider factors including communication skills, teaching ability, time, and patient-centered care).▪ Self care (patient factors including motivation, problem solving, self-efficacy, knowledge/skills, & extrinsic factors (support technologies, mass media, health education, resources).Health outcome: no specific outcomes specified	Considers not only patient-level characteristics, but also characteristics of the health care system as component-cause mechanisms of the relationship between HL and health outcomes. Strengths:▪ Causal model focusing on pathways between HL and health outcomes.▪ Presents factors that could explain the association between HL and health outcomes. Limitations:▪ Model does not address inappropriate use of services such as overuse of the emergency room, level of patient activation, patient health behaviors.▪ Framework is unidirectional.	▪ Sociodemographic variables.▪ Individual capabilities.▪ Navigation skills (but included as a component of HL skills in RTI framework, rather than a mediator of relationship between HL and health outcomes).▪ Mediators of the relationship between HL and health outcomes:– Individual/ patient mediators (motivation, self-efficacy).– Health care provider.– Health care system. – Media.
7. Rootman et al. (2002) Individual-level model Static (focus is generally on literacy)	No definition offered.	Conceptual model. Actions (including policy, community development) and determinants (living & working conditions, socioeconomic status, education, personal assets) affect literacy. Literacy:▪ General literacy (reading ability, numeracy, judgment, critical thinking, interpretation of evidence, communication, and negotiation skills).▪ Health literacy (knowledge of health, ability to seek health info, ability to interpret health info, knowledge and ability to seek health care, ability to understand and give consent, and ability to understand "risk."▪ Other literacy (political, economic, etc.).Effects of Literacy:▪ Direct: medication use, compliance, etc. → health status → quality of	Strength: comprehensively and separately considers literacy and HL skills, but includes them both in their model.	Health information seeking as a HL skill.

		life.▪ Indirect: use of services, lifestyles, income, safety practices, work environment, access to health info, stress level → health status → quality of life.		
8. Schillenger (2001)	"Functional" HL: measure of a person's capacity to function in the health care setting as determined by literacy (comprehension of written health care materials) and numeracy (ability to understand and act on numerical health care instructions).Person may also have difficulties processing oral communication.	Framework for association between functional HL and chronic disease outcomes. Being a patient with low functional HL is related to: Ineffective visit-based clinician-patient communication:▪ Poor understanding of disease process.▪ Poor recall/comprehension of advice and instructions.▪ Passive communication.▪ Nondisclosure of functional HL problem.▪ Unorthodox health beliefs And Ineffective home-based monitoring and disease management support:▪ Poor adherence.▪ Inadequate self-care.▪ Poor self-management.▪ Poor problem-solving skills.▪ Low self-efficacy. Outcomes:▪ Worse clinical outcomes.▪ Worse functional outcomes.▪ Higher utilization of services.	Model conceptualizes how worse outcomes among those with chronic diseases are because of visit-based and/or home-based care mediators such as self-efficacy, lack of comprehension or ability to perform self-care, or inability to correctly interpret or act on results. Limitations:▪ Does not consider social support.▪ Does not integrate into health outcomes model, health system, or physician/provider factors. The latter are included in a separate model.	▪ Key role of patient-provider communication in model but included as an outcome in RTI framework, rather than as a mediator. ▪ Self-efficacy as a mediator of the relationship between health literacy and health outcomes.
9. Sørensen et al. (2012) Model incorporates individual- and population-level components Dynamic	Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.	Antecedents of health literacy include societal, environmental, situational, and personal determinants. Dimensions of health literacy include the abilities to access, understand, appraise, and apply health information, which are affected by knowledge, competence, and motivation. These competencies allow for the navigation of three health-related domains: the healthcare setting, disease prevention, and community health promotion efforts. The consequences of health literacy, defined at the population level, include health service use and health costs, health behavior and health outcomes, participation	Strengths:▪ Offers a conceptual model based on a comprehensive review of existing models of health literacy▪ Provides a broad perspective of health literacy across health-related domains Limitations:▪ Does not specify pathways at the individual level▪ Does not consider ecological or environmental influences on the health literacy process▪ Does not	▪ The use and application of health literacy skills across a range of health contexts▪ The influence of situational and individual determinants on the development and use of health literacy skills

		and empowerment, as well as equity and sustainability.	include individual-level mediators of the effects of health literacy on health-related outcomes	
10. von Wagner, Steptoe, Wolf, & Wardle (2008) Individual-level model Dynamic	Presents IOM and Healthy People 2010 definition": "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions "Authors' definition: HL is a combination of cognitive skills, knowledge, and experience attained throughout the life span. The relationship between HL and health action is mediated by at least 2 processes: motivation based and skill based.	Theoretical basis for model: Unlikely that HL has direct effects on most health outcomes; likely to depend on a range of mediating factors, called health actions (actions to promote health, prevent disease, comply with diagnosis and treatment) Uses constructs from social cognition models of health to integrate HL into a wider framework of health actions. Epidemiological or structural determinants (of reading and math skills and resulting HL):▪ Individual influences: Cognitive abilities, Age-related cognitive decline; and Knowledge▪ External influences: Environmental influences; Formal educational opportunities; Experiential learning Sociocognitive or psychological determinants (mediators of HL, including motivational constructs that affect the performance of health outcomes):▪ Motivational phase: knowledge and understanding; affecting beliefs and attitudes.▪ System factors: health care costs; accessibility of health information.▪ Volitional phase or action control: implementation skills, including task-specific skills. Actions based on Sociocognitive or psychological determinants:▪ Access and use of health care.▪ Patient-provider interaction.▪ Management of health and illness.	▪ Presents theory for role of HL on health outcomes based on social cognition models of processing.▪ Builds on framework by Paasche-Orlow & Wolf (2007), adding additional explanation.▪ Framework described as having been tested retrospectively (i.e., applied to earlier studies), but not prospectively.▪ Applied to shared decision-making (consent comprehension), access, and use of primary prevention services (recommendations for screening) and adherence to mediation (management of chronic disease).Limitations:▪ Does not include cultural or media influences.	▪ Quality of the patient-provider interaction as an outcome.▪ Knowledge as a moderator of health literacy skills.▪ Psychological determinants, such as beliefs, attitudes, knowledge and decision making as mediators.

Source: (Squiers et al., 2012)

APPENDIX E

Card Study Instrument

Provider

1. Did you write a prescription for this patient today? Y / N
2. Is this a new prescription or a refill? New / Refill
3. Is this for: an acute condition ___, a chronic condition ___, both ___
4. Are you aware of any barriers that this patient may have that could prevent him/her from obtaining this medication? Y / N
    - If yes, please check any barriers that you believe may prevent the patient from obtaining this medication.
    - __ Cost
    - __ Distance to a pharmacy
    - __ Transportation to a pharmacy
    - __ Trust
    - __ Language
    - __ Other _____
5. Did you discuss any potential barriers to filling this prescription with the patient? Y / N
6. Are you aware of any alternative treatments or medications that his patient is using? Y / N
7. Does this patient have someone who helps him/her get prescriptions? Y / N / Don't know

APPENDIX F

Card Study Results

		Respondents	Percent Totals	No Answer	% No Answer
Did you write a prescription for this patient today?	Yes	32	59%	1	2%
	No	19	41%		
Is this a new prescription or a refill?	New	18	56%	2	4%
	Refill	15	47%		
Is the prescription for:	Acute	20	63%	2	4%
	Chronic	14	44%		
Are you aware of any barriers that this patient may have that could prevent him/her from obtaining this medication?	Yes	10	19%	14	27%
	No	28	54%		
Barriers mentioned	Cost	7	13%	38	73%
	Distance	3	6%		
	Transportation	2	4%		
	Trust	0			
	Language	1	2%		
	Other	4	8%		
Did you discuss any potential barriers to filling this prescription with the patient?	Yes	16	31%	14	27%
	No	22	42%		
Are you aware of any alternative treatments or medications that this patient is using	Yes	16	31%	14	27%
	No	22	42%		
Does this patient have someone who helps him/her get prescription?	Yes	14	27%	9	17%
	No	19	41%		
	Don't know	10	19%		

APPENDIX G

Interview Guidelines

Seniors Interview Guide

Demographic Questions

1. Age
2. Marital status
    a. Spouse or partner age
    b. Length of marriage
    c. # years widowed/divorced
3. Children?
    a. Sex
    b. Ages
    c. Where do they live?
    d. How often do you have contact with them?
4. Do you drive?
5. Income
    a. Annual income
    b. Sources
    c. Public assistance
6. Education

Illness

1. How is your health?
    a. Do you take prescription medications?

2. Tell me about the medications you take?
    a. How many are prescriptions?
    b. How many are OTC like Advil or Tylenol
    c. How many are herbs or other types of medicines?
    d. How many are vitamins?
3. Prescriptions
    a. What are your prescriptions for?
    b. Do the medicines help? Is there anything you don't like about your meds?
    c. What form do they come in (liquid, pills, chewable, other)?
    d. Do you take them as prescribed?
        i. Tell me about any difference between the way they are prescribed and the way you take them.
    e. Are you always able to purchase all your medications?
        i. If not, how do you get them?
        ii. Do you ever skip some because you are not able to purchase them?
    f. Do you ever purchase your prescriptions from somewhere besides a local pharmacy?
        i. Where?

Goal #2: Describe perceived barriers that hinder access to medicines and thus interfere with adherence to prescribed medication regimens

1. Is there anything that makes it hard to get your medicines?
2. Tell me about a time when you had trouble getting your prescriptions.

3. How much do you trust that your doctor/nurse practitioner knows what he/she is doing with respect to your health?
4. Which pharmacy do you typically use?
5. How well do you know your pharmacist?
6. Do you ever talk to your pharmacist about your medicine?
7. Does your pharmacist ever ask you how you are and how your medicine is working?

Goal #3: Understand perceived facilitators to accessing prescriptions

1. Sharing
    a. Have you ever shared your prescription medicine with anyone?
    b. Has anyone ever shared their prescription medicine with you?
2. What makes it easier for you to get your meds?

Goal #4: Learn how social support networks play a role in helping decision-making about filling prescription medications.

1. Who is the main person that you count on for support with your medicines?
    a. What kind of support do you get from that person?
2. Is there anyone who helps you get your medicines?
    a. Who are those people?
    b. How do they help you?
3. Is there anyone that you trust to give you advice about your medicines?
    a. Who is that?
    b. What kind of advice have they given you?
    c. Do you think that their advice is generally good?
    d. Do you usually follow their advice?

e. Is there more than one person who gives you advice?

4. Name all of the people who help you with your health care needs (including taking meds, reminding you to take your meds, money, transportation, mobility, ADLs, etc.)
    a. What does each person help you with?

Goal #5: Describe the process to move from potential access – the desire to fill prescriptions, to revealed access – the actual ability fill prescriptions.

1. If you have trouble getting all of your medicines how do you decide which ones to get?
2. If you have trouble getting your medicines do you ask anyone to help you?
3. Which of your medical problems is the worst?
    a. What makes it the worst?
    b. How do you deal with that medical problem?
4. Have you ever had to decide to buy only some of your medicines?
    a. How did you decide which ones to buy?

Pharmacist Interview Guide

1. What barriers, if any, do you believe your senior clients have in trying to access their medications?
2. Do you think that most patients are able to comply with their medication regiment? How do you know?
3. Do you have any problems in trying to dispense medication to seniors?
4. What percent of your senior customers require regular medications?
5. Are you able to provide any type of assistance help seniors buy their medications?
6. How does access to medications affect your business?

7. How much time do you spend dealing with insurance company claims?

APPENDIX H

Demographic Information On The Counties In This Study

	Alamosa	Conejos	Costilla	Saguache	San Luis Valley	Colorado
Land area	723	1287	1227	3168	8192	103642
Persons per square mile	21.4	6.4	2.9	1.9	5.6	48.5
Population	15,445	8,256	3,524	6,108	46,027	5.026 mil
Population change from 1990	3.2	-1.7	-3.8	3.2	-0.4	16.9
Population over 65	11.3	15.2	22.9	14.6	14.8	10.9
Median age	32.9	38.2	49	43.3	42.9	36.1
% Hispanic	46	56	66	40.1	46.9	20.7
% Non-Hispanic Whites	49.6	42.9	30.8	56.4	49.8	88
Poverty rates % over 65	19.6	13.8	16.8	16.5	14.9	8.4
Avg. weekly wage	$603	$510	$489	$504	$563	$901

Source: San Luis Valley Resources Development Group