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Constructing a Healthcare Assets Map in Rural Appalachia: An Analysis of Healthcare Services and Perceived Health Threats

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Constructing a Healthcare Assets Map in Rural Appalachia:

An Analysis of Healthcare Services and Perceived Health Threats

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Arts
Department of Anthropology
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Abstract

Using data gathered over the course of two months through participant observation and semi-structured interviews with health providers (n=19) and community members (n=20), this research analyzes patient access to health care resources and describes community members' and health care providers' perceptions of pressing health concerns in their area. The results of this research show the types of health care resources in the county, the similarities and differences between health providers' and community members' perceptions, and how the unique characteristics of this community influence health care access and health disparity.

Chapter One: Background and Previous Research

Appalachia is a region of the United States that lags economically behind the nation as a whole. The economic hardships of this area correspond with poorer health outcomes as evidenced by higher all-cause premature mortality compared to the national average (Halverson and Bischak 2008). Research, predominately in the fields of economics and public health, has demonstrated the association between low socioeconomic status and poor health outcomes in Appalachia. As a region, Appalachia comprises 420 counties located in southwest New York; western Pennsylvania, Maryland, Virginia, North Carolina, and South Carolina; West Virginia; southern Ohio; eastern Kentucky and Tennessee; and northern Mississippi, Alabama, and Georgia (ARC n.d.-a).
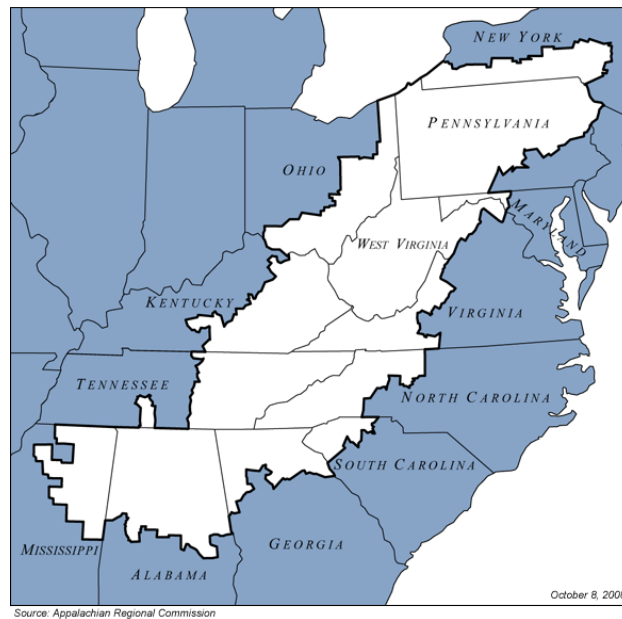
Figure 1: The Boundaries of Appalachia (ARC n.d.)

The regional core and the focal area of the traditional culture of Appalachia, however, is the central region which spans north through West Virginia and south to Tennessee (Williams 2002). Eastern Kentucky, the focus of this research, lies in the center of the core of Appalachia.

The rural landscape of Eastern Kentucky, coupled with the poor socioeconomic environment and unique Appalachian culture, create an interesting milieu in which to study health care access. Many counties in Appalachia, including Leslie County, the focus of this project, are designated as health provider shortage areas (HPSA) and medically underserved areas (MUA) according to the Department of Health and Human Services. HPSA status is determined by the patient to doctor ratio in three fields: primary care, dental, and mental health. MUA status is determined through four variables: primary care physicians per 1,000 residents, infant mortality rate, poverty rate, and percentage of elderly population (HRSA 1995; HRSA n.d.).

Due to the relative lack of providers in the region, an Appalachian Regional Commission (ARC) report on the status of health resources in Appalachia specifically calls for an analysis of "local differences in availability to local medical care resources" (Halverson and Bischak 2008:iv). This research seeks to address that call to action by analyzing the availability of health care resources in Leslie County, Kentucky. Using data gathered over the course of two months, this research will analyze patient access to health care resources and describe community members' and health care providers' perceptions of pressing health concerns in their area. Finally, in order to synthesize all of these results, I will discuss the availability of resources in relation to common health problems. Accordingly, the questions guiding this exploratory research are:

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1. What are the most pressing health problems in the county as perceived by health care providers and community members?
2. What health resources are available to meet patients' needs?
3. How accessible are these resources?
4. What makes certain resources successful or popular among community members?

The first two chapters in this manuscript frame this research in terms of previous research, geographical setting, and anthropological theory. Exploring the unique cultural, geographical, and historical aspects of life in Appalachia is a vital aspect of understanding the scope of this project. Chapter One provides an overview of previous research on the topic of health care access and health disparity in Appalachia, including the theoretical approach that framed this research, while Chapter Two delves into the history, culture, and demography of the region.

Chapter Three turns the focus to the methodology used to conduct this research over the course of two months. In the process of developing an assets map of the county and gauging perceptions of health disparities, I used semi-structured interviews, free lists, and rank ordering. Each method will be discussed in turn.

Chapter Four presents the results of this research. The results are divided into three main sections: a description of the health resources in the county, community members' health perceptions, and health providers' perceptions. The rationale participants gave for commonly mentioned concerns are also discussed.

Chapter Five synthesizes these results in a discussion of the themes that arose during this research. I show that Leslie County residents rely heavily on nurses for primary care, but elect to leave the county for more specialized care. In addition, the close-knit nature of the community leads to interesting dynamics, both negative and positive, related to health care access. In terms of perceived health threats, community members' and health care providers' perceptions are

slightly different as each group weighs certain health problems more heavily than others. In addition, the conclusions made from this research will be related back to previous research that has been conducted in Appalachia and the theoretical framework that guided this project. Finally, Chapter Five concludes with a discussion of recommendations, limitations, and possibilities for future research.

Healthcare Access and Health Disparity in Appalachia: Previous Research

Health in Appalachia is characterized by higher rates of certain diseases and conditions than are seen in the American population as a whole. A report published by the ARC in 2004 shows that Appalachia has a higher rate of all-cause mortality than other areas of the country. This includes elevated rates of mortality from cancer, heart disease, stroke, and diabetes (Halverson and Bischak 2008; Hare and Barcus 2007). For example, the rate of cervical cancer mortality in Appalachian Kentucky is approximately 50% higher than the national average. Additionally, Appalachians face higher rates of "serious psychological distress," depression, and drug abuse, especially prescription drug abuse (Zhang, et al. 2008). . Additionally, central Appalachia has higher rates of obesity, smoking, and physical inactivity, which have direct links to many other health problems. Also of note is that approximately half of the counties in Appalachia are designated health professional shortage areas and thus do not have a sufficient number of health providers to cover the population's needs (Halverson, et al. 2004; Lawson, et al. 2004).

Within Appalachia, health disparities are even more pronounced in mountaintop coal mining communities like Leslie County. Even after controlling for factors like smoking, obesity, income, and education, researchers found that residents of mountain-top mining areas suffer

from poor mental and physical health (Zullig and Hendryx 2011). In another comparative study conducted in areas with and without coal mining, researchers found that self-rated health status, frequency of illness symptoms, asthma, COPD, and hypertension were worse in mining areas. This author introduces an environmental component into the discussion on health disparity, positing that environmental pollution near mining sites, coupled with socioeconomic factors, may exacerbate health concerns (Hendryx 2013).
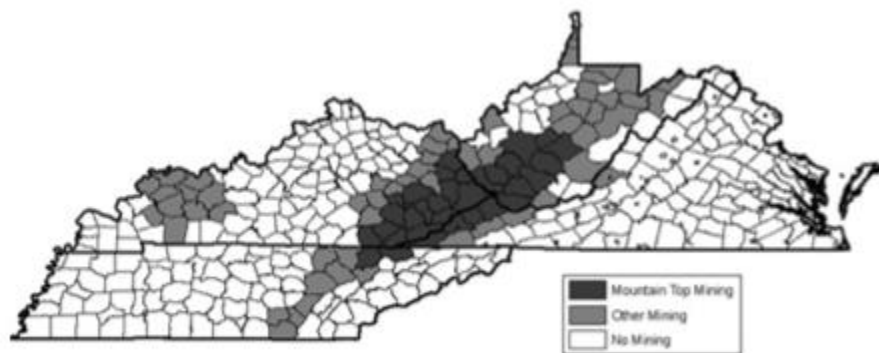
Figure 2: Mountaintop Coal Mining by County, 1994-2006
(Zullig and Hendrix 2011)

Patterns of Disease in Appalachia

The Kentucky Cabinet for Health and Family Services publishes an annual report of leading causes of death on both a state and county level. Below (see Table 1) is a summary of the most recent data (2005) compared with rates for the United States (Kung, et al. 2008). Rates reported are per 100,000 people.

As evidenced by these data, Leslie County has elevated mortality rates from cancer, chronic lower respiratory diseases, diabetes, and drug abuse. The mortality rate from heart disease is slightly lower than in the state as a whole, but still higher than the national rate.

Table 1: Selected Causes of Death, 2005

Cause of death	United States	Kentucky State	Leslie County
Heart disease	220.0	253.4	232.9
Malignant neoplasm (cancer)	188.7	223.9	282.8
Chronic lower respiratory diseases	44.2	61.0	149.7
Diabetes	25.3	28.0	74.9
Drug induced	11.3	15.4	33.3

Several studies have illustrated how these health problems disproportionately affect residents of rural Appalachia. Obesity and cancer, two health indicators that correlate with poverty in low socioeconomic areas, can both be promoted by 'lifestyle factors' such as poor diet and lack of exercise. (Hare and Barcus 2007). Overweight and obesity can exacerbate one's susceptibility to countless other conditions including diabetes, heart disease, hypertension, stroke, and cancer. Accordingly, heart disease, cancer, and stroke cause the most deaths in Appalachia (Crooks 1999).

In one study, anthropologists researched childhood growth patterns, a key indicator of the relationship between socioeconomic status and health (Crooks 1999). A population of elementary school students in rural Eastern Kentucky was analyzed for height, weight, and Body Mass Index (BMI) and researchers found that 33% of the students were overweight (above the 85th percentile for weight) and 13% of students were obese (above the 95th percentile for weight). Socioeconomic findings indicated that 78% of the children were eligible for free or reduced price lunches, and 23% were from families in which neither parent was employed (Crooks 1999:131). The authors propose possible explanations for increased weight and stunted growth, including inability to purchase nutritional food and lack of participation in afterschool activities due to insufficient transportation.

A subsequent study elaborated on the possible explanations for increased weight by analyzing the diets and activities of school children in Appalachia. In this case, researchers noted that children's diets were very high in fat and sugar and low in fiber and protein; this diet was aggravated by a sedentary lifestyle that included a higher proportion of low-intensity activities such as reading, watching television, and playing computer games (Crooks 2000). These factors work together to contribute to high levels of obesity in the region beginning from an early age.

As previously noted, cancer incidence and mortality are also elevated in rural Appalachia. Of particular interest are the elevated rates of cervical and breast cancers given the existence of diagnostic tools that can greatly improve a person's prognosis. The Pap smear is the diagnostic tool of choice for early detection of cervical cancer and mammography is used to detect breast cancer. Regular Pap smears and mammograms can detect the disease in an early or even pre-cancerous state; upon early detection, treatment is less expensive and more efficacious. In Appalachian Ohio, for example, incidence of cervical cancer is 37% higher than in non-rural areas of the state and mortality is elevated by 44% (McAlearney, et al. 2010).

Several factors are known to play a role in preventing women from being screened for breast and cervical cancer. Factors associated with lack of regular pap and breast exams include embarrassment about undergoing pap tests and concerns over body size or health status (Schoenberg, et al. 2013). Furthermore, many women do not have a regular health service provider, and thus may not be referred for the exams. Women also see lack of health insurance as a barrier to screening even though the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is designed to provide screening, diagnostic, and treatment services for low income and uninsured women (Schoenberg, et al. 2013).

Research has shown that the ratio of early- to advanced-stage breast cancer is lower in Appalachia than the national average, which illustrates that there is a higher rate of advanced-stage breast cancer in this region compared to the United States as a whole (Dignan, et al. 2009). The increased prevalence of both obesity and certain types of cancer raises questions about the level of quality health care access in Appalachia. These disparities may be attributed to various aspects of the health care system.

Behavioral health indicators show elevated rates of smoking, obesity, and drug abuse in the region, as well. As of 2010 in the Kentucky River District, 27.7% of adults smoke cigarettes, which is above the national average of 17.3%. (Peyton, et al. 2013). In addition, rates of prescription drug abuse as well as opiate use are higher in Appalachia than in the rest of the country (Zhang, et al. 2008).

One study shows that the epidemiological reality of health in Appalachia is reflected in residents' understanding of their community's health threats. Through the use of focus groups among women in Appalachian Kentucky, Schoenberg, Hatchen, and Dignan (2008) assessed women's perceptions of the health threats facing their communities. The major community health concerns identified by women were drug use, cancer, heart disease, diabetes, smoking, obesity, lack of exercise and communicable diseases such as HIV and hepatitis (Schoenberg, et al. 2008).

Participants attributed all of these health problems to living in an unhealthy environment. For example, drug abuse was attributed to three factors. First, participants said that people were not able to deal with "life's harsh realities" including economic hardship and unemployment (Schoenberg, et al. 2008:4). Additionally, participants identified the breakdown of social organization and physicians who overprescribed medications as additional contributors to the

drug use epidemic seen in Appalachia. Heart disease, diabetes, and obesity, and poor diet were partially attributed to individual characteristics such as 'laziness', but also to socioeconomic factors such as high cost of groceries and a breakdown of the traditional farming economy (Schoenberg, et al. 2008). Thus, women in rural Appalachia were aware of the health burdens facing their community as well as the complex role of both structural and personal factors in the development of health disparity.

Health and the Rural Landscape

The rural landscape of the region also factors into the development and perpetuation of health disparities. The obstacles associated with rural health care delivery include staffing shortages, long travel distances, inadequate modes of transportation, and affordability (Lawson, et al. 2004). Beginning in the early 1900s, the United States medical education system began to focus more on training specialists rather than general practitioners in response to the 1910 Flexner Report on medical education. However, the constraints of training this type of doctor led to a high concentration of doctors in urban rather than rural areas. The launch of the National Health Service Corps (NHSC) in 1970 aimed to address the shortage of health care providers in underserved areas of the country, including rural areas, by promising loan cancellation to medical students who chose to practice in areas of need (Gesler, et al. 1992). This program ultimately did not have a lasting positive impact on rural regions because they were not equipped to train or recruit their own physicians after funding was cut to NHSC programs.

As previously mentioned, many areas of rural Appalachia continue to be MUAs and HPSAs. The federal government has undertaken continued efforts to improve health care access to rural areas in part through programs that encourage the development of rural clinics. When a

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clinic has a federally-approved status as a rural health clinic (RHC), the facility receives the benefit of having a different federal reimbursement structure than clinics without RHC designation (2013b). This is designed to offset the fact that rural clinics do not receive as many patients as their more urban counterparts; additionally, patients in rural areas are more likely to be insured through Medicare or Medicaid which reduces the profits associated with treating them. To qualify as a RHC, a clinic must be located in a non-urbanized area that is designated as a HPSA or MUA, employ a nurse practitioner or physician's assistant, and provide diagnostic and preventive services as detailed by the federal regulations. For a list of the RHC qualifications, see Appendix A. There are approximately 3,800 designated RHCs in the United States, including five in Leslie County (2013a; 2013b).

Another provision designed to promote more health providers to work in MUAs is targeted at foreign doctors. Many foreign doctors, when attempting to practice medicine in the United States, must serve in a MUA for a certain number of years as a requirement of their visa.

Access to Healthcare

The rural landscape of central Appalachia presents several challenges to health care access, the most obvious of which is physical access to services. More than half of the counties in the region have a shortage of health care providers and research has shown that a woman's physical distance from a health care provider and lack of insurance can both impede her ability to access cancer screening (Halverson, et al. 2004). For example, breast cancer is more likely to be detected at an advanced state in individuals who live more than 15 miles away from a health center or who lack health insurance (Dignan, et al. 2009).

Another possible barrier to healthcare access is the perceived cost of health care services. In an Appalachian community in Ohio, 80% of women did not know how much a Pap test costs, and those who postulated a cost were likely to overestimate by a significant amount (McAlearney, et al. 2010). In this case, the assumption that they could not afford it was enough to prevent women from pursuing the preventative test. Similarly, women in Appalachian Kentucky cited lack of insurance as a reason for not undergoing a Pap test despite the availability of testing through the National Breast and Cervical Cancer Early Detection Program NBCCEDP (Schoenberg, et al. 2013). These studies make it apparent that both distance and cost present barriers to health care access in the region.

Despite the prevalence of these barriers in Appalachia, a study relating to heart disease in Kentucky observed that individuals do frequently utilize their local health care resources (Hare and Barcus 2007. The authors concluded that there were high patterns of utilization, but that mortality from heart-related disease also remains very high. An explanation for this could be that, although individuals go to the hospital multiple times for poor health, they often cannot afford preventative care, and they might be turned away from a hospital for lack of insurance only to return at a later date for the same problem (Hare and Barcus 2007).

Efficacy of Healthcare Providers

The previously mentioned study suggests that although direct access to health care facilities may not always be a problem, the effectiveness of doctor visits should be called into question. People in low-income areas were likely to report that they could not fill prescriptions or visit a specialist because of the costs involved, whether directly related to the price of the

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medication or appointment, or other costs such as time, gasoline, and other priorities (Lawson, et al. 2004).

Other evidence implies that doctor visits may not be productive because of the information provided by the doctor. For example, Muratova, et al. (2003) show that doctors may not adequately advise patients about the risks of and possible ways to prevent obesity. In this study, only 63% of parents with obese children were informed by their doctor of their child's clinical obesity; of these, only 33% of the children were advised to try to lose weight, 56% were advised to change eating habits, and 48% were advised to increase exercise. This leaves nearly half of the obese children in the study without any advice from their doctor about how to improve their health.

The role of doctors in promoting cancer diagnostic screening shows a similar trend. 66% of rural Appalachian women surveyed reported that their doctor did not advise them to get a Pap test and only 39% of doctors reported that they always recommend cancer screening to their adult patients (McAlearney, et al. 2010). Corroborating this observation, doctors in one study reported lack of time as a provider (i.e. having too many patients) as a barrier to recommending cancer screening (Shell and Tudiver 2006). Thus, even if a person does regularly go to doctor appointments, he or she may not be receiving adequate care.

The Role of Culture in Healthcare

Unfortunately, misunderstandings or incorrect assumptions between patient and provider may cause appointments to be unproductive. For instance, one study showed that doctors in Appalachia can attribute patients' poor health to perceived cultural traits such as relative unimportance of health, a strong sense of fatalism about cancer and other diseases, and a belief in

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religious explanations for disease; this sense of judgment and assignment of blame, rather than financial or other explanations, may contribute to patients' not returning to the doctor's office for follow up care (Shell and Tudiver 2006).

Similarly, Sovine (1988) found that providers often blamed patients' behaviors on their 'culture'. This led to frustrations on both sides of the interaction. For example, practitioners viewed patients negatively because of the perception that patients wanted to be diagnosed with psychiatric illnesses in order to receive welfare benefits. She argues that this type of negative attitude demonstrates the need to systematically educate professionals on how to successfully work in the region. The association of culture with the above description also show the fluid nature of the concept of culture, which can be taken by doctors to encompass things like poverty and education along with those elements typically associated with culture, such as beliefs and traditions.

Additional disconnects between patient and provider can compromise the quality of service delivery in the region. For example, health practitioners have been observed to describe patients as uncooperative or ignorant, unwilling to comply with directions, or lazy for not working. However, these descriptions fail to address both structural factors involved with unemployment and cultural factors that may lead to miscommunication (Blakeney 2006). Providers may say that patients do not to enough to care for themselves while failing to acknowledge the constraints that poverty places on their behaviors.

The aforementioned perceptions of patients' culture and behaviors are reminiscent of the culture of poverty model, which was popular in the 1960s and emphasized that 'traditional' cultural traits such as fatalism, suspicion of authority, and feelings of helplessness, developed in response to long-term poverty and isolation, make certain cultural groups less able to cope with

modernization and contemporary society (Billings and Blee 2000; Gazaway 1969; Keefe 2005b; Weller 1966). Thus, culture was blamed for the persistence of poverty and inability to be part of the modern world. Rather than addressing the structural factors that lead to the traits previously described, the culture of poverty model views these traits as personal deficits (Billings and Blee 2000; Billings and Blee 2012; Keefe 2005b).

Despite the theory's disfavor in the field of anthropology, the culture of poverty model still holds ground in popular opinion of the region. Many people, including health care providers, still view the rural poor as belonging to a cultural group that is overly fatalistic and religious and puts little importance on health (Shell and Tudiver 2006; Sovine 1988). Thus, although the culture of poverty model is no longer a valid theoretical construct, it is important to consider that people outside of the field still attribute negative socioeconomic and health indicators to perceived cultural flaws.

It is evident through the review of literature on health disparity in Appalachia that this is a multifaceted and complex topic. Structural factors such as economic status certainly play a role in a person's ability to financially access health care and maintain a healthy lifestyle. Likewise, physical access has also been shown to influence utilization of resources, especially in rural settings such as Eastern Kentucky. However, doctors' and patients' attitudes toward health and illness and experiences within the clinical setting can have just as much, if not more, influence on resource utilization and efficacy than structural factors. Thus, each of these factors must be considered when analyzing health disparity in rural Appalachia.

Theoretical Framework

A theoretical framework is an integral aspect of a research project, not only to define the scope of a project, but to provide a lens through which to analyze the results. Underlying the theoretical premise of this research is the importance of considering how both micro- and macro-level factors contribute to behaviors associated with health care. From a materialist perspective, macro-level forces such as structural and economic barriers certainly affect access to health care in Appalachia. As Sovine puts it, in Appalachia "…the poor are poor because of the nature of the system of ownership, production, and distribution" (1988:223).

Wagner (1987) defines the political economy of health as, "a macroanalytic, critical, and historical perspective for analyzing disease distribution and health services…with particular emphasis on the effects of stratified social, political, and economic relations within the world economic system" (132). Thus, political economy takes into consideration the historical roots of a region's economic and social oppression in order to understand existing health disparities (Ortner 1984).

As will be discussed further in Chapter Two, although policy changes have been designed to address structural inequalities in the region, some residents continue to live without basic needs such as affordable food, quality education, and solid public infrastructure (Shannon 2006). High rates of unemployment and poverty paired with the extant health disparities further substantiate the link between political economic and health factors in the region.

Though examining economic and historical factors is imperative in order to understand health disparity in Appalachia, improving health outcomes in the region "requires more than an increase in financial resources…[because] financial resources do not ensure accessibility of services" (Keefe 2005:16). As evidenced by the existence of the breast and cervical cancer

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treatment subsidy program, affordability neither ensures utilization of health services nor compliance with doctors' orders. Thus, understanding the micro-level factors that influence health care decision-making is an important addition to the discourse on health service availability and utilization in the region.

A phenomenological approach to health in Appalachia allows micro-level analysis without blaming culture for patients' behaviors. This type of approach addresses experiential factors that influence health in addition to structural and economic factors. According to Willen and Seeman's overview of phenomenological approaches in anthropology (2012), "the turn to experience in contemporary anthropology…[has] provided a conceptual bridge between individual lifeworlds and the much broader political-economic trends and cultural-symbolic systems that constrain and inform them" (6). While acknowledging the importance of political economy in influencing people's lives, "life is open ended and largely underdetermined by what we might imagine to be its structural constrains—including culture" (Willen and Seeman 2012:10).

Through the lens of phenomenology, anthropologists can gain an understanding of individual agency and decision-making beyond the constraints of social structures. In contrast to materialist macro-level reasoning, a phenomenological approach stresses the individual's experience with and interpretations of their own reality. Desjarlais and Throop (2011) describe the necessity of a phenomenological approach to social understanding: "Anthropology had come to focus unduly on questions of meaning, discourse, structural relations, and political economy to the neglect of the everyday experiences, contingencies, and dilemmas that weigh so heavily on people's lives" (Desjarlais and Throop 2011: 92-93). Examining individual's lived experiences has been shown to cast new light on health disparities.

The use of phenomenology as a theoretical lens affords patients more agency in making decisions about their health rather than portraying them as passive 'victims' of social structure. Sovine (1988) postulated a connection between health outcomes (specifically, mental health) and the lived experience of poverty in the region:

> Comprehending cultural meaning as it infuses personal meaning is necessary to the practice of mental health care. For example, if social inequality, powerlessness, dependency, and exploitation pervade the lives of the Appalachian poor, how do these conditions affect the individual's developing sense of self, and how does an unempowered view of one's self contribute to mental illness among the region's people? (Sovine 1988:234).

This type of approach to health in Appalachia merits further investigation, especially regarding its applicability to general health care access.

These two theoretical frameworks—political economy and phenomenology—each address a different level of social understanding. Ranging from macro-level political economic factors to micro-level experiential factors, these frameworks are both important contributions to the discourse surrounding health disparity in rural Appalachia. Based on accounts of Appalachian history, culture, religion, and economy, it is clear that neither of these theories can stand alone in explaining the complex social and structure factors that contribute to health disparity. Therefore, both of these theories have informed the development of the questions explored in this research with the goal of situating individual experiences within the broader political-economic structures that influence society.

Chapter Two: Study Setting

This chapter will first provide an overview of the history, demographics, and cultural traits of Appalachia as a region and subsequently focus more specifically on Leslie County as the site of this research.

<u>Economy/Demographics</u>

Central Appalachia has a higher a poverty rate and lower per capita income and levels of education than the country as a whole. While the poverty rate in the United States between 2006 and 2010 was 13.6%, in some regions of Appalachia nearly one quarter of the population lives in poverty (ARC n.d.-b). A majority of the counties in Appalachian Kentucky and West Virginia reported per capita incomes below $25,545, compared to the national per capita income of $39,635 (ARC 2012).In addition, in many areas of central Appalachia (i.e., Eastern Kentucky and West Virginia) only about half of the adult population has completed high school, compared to the nation-wide rate of 80% high school completion (ARC 2009). Without a high school diploma, employment opportunities are limited. This, combined with the limited array of jobs in rural areas, has contributed to the region's low income levels.

Poverty in the Appalachian region is not a new occurrence, but rather is the product of a combination of factors, including decades of exploitation by outside interests. Around the time of the American Revolution, Appalachia mainly had an agricultural subsistence economy based on family-run farms, which was the center of Appalachian economy until the nineteenth century

(Straw 2006). During the period of industrial development, Appalachia gained a more prominent position in the economy of the United States due to its plentiful natural resources like coal and timber. Following the Civil War, industrialization in other parts of the country led to a large demand for coal and timber that was filled by resource deposits in Appalachia (Shannon 2006).

Outside investors were quick to purchase land and mineral rights, so coal mining and timber industries emerged throughout the region (Billings and Blee 2012; Shannon 2006). Other industries such as textile mills and furniture factories also moved into the region, though these were not as influential as the coal industry. Towns were developed specifically to house the workers in these industries, so it was not uncommon for them to be populated entirely with coal miners' families. Whereas previously most land was owned by families and used for family farms, by the late 1800s large areas of land were owned by outside financiers (Shannon 2006; Straw 2006).

However, the mining industry was precarious because it was subject to dramatic fluctuations based on supply and demand. Additionally, workers faced dangerous working conditions and were paid poorly. (Shannon 2006). Following the downturn of the coal industry after the two World Wars, Appalachia experienced a significant out-migration of "economic refugees" (Shannon 2006:75). Unfortunately, since other industries and businesses were not extensively developed in the region, coal town settlements became defunct and families were left with few opportunities for employment after the demand for coal decreased (Straw 2006).

The traditional agricultural system of the region was virtually destroyed by the development of industry in the region. Logging cleared previously dense forests and disrupted the ecology of the region and soil nutrients were depleted by the over-working of small plots of land (Sarnoff 2003). Small farms could not compete with the commercial farms in the Midwest

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and local markets were lost in favor of inexpensive commodified food distribution systems (Shannon 2006).

The New Deal, enacted by Franklin Roosevelt in 1933, attempted to address the economic hardships that had struck the United States during the Great Depression. However, this legislation did not address the structural causes of joblessness in Appalachia, but instead "shifted the dependence of many mountain people from the coal companies to the federal government" (Straw 2006:16).

In the 1960s, John F. Kennedy targeted Appalachia as one of the areas of poverty that he hoped to address in his presidential campaign. Through his campaign, Kennedy was able to bring media attention to the widespread poverty in the region. Lyndon Johnson continued Kennedy's emphasis on Appalachia through his War on Poverty, passing the Appalachian Regional Development Act in 1963 to increase federal funding of public works projects such as highway construction and educational programs (Straw 2006). This legislation also set up the Appalachian Regional Commission, which served to give the region an official geographic definition and to improve infrastructure.

Overall, these programs did little to address the structural inequalities in Appalachia. The limited availability of jobs in the region has led to significant dependence on welfare and Social Security benefits (Anglin 2002). Though certain areas in the region have seen growth in the past few decades following the immigration of wealthy retirees and the development of colleges and universities, the overall economic status of Appalachia continues to lag behind the rest of the country (Shannon 2006). Given the legacy of economic exploitation and poverty, the economic history of the region is important to consider when approaching questions of health.

The culture of Appalachia, unique in many ways when compared to mainstream American culture, is also important to consider when discussing health in the region. In her book Appalachian Cultural Competency, Susan E. Keefe (2005a) enumerates several factors that are influential in understanding the cultural milieu of Appalachia, including a unique dialect, a family-based social system, an adherence to sectarian Protestantism, egalitarianism, independence, love of the land, and avoidance of conflict.

Keefe is careful to acknowledge that these cultural traits are by no means all-encompassing or evenly distributed in the region. These traits tend to be most evident in central Appalachia or the "core" of Appalachia. She also advises readers not to view these cultural differences as deficits, which has commonly been done in popular portrayals of Appalachians like the movie *Deliverance* (Keefe 2005a).

The religious tradition of Appalachia merits special attention because of its unique impact on health beliefs and behaviors. Though many different denominations are represented, the dominant denominations fall under the category of conservative Christian such as Baptist, Pentecostal and Holiness churches (Wagner 2006). However, these denominations as practiced in Appalachia differ significantly from mainstream practice (Keefe 2005a). Christianity in Appalachia is characterized by piety, purity, and fundamentalism. This means that churches tend to emphasize a literal interpretation of the Bible, value a personal relationship with God, and sometimes partake in traditional rituals like feet washing and immersion baptism (Wagner 2006).

In fundamental churches, God's will is accepted as unavoidable, which is sometimes interpreted as fatalism. It is important to note that fatalism in the Appalachian context should not be—but often is, by outsiders—conflated with behavioral or emotional resignation in the face of adversity such as illness:

An often-heard homily in Appalachia is "God doesn't give a person more than he can handle." But we go astray when we see fatalism as leading to a "There's nothing I can do" attitude throughout the region. If fatalism prevented doing anything about social problems, how would labor union activity, for example, be explained? In fact, the union activist and the ardent churchgoer is the same person in Appalachia (Wagner 2006:187)

That being said, many people turn to their faith for security and comfort and there is a general distrust of "outsiders" because of a history of mistreatment from missionaries and social workers (Humphrey 1988). Historical, religious and cultural traditions each must be considered with analyzing the existence of health disparities in an area like Appalachia.

Leslie County, Kentucky:

From a geographical, cultural, and demographic standpoint, Leslie County is somewhat representative of Appalachia as a whole. Leslie County is located in Eastern Kentucky and is one of the seven counties that make up the Kentucky River District. The population was 11,310 as of the 2010 Census, 98.8% of which is non-Hispanic white. With a population density of approximately 30 people per square mile, Leslie County is considered a rural county. 51.5% of the population 25 and older have at least a high school diploma, but only 9.6% have a college degree or higher education (CEDIK n.d.). As with all of the counties in the Kentucky River District, it is classified as distressed according to the Appalachian Regional Commission, which indicates that it has fallen into the bottom ten percent of all counties in the country ranked by three-year average unemployment, per capita market income, and poverty rate (ARC 2012b).

Unemployment in the area has consistently measured above national averages. Between 2008 and 2010, unemployment in Leslie County averaged 11.5%, compared to 8.2% in the United States as a whole. Similarly, in 2009 30.8% of the population living in poverty, compared to 14.3% in the United States during the same year (CEDIK n.d.). The per capita market income

(that is, per capita income less the value of transfer payments) in this area is only 42.8% of the U.S. average. Based upon the indicators of unemployment, poverty rate, and market income, Leslie County is ranked 3,002 out of the 3,110 counties in the United States (ARC 2012a).

One main road comprises the only city—population 365—in the county. The road is lined on either side by small store fronts, a few out of business, but most with a handful of cars parked in front during business hours. One stop light marks the center of town; go one way to the health department and community college, the other way to the grocer, bank, and fast food restaurants. A riverside park is located in the center of town and features basketball courts, a playground, and a walking path. Known as the Redbud Capital of the World, Hyden is surrounded in the spring by the bright pink trees that blanket the mountain side. Driving a few minutes out of town, the roads get winding and diverge every few feet up or down the slope into steep, unpaved driveways leading to small houses tucked seemingly impossibly on the side of the mountain.

Residents of Leslie County share many cultural traditions typically associated with Appalachia. The county is home to a plethora of churches, most of which fall into sectarian denominations, like Pentecostal, that are common in Appalachia. For many people, the church serves as a means not only of social unity, but also of familial and social identity. It is not uncommon to hear a person being described using the church he or she attends as a reference point. This type of identification was second only to description through family ties. In the center of the town, a converted auction house is now used for weekly bluegrass concerts that attract dozens of spectators from around the county.

One aspect of Leslie County that distinguishes it from other areas of Appalachia is its unique history related to healthcare. Leslie County was the birthplace of the Frontier Nursing Service (FNS), an organization whose successor—Frontier Nursing University—is still located

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in the county. FNS was founded in 1925 by a Kentuckian named Mary Breckinridge who, trained as a nurse-midwife in England, saw a need to "conserve lives of mothers and children" in the mountains by designing a health system in Leslie County that catered to the unique challenges of a rural landscape (Bocker 1967). A large part of this challenge was the lack of roads in the area; to overcome this challenge, FNS nurses made home visits on horseback (Breckinridge 1952).

Breckinridge designed FNS to be a "broad, preventive public health program" to address the high mortality levels associated with childbirth and communicable diseases such as typhoid, diphtheria, and worms. She designed outpost rural hospitals where nurse midwives could offer prenatal services, delivery, and postnatal infant and mother care (Bocker 1967). Over the years, nine outpost clinics were established in areas of the county to ease patient access to services, but unfortunately many of these clinics have since been closed due to economic necessity or environmental factors such as floods. The focal point of the services was the young child, but she intended to reach the entire family through the child:

> "Even after his birth the young child is not an isolated individual. His care not only means the care of his mother before, during and after his birth, but the care of his whole family as well…It means including the whole family, because the young child is part of his family. Health teaching must also be on a family basis—in the homes."

In 1939 FNS began training nurses and midwives specifically for work in rural areas; in 1970, a family nurse practitioner curriculum was added to the program. Five years later, the Mary Breckinridge Hospital opened in Hyden to better meet the needs of the residents of Leslie County. Other clinics have been purchased by a company called Appalachian Rural Healthcare (ARH) and therefore are no longer affiliated with FNS. The Mary Breckinridge Hospital stopped offering OB/GYN services in 2001 due to budgetary concerns; thus, despite Breckinridge's

enormous contributions to maternal/child health care in Leslie County and in rural Appalachia as a whole, women must now travel to a hospital in a neighboring county to give birth.

Summary

Leslie County shares many qualities with the larger region of Appalachia, including both cultural and economic traits such as adherence to religion, reliance on coal mining, and high rates of poverty and unemployment. The region's unique history, which involved decades of exploitation from outside industry, has contributed to the persistent poverty that has lingered for generations. What distinguishes Leslie County from other Appalachian areas is its tie to the Frontier Nursing Service, which pioneered health care access for residents of the mountains. Understanding the history and characteristics of this area as a study setting is vital in order to appreciate the research process and results.

Chapter Three: Methodology

This research was conducted over the course of two months, March and April 2013. During this time, I conducted participant observation in the Leslie County Health Department. This included unstructured interviewing of health providers (n=7), riding along with nurses and other health workers on home visits, advertising services at a community fair, assisting with well child physicals, and observing the everyday activities of the clinic. This site was chosen for my internship based upon its central location in the county, its vital role in providing health care to residents, and the staff's willingness and enthusiasm to work with me. I spent approximately six hours at the health department per day, four days per week for seven weeks. In addition, because I was living in the area, my time outside the clinic was spent interacting with community members by attending community events such as weekly bluegrass shows, church, and family gatherings. Using both convenience and referral sampling, I contacted community members and health professionals for interviews.

Interview questions were developed to address the four questions guiding this research:

1. What are the most pressing health problems in the county as perceived by health care providers and community members?
2. What health resources are available to meet patients' needs?
3. How accessible are these resources?
4. What makes certain resources successful or popular among community members?

In total, I conducted 20 interviews with community members and 19 interviews with health professionals. Interviews lasted between 20 minutes and 2 hours. Community member interviews served two purposes: first, to develop an assets map of the county, and second, to

elicit discussion about common health problems through the use of free list and rank order exercises. Some participants (community members: n=3 and health providers n=1) were unable to complete the full interview due to time constraints and thus only participated in either the asset mapping or the free list and rank order exercises. Two community member interviews were conducted as group interviews (with two people each) and thus produced one combined free list and two rank orders per interview. The nature of the rank order activity allowed participants to complete separate rankings, whereas the free list activity was conducive to producing one combined list. Health provider interviews included a discussion about the services they provide (cost, type of insurance accepted, types of services provided, etc.) as well as the free list and rank order exercises.

A major portion of the community member interview was dedicated to creating an asset map. The purpose of creating a community asset map was to focus on the positive aspects of a community, which can be capitalized upon to meet the needs of residents. More specifically, "assets mapping involves documenting the tangible and intangible resources of a community, viewing it as a place with assets to be preserved and enhanced, not deficits to be remedied" (Kerka 2003:1). The benefit of an assets map over a needs assessment is that it focuses on empowerment and efficacy rather than deficiency (Beaulieu 2002). To map the assets of this county, questions were asked to gauge the types of resources used for various aspects of health. The complete list of questions can be found in Appendix B. In addition, I engaged several participants in participatory mapping when it became apparent that regions of the county were colloquially referred to by names other that what were found on the map. Further information about this can be found in Chapter Four: Results.

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The second goal of the interviews was to elicit perceptions of the county's most prevalent health concerns. With both community members and health providers, free lists were completed to compile a list of common health concerns in the region. The list was elicited through a grand tour question, "What are the major health problems in this area?" and followed up with re-phrased questions such as "What are health problems are common here?" and "What are common health concerns in Leslie County?" to elicit more specific responses. Participants were encouraged to discuss the items on their list and provide reasoning for what they included. Lists, separated by participant type, were entered into Anthropac for frequency and saliency analysis. Participants' rationales for their responses were also recorded.

A rank order exercise was completed using eight index cards with a different health problem written on each. The eight health problems were selected from Schoenberg, et al.'s (2008) study of perceived community health threats among women in central Appalachia, namely, drug abuse, cancer, heart disease, diabetes, smoking, poor diet/overweight, lack of exercise, and communicable diseases like hepatitis and HIV. Thus, these results were used as a starting place for initiating a discussion on perceptions of common health problems. Participants were asked to rank the health problems in order of what they thought was the biggest problem and encouraged to discuss and provide rationale for their order. Rank order data were entered into Anthropac for ranking and saliency analysis.

Salience is the degree to which participants agree on a certain list entry. It is calculated using Smith's S, which incorporates how often an item is mentioned as well as its relative rank using the following formula:

$$Free\ List\ Salience = \frac{sum\ of\ percentile\ ranks}{total\ number\ of\ lists}$$

$$Percentile\ Rank = \frac{total\ number\ of\ items\ in\ list - rank\ order\ of\ item}{total\ number\ of\ items\ in\ list}$$

Thus, salience is a measurement that indicates frequency of inclusion as well as relative rank (Bernard 2011; Smith 1993).

In each interview, free list data was always collected before the rank order exercise to avoid participants' responses being influenced by the conditions listed on the index cards. These two methods were used in tandem to allow participants to introduce health concerns and topics other than the conditions listed in the previous study.

This research was subjected to ethical review by the University of South Florida Institutional Review Board (IRB Study # 10363) and was classified as "exempt." Informed consent was obtained verbally from each participant according to IRB protocol. In addition, all data were recorded without identifying information and all records are confidential and will be stored according to IRB protocol to protect the privacy of participants.

Chapter Four: Results

<u>Sample Characteristics</u>

Community Members

In all, 20 community members participated in this study. Their ages ranged from 21 to 80 with a median of 40 years (Table 3). Fourteen of the respondents were female and six were male. Of the 20 participants, a majority had less than a college education, though 30% had a master's degree (Table 2). This level of education is higher than the average for the region which may be attributed to sampling bias; people who had been college or graduate students themselves may be more likely to volunteer to help a fellow student. In addition, the snowball sampling method may also contribute to this occurrence. Participants lived between 2 and 45 minutes away from Hyden, with a mean of 18.6 minutes, representing a wide range of locations within the county.

Half of all respondents were employed, while 25% were unemployed, 15% were retired, and 10% did not work because of disability. This is not precisely representative of the underlying population, since Leslie County has averaged 11.5% unemployment between 2008 and 2010 (ARC 2012a). However, unemployment numbers do not necessarily represent of all of those without work, since many people in Appalachia are no longer seeking employment. Income was measured through self-report of income range. 20% of participants had an annual household income below $10,000, 25% earned between $20,000 and $29,000, and 35% earned over $50,000 per year (Figure 3). 20% of participants were uninsured; 50% had insurance through work, and the remaining 40% of participants were covered by either Medicaid or Medicare.

Finally, just over half (n=11) received some type of public assistance, including WIC, food stamps, Medicaid, or Medicare.

Table 2: Community Member Education Level (n=20)

Highest Level of Education		
Level	Frequency	Percent
bachelor's	3	15.0
high school	7	35.0
master's	6	30.0
some college	4	20.0

Table 3: Community Member Age (n=20)

Age	
Minimum	21
Maximum	80
Mean	44.40
Median	40.00
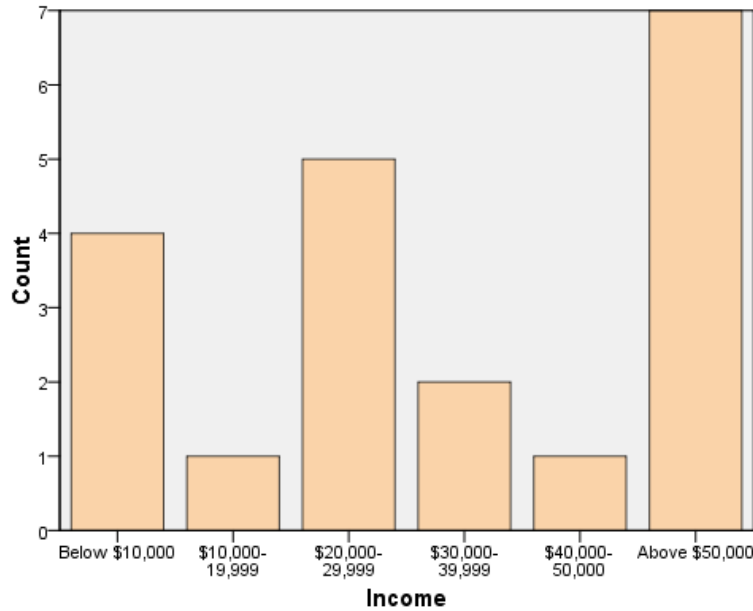
Figure 3: Community Member Income (n=20)

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Health Providers

Fifteen participants were female and three participants were male. They ranged in level of education from high school diploma to MD, with the majority ranging from vocational degree (2 years of college) to Master's degree (Figure 4). A wide variety of health care providers participated in this research, including people in administrative (i.e. clinic directors), counselors, dieticians, doctors, nurses, and nurse practitioners (Figure 5). Nurses averaged 19 years working in the area, while the two doctors interviewed had been there for one year each (Table 4).
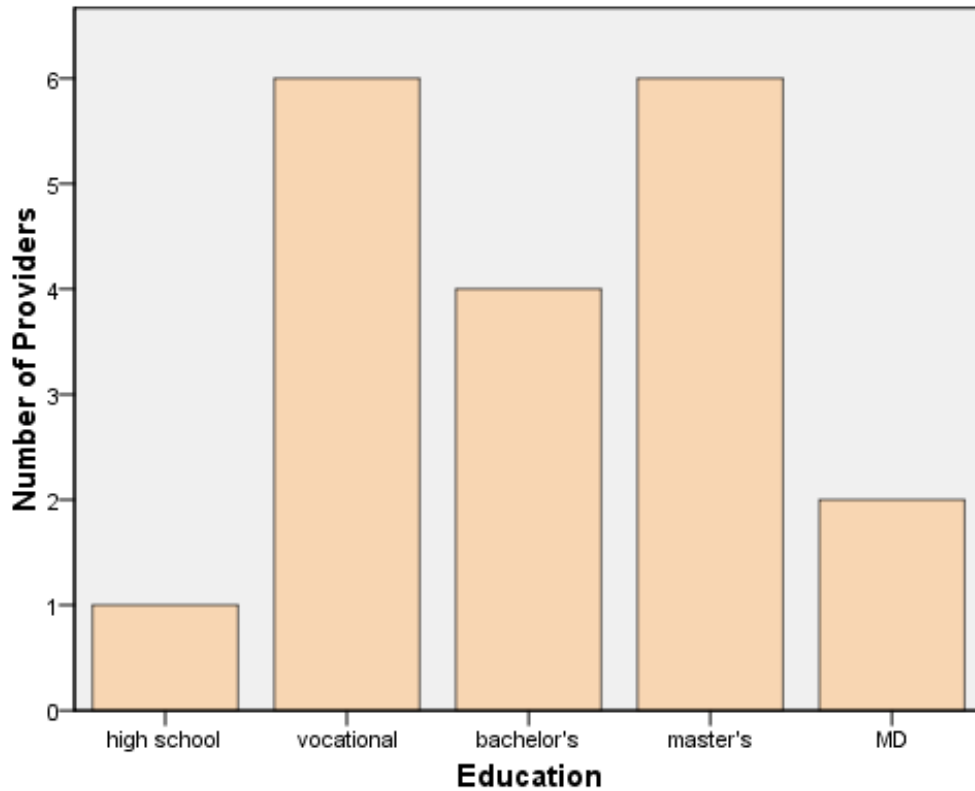
Figure 4: Health Care Provider Level of Education
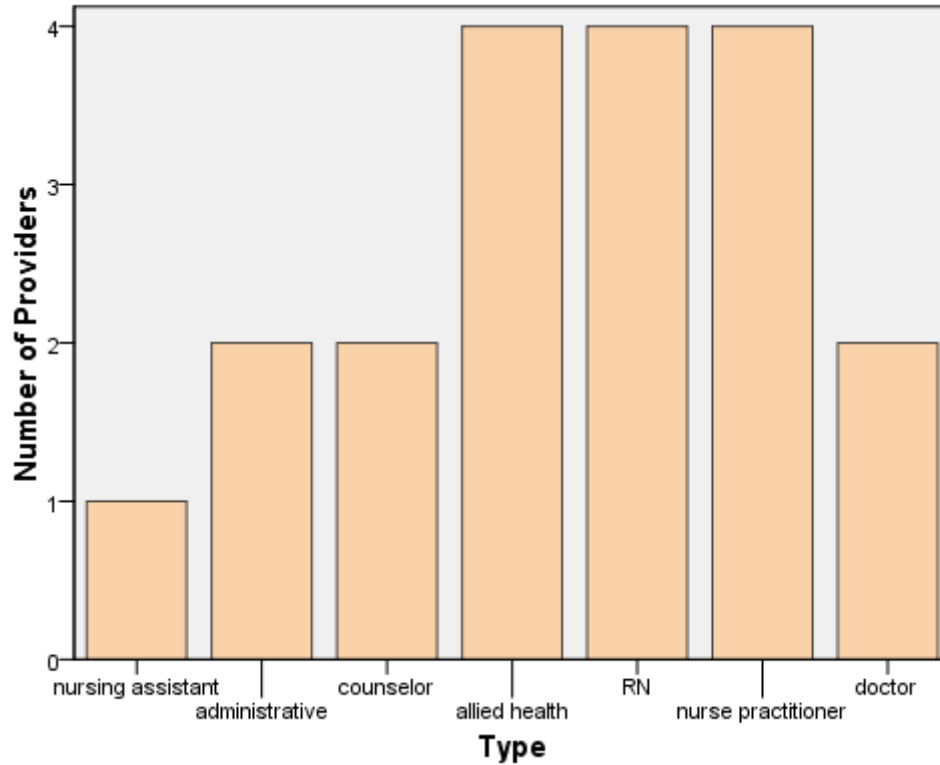
Figure 5: Health Providers by Type

Table 4: Health Care Providers' Years of Experience

Years of Experience				
N	Minimum	Maximum	Mean	Std. Deviation
16	1	49	17.22	14.345

Health Care Assets

Hyden ARH and Mary Breckinridge Hospital

The Mary Breckinridge Hospital is located in central Hyden and shares a building with the Hyden ARH Clinic. In addition to sharing the building, these two entities share doctors. The hospital and clinic have three doctors: two internal medicine physicians and one pediatrician. Once per month a nephrologist, who serves three different counties, sees patients in Hyden. The

hospital provides primary care services and has the capability to perform mammograms, CT, and x-ray. MRI is available once per month. A nurse practitioner offers well-woman checkups, but OB/GYN services are not currently offered in Hyden.

Community members who had taken children to see the pediatrician at Hyden ARH/Mary Breckinridge Hospital had very positive opinions of his services. However, the doctor is new to the area, having been raised and educated in India. He practices in Hyden by necessity to fulfill the visa requirement of serving in an underserved area for three years; because his wife cannot find work in the area, he told me that he does not plan to stay once his requirement is met. He broached this topic during our interview to demonstrate why physician turnover is so high in places like Leslie County. While nurses in the region have been working there for decades and know patients and their families well, doctors face high turnover rates and therefore have difficulty establishing patients' trust.

The hospital also has an emergency room and the capability to medevac patients in critical need to better-equipped facilities. Community members reported that they would likely drive to Hazard if they had an emergency, rather than going to the Hyden emergency room, because they have more trust in the facilities and emergency doctors in Hazard. One family lost their father to a heart attack due to the emergency room's inability to stabilize him before flying him to Hazard; that family, and other participants, cited this specific event as a reason they would not trust the emergency room in Hyden.

Regarding financial accessibility, the hospital only accepts coverage under one of the three Medicaid Managed Care Organizations (MCOs), which means that patients with coverage under the other MCOs are turned away to another hospital for treatment. Uninsured patients are covered under a charity program and generally pay $20 per visit depending on income; patients

with an alternate MCO do not qualify for the charity program because, technically, they are insured albeit not covered by the hospital's contracts.

Health Department

The health department, situated in downtown Hyden adjacent to the middle school and community college, provides a plethora of services for the residents of Leslie County. It is the only place where parents can enroll their children in the WIC program and it also provides well child checkups including vaccinations, family planning services like birth control and pregnancy tests, cancer screening (Pap tests and breast exams), and preventative primary care. The health department is staffed by two nurses; six times per month, a nurse practitioner provides well-woman appointments including Pap test and breast exams. Once per month a doctor comes to the clinic to review charts and very occasionally to see a patient. If there is a concern related to the well child checkups, patients are referred to a pediatrician for which the state will pay. The health department additionally has a contract with the hospital in Hazard (but not Mary Breckinridge Hospital, located right next door to the health department) to offer discounted mammograms and follow-up pap tests. If a patient has cancer, she is eligible for a temporary medical card that subsidizes all of their treatment.

The health department is also home to a part-time dietician who shares her time between all of the health departments in the Kentucky River District and provides medical nutrition therapy for patients with diabetes, hypertension, or adults or children who are overweight. Although her services are available to all patients, they are not frequently utilized, according to participants. The clinic also offers a free smoking cessation class that provides participants with nicotine patches, informational classes, and a support group. This class is not widely known by

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community members, many of whom reported not knowing of any smoking cessation resources in the county.

Two other health services share the building with the health department. A home health service is run out of the same building as the health department. It assists home-bound patients with daily self-care and provides minor health services. Finally, the health department houses the HANDS program, which stands for Health Access Nurturing Development Services. This program provides support for expectant and new mothers who meet the program's criteria, including being a teen or single mother, unsuccessfully seeking an abortion, or failing to seek prenatal care. Clients are referred to the program through either the health department or their OB/GYN and are offered are offered a curriculum that covers infant development, care, and feeding; mental health and substance abuse services; and early childhood education through periodic home visits.

Cutshin Clinic

The Cutshin Clinic is somewhat of an institution in Leslie County. Tucked in the mountains about 40 minutes from Hyden, the clinic has been situated in the same house next to a creek since 1956. It is staffed by a nurse practitioner and a nurse; once per month a doctor from Manchester meets with patients at the clinic who cannot travel all the way to her office. The nurse practitioner who works there has been serving that clinic for 49 years and claims to have served five generations of some families in the area. At age 76, she still provides primary care to patients in Leslie County and the two neighboring counties regardless of insurance coverage.

A testament to its renown in the county, two health care providers and one community member cheekily reminisced that the Cutshin Clinic is where they would go for an appointment

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if they were "not feeling well" and wanted an excuse to miss class in high school. Since until recently a visit only cost $5, a student could easily drive out to the clinic and visit the nurse for a check-up during the school day. In terms of its more meaningful contribution to the county, the clinic provides services to patients in the southeastern part of the county, for whom driving to Hyden or Hazard could pose financial or physical barriers.

The clinic charges a flat rate of $10 per visit ($15 for a new patient) plus a small fee for tests that must be run (for example, $7 for urinalysis, $5 for a pregnancy test). Patients can receive care for high blood pressure, diabetes, bronchitis, strep, and other primary care concerns, but the nurse does not provide immunizations or STD testing. The nurse practitioner and her helper (who is 91 and handles paperwork and patient intake) live in the clinic. As a member of the fire department, the nurse practitioner also makes ambulance runs on occasion.

The clinic is affiliated with a mission church that is on the same property; the church, along with individual donations, supports the clinic. In regards to the tenuous funding of the clinic, the nurse practitioner does not doubt that whatever funds they receive will be sufficient; she says, "The Lord has made it stretch." However, she noted in an interview that she "hates computers" and refuses to keep electronic records, saying, "If Obamacare makes me [start using electronic records] I'll retire!" The clinic does not advertise or actively recruit new patients, so the majority of its renown comes from word of mouth since they have served the needs of the county for generations.

Red Bird Clinic

The Red Bird Clinic, associated with the United Methodist Mission of the same name, is located a winding 22 miles outside of Hyden, just past the border of Leslie County. This clinic is

more accessible to residents in the southwestern region of the county than the clinics located in or around Hyden. The Mission and the clinic offer many outreach programs such as health fairs, free hearing aids, and provision of donated of medical equipment (wheelchairs, walkers, etc.). Maternal/infant outreach workers provide free educational services to new and expectant mothers. The clinic, which is associated with Manchester Memorial Hospital (located approximately 50 minutes away from Red Bird and 40 from Hyden), has two practitioners who provide primary care services including childhood immunizations, physicals, and chronic disease education and care. First-line mental health treatment (drugs for depression and anxiety) are available from the nurse practitioner, but other mental health needs are referred to KRCC (Kentucky River Community Care). Though a smoking cessation class is offered at the mission, the clinic does not do referrals for drug treatment.

Additionally, diagnostic procedures like labs, x-rays, mammograms, and colonoscopies are performed at the hospital in Manchester, approximately 50 minutes away. Uninsured patients qualify for a discount program that adjusts costs based on income; most uninsured patients pay $20 for a visit. The mission used to have its own hospital, but as mines closed and people moved out of the area, the hospital was forced to shut down.

Kentucky River Community Care (KRCC)

Located in the center of town next to the bank, post office, and grocery store, KRCC is the main source of mental health care in the county. This service employs a therapist and a social worker, as well as several case managers. Psychiatry services are offered as needed through telehealth communications with Lexington. The main role of KRCC in Leslie County is to provide services for the county drug court. A vast majority of their patients are mandated into

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care through this avenue. Although they ostensibly offer substance abuse treatment to patients besides drug court clients, they do not have inpatient treatment. It should also be noted that, in general, in the interviews community members stated that they did not know anything about KRCC substance abuse treatment beyond that it handles drug court referrals. KRCC also provides outpatient therapy to children, including case management and social services, through the county schools.

Big Creek ARH Clinic

The Big Creek Clinic, located 20 minutes south of Hyden, is owned by ARH. The sole practitioner for the clinic is a nurse practitioner who has been working there since 2002. Occasionally she is joined by a doctor who schedules appointments for patients who cannot travel to the doctor's office for care. The nurse sees patients of all ages, from new born to elderly, and provides primary care including physicals, well-woman exams, and general practice services like diabetes, cholesterol, and blood pressure maintenance. In addition, the nurse provides first-line mental health services since she has the ability to prescribe antidepressants and anxiety medications and also to provide limited counseling services.

This clinic is a valued source of primary care in the Big Creek area. When the clinic was on the verge of closing in 2010 due to insufficient funds, the community united to sign a petition and to write a proposal to obtain grant funding. Even though they did not receive the grant, this brought the community together and showed how much they cared about the clinic, which was purchased by ARH and reopened in 2011. Due to the service hiatus in 2010, the nurse practitioner reported that she thinks some patients are not aware that the clinic has reopened.

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Appalachian Clinic

Similar to other area clinics, Appalachian Clinic in Hyden provides primary care services. Annual physicals and checkups, chronic disease (but not pain) management, and allergy care are the types of services available at this clinic. Community members who used this clinic reported going there for general health concerns, like to get a check-up or if they had the flu. They reported that the clinic does not usually have a large crowd, so it is possible to see the nurse without a prior appointment.

If patients are not insured, an appointment costs $45 or less depending on income. The clinic accepts private insurance as well as all Medicaid MCOs, but encounters a problem when referring patients for labs or screenings at the hospital, since Mary Breckinridge does not accept all MCOs. If the hospital turns their patients away for having the wrong MCO, patients have to travel to Hazard or Pineville hospitals for tests, located 30 minutes and an hour and a half way from Hyden, respectively.

Mercy's Way

Formed in December 2011, Mercy's Way is a faith-based drug treatment program. Through weekly support groups, this program offers support for current drug users and recovering addicts. The premise behind the program is that "Jesus fills the hole left by drugs" and gives people the tools to deal with their life after addiction. Although the only program of its kind in the county, Mercy's Way only sees between 2 and 10 people per meeting.

Specialists

Specialty services are not available in Leslie County. For OB/GYN services, patients must travel to Hazard (30 minutes away), Harlan (45 minutes away), or Lexington (2 hours away). Hazard also has a dermatologist, pain clinics, chemotherapy, and pediatric in-patient care. Community members reported that they would go to Lexington for cancer treatment or more intensive pediatric conditions. Some community members reported that they specifically prefer to go to all the way to Lexington because it is a big city and they trust the doctors there more. Several participants reported making a family trip to Lexington with the family's doctor appointments all scheduled for one day.

Health providers identified the towns of Harlan, Pikeville (1 hour 45 minutes away), and Ashland (2 hours 30 minutes away) as offering inpatient drug treatment facilities, although they are very expensive and have a waiting list several weeks long. Several community members commented about family members not being able to enter inpatient drug treatment programs because of the wait time and cost. Community members are generally not aware of drug treatment facilities in the region, knowing only that KRCC is where people from drug court go.

Community Member Results: Free List and Rank Order

As previously stated, the free listing and rank order exercises gave participants the opportunity to discuss their opinions and interpretations of common health problems in their county. By approaching the topic in two different ways, participants had the opportunity to discuss topics that they had not mentioned in the free list and, conversely, to mention health topics not included in the rank order. This compensates for participants who tend to be more reserved or hesitant in answering open ended questions. I will first present the results of the free

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list and rank order, respectively, and then provide examples of the rationale participants used to justify their responses. Likewise, the provider data will be presented subsequently. Only free list responses that were mentioned by more than one respondent are included.

Table 5: Community Members Free List, n=18*

Item	Frequency (#)	Frequency (%)	Salience
Cancer	12	66.7	0.527
Drug abuse	9	50	0.315
Heart disease	7	38.9	0.206
Diabetes	6	33.3	0.128
Obesity	6	33.3	0.206
Smoking	6	33.3	0.241
Flu	4	22.2	0.181
COPD	4	22.2	0.148
Insufficient services	2	11.1	0.032
Lack of insurance	2	11.1	0.074
Mental illness	2	11.1	0.059
Black lung	2	11.1	0.057
Hypertension	2	11.1	0.03
Staph infection	2	11.1	0.086
Poor diet	1	5.6	0.044
Stomach virus	1	5.6	0.044
Arthritis	1	5.6	0.033
Oral health	1	5.6	0.011
Asthma	1	5.6	0.056
Environmental health	1	5.6	0.011

*due to interview constraints, free list data is based on 18 respondents.

Table 6: Community Members Rank Order, n=20

Item	Average Rank	Salience
Drug abuse	2.25	0.844
Cancer	3	0.750
Smoking	3.95	0.631
Heart disease	4.25	0.594
Diabetes	4.55	0.556
Obesity	4.7	0.538
Lack of exercise	6.55	0.306
Contagious diseases	6.75	0.281

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Cancer

This health problem was included often in free lists and was ranked second in the rank order activity. The types of cancer that were specifically mentioned were breast, lung, colon, and pancreatic cancer. One participant, in justifying her high rank of cancer, stated that it should be ranked above drug abuse because "it's not induced yourself—you can't really control it." This lack of control and unpredictability associated with cancer was commonly brought up. Participants also stated that it is one of those health problems that affects every family and is "not just a disease for old people." It should be noted that a student at the county high school died of cancer one week before I arrived in Leslie County, a point that was often raised in interviews and indubitably influenced the high rank of this health problem compared to others.

Heart Disease

Although heart disease was perceived as being a common health problem (n=7, rank 4), participants did not express strong opinions or dwell on this topic during interviews. When it was discussed, it was often in terms of its relatedness with other health problems like obesity and diabetes. This observation could be due to the fact that, compared to other disorders, heart disease is not outwardly visible.

Obesity

Participants ranked obesity relatively low, yet it was included in the free list of 7 participants. In the same way as heart disease, obesity was only discussed in terms of relating to other health disorders. Specifically, obesity was described as the causative factor for other conditions like heart disease and diabetes. Interestingly, some people used this reasoning to put

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obesity high in their rank order, while others used it to justify obesity being low on their list. Even if it was placed lower on the rank order than the diseases it caused, community members considered obesity to be a very severe problem because of its etiological relationship with heart disease and diabetes.

Smoking

Smoking ranked third overall in the rank order activity but was only included in six participants' free lists. It was often described as a bad habit that caused many other health problems. Although some participants mentioned the importance of quitting smoking to improve health, one woman said, "It seems like everyone does it and no one wants to listen about quitting." Smoking was often conflated with cancer, and this seemed to contribute most to its high ranking.

It should be pointed out that one respondent downplayed the danger of cigarette smoking, saying that "they make it out to be a really bad thing…but coal dust is worse." She said that people could get lung cancer without smoking (or, she later ceded, "just smoking a little bit"), so she was not convinced that smoking was as bad as 'they' say. Her beliefs were based upon a family member who had lung cancer despite "just smoking a little bit." This is an interesting example of how acutely personal experiences affect the ranking of health concerns.

Diabetes

Diabetes was listed by six respondents and ranked fifth, and although participants knew diabetes was a common occurrence, they generally did not regard it as a serious concern. A clear example of this was one woman who said that she did not see a lot of people with diabetes, but

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then immediately went on to list several family members and friends whom she knew that had the condition. Knowing many people with diabetes but still not recognizing it as a common health problem is an interesting conundrum. It could be related to the fact that it was mostly associated with older people, or that it was simply not perceived as being as dangerous as other health concerns. Two people mentioned knowing people who had lost toes or feet due to diabetes, but these people still ranked diabetes in the bottom half of their list.

Lack of Exercise

With regards to lack of exercise, all participants agreed that this was a significant problem in their community but, compared to more acute conditions, it did not rank highly. This topic did not elicit very much discussion. A few community members commented that people are not as active in Leslie County as in larger cities and towns: "You never see people walking here like you do in Louisville." Logically and expectedly, people connected lack of exercise with obesity as a cause for many of the other health concerns.

Contagious Diseases like HIV and STIs

Contagious diseases occupied the lowest rank of all of the health concerns in the rank order activity. Generally, participants did not see diseases like STIs as a common problem in their communities. Those with personal or family experience with drug abuse tended to rank contagious diseases higher; their reasoning was based on their observation that drug use is associated with communicable diseases like hepatitis and HIV. Otherwise, many participants were ardent that those diseases were uncommon and they never heard anyone discuss them.

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Drug Abuse

Drug abuse was the second most commonly mentioned free list item (n=9), yet ranked highest in the rank order. This topic elicited by far the strongest reaction from all participants during the rank order activity. Many spoke candidly about the experiences of their brother, uncle, father, friend from high school, or even themselves, when explaining their rationale for placing drug abuse highly on their list. Respondents in their twenties lamented the numerous classmates from their high school that they knew had gone on to become drug addicts. One woman, a grandmother who cares for her grandchildren, said that parents used to worry about their kids going out and getting drunk. Now they have to worry about meth labs and people "mixing up remedies to fry their brains." Echoing that sentiment, many participants were concerned that drug use has increased significantly in the past decade; particularly, prescription drugs (pain killers and anxiety medications—"nerve pills") and methamphetamine ("crystal meth") were reported by participants as the most common drugs of abuse in the community.

Although epidemiological data suggests that prescription drug abuse is more common than methamphetamine use (Zhang, et al. 2008), participants expressed much more concern about the growing use of methamphetamine in the region. This is because the effects of methamphetamine are more outwardly visible and perceived to be more socially damaging. Also important in this discussion is how simple and inexpensive methamphetamine is to produce. The so-called 'shake and bake' method of cooking meth requires only a few inexpensive and easily accessed ingredients and is "easy to hide in the mountains"

Many participants spoke of how obviously they could tell if someone was using crystal meth. For example, "They have hardly any flesh on their face, their eyes are set deep in their sockets, and their faces look sunken from using drugs so often. They are like hermits…you only

see them occasionally when they need to buy food. The change is catastrophic." Another

participant echoed those sentiments more succinctly: "You can see it all over their faces."

Another person, evoking religious imagery, stated bluntly that "Drugs is the devil. That's the

way I see it."

Central to the perceived severity of drug use is the potential effects drug abuse has on

people who do not use. On one hand, several participants expressed concern about the effect

drug abuse has on children, especially children of users: "kids grow up in that atmosphere, and

then that's all they know." Two teachers conjectured that the behavioral changes they have

observed in their students over the past few years may be attributed to exposure to drugs in utero

or to being raised by parents who use drugs. Additionally, teachers can see that "the kids are

hungry" and that their needs are not being adequately met at home. Besides the effects on

children of drug users, others worry about the effect of volatile fumes (which are said to smell

like ammonia or cat urine) that are a by-product of methamphetamine production as well as the

possibility of fires or explosions in home meth labs that are commonly reported on the local

evening news.

Many people expressed concern that drug abuse was affecting young people more than

other generations. Interestingly, some participants used this to justify placing drug abuse high on

their list while others said that it belonged lower on the list because it *only* seemed to affect

young people.

Other

Flu and COPD each garnered 4 free list inclusions. Given that many of the participants

were teachers or parents of young children, it is understandable that the flu is a common health

concern. COPD is also not a surprising addition given the influence of the mining industry as

well as the prevalence of smoking.

Health Provider Results: Free List and Rank Order

Table 7: Health Providers Free List, n=19

Item	Frequency (#)	Frequency (%)	Salience
diabetes	13	68.4	0.556
drug abuse	11	57.9	0.313
hypertension	10	52.6	0.416
heart disease	8	42.1	0.232
obesity	7	36.8	0.227
cancer	6	31.6	0.144
copd	5	26.3	0.16
high cholesterol	5	26.3	0.145
smoking	5	26.3	0.154
mental illness	5	26.3	0.074
lack of education	2	10.5	0.101
thyroid problems	2	10.5	0.029
poverty	2	10.5	0.099
oral health	2	10.5	0.053
chronic pain	2	10.5	0.057
lack of preventive care	1	5.3	0.021
teenage pregnancy	1	5.3	0.032
patient noncompliance	1	5.3	0.026
poor diet	1	5.3	0.032
underdiagnosis of health problem	1	5.3	0.004
arthritis	1	5.3	0.011
black lung	1	5.3	0.039
congestive heart failure	1	5.3	0.018
allergies	1	5.3	0.022
alcohol	1	5.3	0.039
lack of parental involvement	1	5.3	0.039
injuries	1	5.3	0.053
lack of follow up	1	5.3	0.013
fatty liver	1	5.3	0.013
hepatitis	1	5.3	0.021
genetic disorders	1	5.3	0.015

Table 8: Health Providers Rank Order, n=17

Item	Average Rank	Salience
Drug abuse	2.88	0.765
Smoking	3.29	0.713
Diabetes	3.88	0.64
Obesity	4	0.625
Heart disease	4.71	0.537
Lack of exercise	5.12	0.485
Cancer	5.41	0.449
Contagious diseases	6.71	0.287

Diabetes

Diabetes was the most frequently mentioned by health care providers (n=13), but was third on the rank order. Not only is diabetes a very common health problem, but complications associated with diabetes are also common. Patients who also smoke, or have hypertension, or who maintain a poor diet suffer more often from complications like renal failure or limb amputation. One provider lamented that diabetes patients often do not receive follow up after their diagnosis. He said that he often "sees patients who were diagnosed with diabetes years ago and were prescribed insulin, but haven't been back to see their doctor." Another said that, "it used to be that people under 20 would never get insulin independent [Type 2] diabetes, but now it's more common." Thus, doctors recognized that type II diabetes is quickly becoming a problem that touches people of all ages rather than just adults.

Cancer

Cancer is noticeably lower on the health providers' list than on that of community members. Despite its low position, cancer was regarded as a serious health problem in the community. Providers said that cancer "is more common than ever before" and "affects both young and old." Lung, breast, ovarian, and cervical cancer were the most commonly mentioned

types. One provider justified putting cancer lower on her list because it is becoming more curable. Several put cancer below smoking because smoking is a contributing factor to so many types of cancer.

Smoking

Smoking ranked second in the rank order analysis and was listed by five providers. Many participants gave smoking a high ranking because of how much it contributes to most of the other health conditions that were listed, including heart disease, diabetes, and cancer. As one participant put it, "it's not that cancer and heart disease aren't bad, it's just that smoking causes everything so it should be put higher." Two participants conjectured that about 50% of their patients smoke: "Just watch the cars go by out here. At least half of them are smoking." Many public places, such as the local bluegrass music venue, are not smoke-free as they are in other jurisdictions, so this exposes others to smoke and makes it easier for people to smoke. However, some providers conceded that they saw fewer smokers now than in the past and that some people they knew had successfully quit smoking.

Heart Disease

Just as in the community member interviews, heart disease was not a polemic of conversation among health providers despite its relatively high rank. It was mostly discussed as it relates to poor diet and obesity. One provider discussed it in slightly more detail, saying that it is common for people to have stints or to have had another heart surgery. In addition, compliance with heart drugs was said to be low, presumably because there are few outward symptoms.

Obesity

All providers agreed that obesity is a common problem in the area. Specifically, seven doctors included it on their free list, with five providers reporting that obesity in children is especially worrisome. Obesity was partially attributed to poor diet and partially to sedentary lifestyle; providers cited fried food, videogames, starches, and soda as contributors to the obesity epidemic in the region. As one nurse said, kids eat more junk food now, whereas when she was younger, junk food was a rare occurrence: they would only receive soda on their birthday, but now it is an everyday occurrence. In previous generations, people only ate what they grew but now the majority of people eat processed junk food.

Other providers brought up the observation that obesity tends to be passed from generation to generation, whether through genetics or tradition, and that people seem to "not know better." Finally, several providers brought up the cost of food as a barrier to healthy eating and weight loss: "Food stamps buy cheap food, not necessarily very healthy things." Obesity was uniformly seen as a serious health problem and providers recognized its multifaceted causes.

Drug Abuse

As with the community members' results, drug abuse ranked highest on the health providers results and was a topic of intense conversation. Prescription pain and anxiety medications as well as methamphetamine were the drugs of main concern. Many of the health services included in this survey purposefully do not address chronic pain management in order not to perpetuate prescription drug abuse. One provider referred to drug abuse as both "a social problem and a health problem," a sentiment that was echoed in many providers' rationales.

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From a health perspective, drugs were tied to an increase in contagious diseases such as hepatitis and STDs in the region. One provider noted that drug users "resort to the needle sooner or later, or have sex for drugs," thus promoting the spread of disease. Additionally, when someone is abusing drugs, "health is the last thing on their minds," so other aspects of health suffer beyond the physical effects of the drugs like missing teeth and skin sores. Babies born to drug users face birth defects, addiction, and learning difficulties that are providers associate with parents' drug use. Finally, when people cook methamphetamine in their homes, it creates a dangerous environment with noxious fumes and risk of explosion that puts themselves and their children in danger.

From a social perspective, providers perceive drugs as affecting the community at large. Many expressed concern over parents being jailed for making, selling, or using drugs, leaving their children to be raised by grandparents. One doctor who was raised in Leslie County described the atmosphere of drug abuse during an unstructured interview. The following is an excerpt from my field notes that captured her sentiments as closely as possible:

> Drug use in a rural area isn't like drug use in cities, where you basically know exactly what part of town to avoid if you don't want to be around drugs. In cities it is almost segregated, the good part of town and the bad part of town. Here, you have really nice houses right next to trailers where you know people are dealing drugs. For the most part, everyone is mixed together and you never know what to expect.

> Also in larger towns, not everyone knows someone personally who has a drug problem. Here, everyone knows someone specifically who has either dealt drugs or who uses them. People from high school who were "normal" "good" people, now have serious problems with drugs. Three brothers from her high school were good friends with her and were very cute and smart; their mom abandoned them for drugs and their dad had drug problems but was always a "good dad" because he attended their sports games and provided for their needs. After they graduated they all three started abusing drugs and have never gotten away from them, even though you would have thought they would know better from seeing their mom and dad both struggle with addiction.

Health providers' discussions about drug abuse, just like those of community members, were by far the most impassioned and emotional than their discussion of other health providers.

Providers described drug abuse in Leslie County as a devastating situation for the whole community, both for its health implications and its social effects.

Patient-Related Concerns

Health care providers, more so than community members, included nebulous concerns in their free lists that reflected social as well as physical aspects of health. For example, poverty was listed by two providers as a health concern. Even providers who did not explicitly include poverty in their free list described similar concerns in their rationale. One provider said, "Parents don't bring their kids for follow ups due to poverty or other priorities, but I don't know what the other priorities are because they don't work." Another provider, specifically relating poverty to poor diet and obesity, pointed out that people on a budget eat a lot of carbs because bread, gravy, and grease are cheaper to buy than other foods and, furthermore, "it's ingrained in them: 'this is the way my mom taught me to cook, this is the way I do it.'" While the first part of that observation relates to poverty, the second relates to something more nebulous still: the role of culture in health.

Several providers alluded to a cultural factor that promotes poor health in the region. One provider listed traditional remedies that some of her patients, especially older patients, may use as a primary treatment, only seeking professional treatment as a last resort if their home remedy fails. The most commonly mentioned home remedy was a hot toddy, mentioned by several nurses, which consists of honey, lemon, and moonshine and is used to treat cold or sinus problems. Other home remedies, which could warrant their own discussion beyond the scope of this research, are documented in Appendix C.

Another provider, echoing the fatalism aspect of the culture of poverty theory, observed that, "Patients do not feel like they are in control of their health. They feel like doctor is in control and there is nothing they [the patient] can do. Life is doing this to me, and I have to react. They act like a helpless victim of their circumstances instead of taking an active role."

However, it was obvious through providers' comments that culture was sometimes conflated with other factors, most prominently lack of education. A common sentiment regarding education levels was "They ought to know it but they don't". A dietician in the county offered the following vignette to illustrate the lack of health education in the area:

> A few years ago she talked to a woman whose sister had diabetes and leg sores; there were maggots in the leg sore and the women did not have any idea what had caused maggots or where they came from. They did not know that the sores had to be covered or flies would lay their eggs in them, leading to a maggot infestation of the open wound.

Her conclusion? With many patients—especially elderly patients—providers are "starting from scratch as far as education goes." Several other health care workers noted that education was an important part of their practice, especially educating patients on their medicines and the importance of taking medications regularly and not just when they felt ill.

Likewise, one health worker commented that "Cultural differences contribute to poor health; education is not up to par. Women [who use her program] don't know when to feed their babies. They start giving table food before 6 months. It's a cycle." Similar to the conception of culture noted by Sovine (1988) and discussed in Chapter One, participants utilized the term "culture" to discuss aspects of life like lack of education and poverty. Poverty was noted for its cyclical nature by one health provider: "Younger people are not concerned [with health]. They just want to draw disability and not work. They may be the 3rd generation on disability. If their parents didn't work, they don't work. Some are actually disabled; others could work if they

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wanted." Other cultural factors were more implicit, such as the role of stigma in influencing health maintenance practices.

The close social ties of the community were described by several providers as a potential boundary to health care access. As one provider said, "Everybody knows everybody around here. Nothing is a secret." While only one provider specifically listed stigma as a health concern in his free list, stigma associated with certain health concerns was a theme discussed by four providers. Regarding mental health, stigma is thought to prevent access to treatment. One provider specifically voiced concern that "patients don't want the stigma of going to KRCC. Everyone would know why they are going there."

A primary care nurse postulated that stigma may also play a role in women getting screened for cervical cancer. Although she makes many referrals for pap tests, the appointments are usually not kept. "Maybe stigma keeps them from going, knowing that [HPV] is an STD…it's not well known that HPV leads to cervical cancer; they stop listening at the STD part." Along the same lines, another nurse observed that stigma related to contagious diseases like STDs caused patients not to disclose their status or seek treatment.

This leads to two other connected items mentioned by many providers: lack of compliance and personal responsibility. One provider asserted that parents need to "take more responsibility" for their children's health; this problem is especially noticeable with parents with low education. Other providers reiterated concerns about patients taking responsibility for and ownership over their own health:

"People are not health conscious"
"WIC clients are less open to changing their behavior"
"Health hasn't gotten better because people don't do what they're told"
"Patients don't always keep referrals. You just have to tell them that it's important and hope they listen. You can't make them do it."

Noncompliance is, in itself, a concept with debatable utility: Paul Farmer (1999) notes that it is an "analytically flimsy concept" (227) because it is most strongly associated with economic factors, rather than personal or cultural factors. Although Farmer's analysis is based upon research in Haiti, economic factors such as income, type and location of housing, and education can logically be extrapolated to health in Appalachia. Nevertheless, an anecdote offered by a public health nurse shows the frustration providers feel when dealing with patients they perceive to be noncompliant:

> A girl was 23 years old and had moderate cervical neoplasia. It was diagnosed years ago, but she won't go to get it fixed. Why not? She had a medical card [Medicaid] until she lost her youngins [to social services], so it's not about money. The clinic would have paid for treatment.

This case illustrates the nurse's confusion about why a woman would not seek treatment, even if it were free of charge, for a condition that could soon develop into cancer. But, as one provider sagely noted, hinting at the structural and personal factors that influence decision making, "People don't have the means to make changes in their lives—the drive and wherewithal to make changes that they want to make."

Summary

Health providers and community members generally agreed on the common health problems faced by the residents of Leslie County. Although certain conditions ranked slightly differently between the two groups, it was obvious that drug abuse, cancer, diabetes, smoking, obesity, lack of exercise and, to some extent, contagious diseases, were salient health concerns just as they were in Schoenberg, Hatcher, and Dignan's (2008) study on perceived health threats. Health providers added an interesting element to the discussion through their inclusion of more socially-oriented concerns like noncompliance, poverty, and personal responsibility in their free

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lists. The next chapter will provide a more detailed analysis of the results provided here along with a discussion of the implications of this research.

Chapter Five: Discussion and Conclusions

Service Options

One thing that was evident from speaking with both providers and community members is that providers offer more services that community members realize. For example, participants were not aware that the health department offers smoking cessation classes and has a dietician on staff; several participants specifically noted that they would like to see those services available in Leslie County. Likewise, community members were not familiar with Mercy's Way program or the mental health services offered by KRCC. This likely indicates a lack of advertisement or communication of services on the part of health care providers. Given that some community members expressed desire for smoking cessation and drug abuse programs, it is obvious that these health services are considered important and would likely be used by more patients if they were more well-known.

Health services, especially those offered by the health department, are also more affordable than participants might have imagined. The health department has contracts with hospitals to subsidize the cost of, for example, cancer treatment even if patients are not insured. In addition, the health department offers promotional days such as "Ladies' Day" which promote cancer screening in women who are past due for screening. Periodical health fairs around the county also provide free blood pressure screenings and health education. Participants may seek these types of services from other counties or simply not utilize them at all if they are unaware of

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their existence. This information demonstrates the disconnect between available services and community members' perception of available services.

Given the limited options beyond primary and preventative care in Leslie County, it is unsurprising that many participants report traveling to other counties for the health care that they need. However, for such a small population of people, there are many primary and preventive care services available for patients regardless of income or insurance. With the exception of Mary Breckinridge not accepting all Medicaid coverage, the existing resources have successfully catered their prices and insurance policies to meet the needs of the population, many of whom are uninsured or insured through Medicare or Medicaid.

The health service that community members most often requested and that health providers frequently lamented not offering was obstetrics. Given the rich history of the Frontier Nursing Service and nurse-midwives in the county, it is especially surprising that there are no services there for pregnant women. One provider aptly noted that "You can't be born in Leslie County anymore, and that's making Mrs. Breckinridge turn over in her grave." Women must instead go to Hazard, London, Harlan, or Lexington to deliver.

Many of the health concerns listed by community members and health providers relate to primary care, for which the county already has a solid infrastructure. Diabetes, obesity, smoking, and contagious diseases can all be addressed in a primary care setting. Heart disease and cancer require specialists, though maintenance care and diagnosis can often be provided through a primary care provider. The one health concern that the county is specifically not prepared to address is drug abuse. Although listed as the primary concerns for both groups of participants, there are limited resources available within the county and, furthermore, the resources available

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are not accessible because none of the participants knew about them. Resources outside the county are perceived additionally as inaccessible because of expense or long wait times.

<u>Factors That Influence Health and Health Care</u>

Community Ties

Community ties were an important aspect of the health resources in Leslie County. Many nurses have worked in the community for generations and not only know all of their patients personally, but know their families, friends, where they go to church, what they do for a living, and where they live. In fact, many of the primary health clinics surveyed did not have a full time doctor on staff, but instead rely on nurses, nurse practitioners, or physicians assistants to provide care for patients. Given the rapid turnover of doctors, nurses play an especially important role in patient trust and retention. The rapport between patients and nurses is obviously not something that is developed overnight. Rather, these nurses display a love and devotion for their patients and their community developed over a lifetime of living and working in the area.

Conversely, the fact that nearly everyone knows everyone else leads to little privacy regarding health matters. One female participant said that she is reluctant to make an appointment with the gynecologist (who is located outside of Leslie County) because she went to school with his daughter. Thus, when faced with the choice between seeing a male gynecologist that she knew, who was the only option available nearby, and not seeing a gynecologist at all, she chose the latter.

Providers also brought up the stigma associated with mental health treatment, which is ubiquitous in the United States but magnified with limited providers and limited privacy. The sole mental health service in the county is located in the center of town, in the same shopping

center as the grocery store, bank, and post office; the conspicuousness of entering the facility could be enough to prevent someone from using their services.

Finally, the close-knit nature of the community can result in an expressly hostile environment for a recovering drug addict. Since jobs are already scarce, it is especially difficult for someone with a reputation for drug use to get a job. As one provider said, "Even if they get clean, they can't get a job because people still look down on them and judge them." Thus, the social ties of a small town community can be an asset for providers, allowing them to develop trust and rapport with their patients, but also has the potential to promote stigma and prevent utilization of certain health services.

Religion

Another factor that relates directly to health in Leslie County is religion. As evidenced by the discussions of drug abuse in Chapter Four, religion plays a significant role in community members' and health providers' conceptualizations of health. Prayer was observed as a coping mechanism to deal with cravings in the smoking cessation courses offered at the health department. Five participants categorically stated that the church was the only way to help addicts. In the words of one participant, "Getting into church and the Lord delivering them is the only thing that will help them. That's the only thing that has ever helped." In this case, the power of the church is seen as a health resource even more potent than any drug recovery program. Religion was something openly discussed and a source of support for many people.

Environment

Coal mining plays an integral role in the economy and daily life of Leslie County. Cars and store windows are commonly plastered with stickers that promote the coal usage and express pride in the industry. However, community members and health providers also concede that the coal industry has a negative impact on health. Many listed COPD and other chronic respiratory problems like lung cancer on their free lists, owing not only to the common practice of smoking but also to the health impact of inhaling coal dust. Other diseases, such as heart and kidney disease, are also related to exposure to chemicals associated with mining (Hendryx 2009; Hendryx and Zullig 2009). Therefore, paradoxically, a major source of livelihood in the region is also a major source of health concern.

Comparing Results to Previous Literature

The results of the health concerns portion of this research were similar to previous results, but with several notable exceptions. Schoenberg et al. (2008) found that women in Appalachia viewed drug abuse, cancer, heart disease, diabetes, smoking, obesity, lack of exercise, and communicable diseases like HIV or STDs as the major health concerns in their community. These health concerns were used as the basis for the rank order activity, which resulted in similar outcomes but revealed that participants in this study did not perceive contagious diseases like HIV or STDs to be a significant health concern in their community; no one listed HIV or STDs as common health concerns in the free list and it ranked last among the rank order responses. However, all of the other health concerns discussed in that research were echoed by participants in this study. In adding the free list exercise, additional health concerns were also mentioned by community members. COPD was the most important addition to the list

of community members' health concerns, and may be reflective of Leslie County's ties to the coal mining industry.

Including health providers' opinions in compiling a list of health problems added a different dimension to the results. Health providers' rankings and free lists show more diversity in responses and order than community members. This could be due to the fact that, depending on the nature of a provider's practice, the health concerns he or she sees on a daily basis can differ widely. For example, the pediatrician does not see as many cancer patients as a primary care doctor and the health department diagnoses and treats many more cases of STIs than other providers. Health providers may also draw on their own personal experiences, and those health problems they see among their family and friends, in listing common health concerns.

A theme that both health providers and community members share is their concern about drug abuse, which ranked first among both groups. The vehemence with which drug abuse was discussed during interviews, as well as the immense knowledge of the subject displayed by community members, was striking. Many community members knew either in general or specific terms how crystal methamphetamine was made, what it smelled like, and how to recognize drug abusers. This body of knowledge, which would be understandable and even expected among some health care providers, was unexpected to find among general community members. Despite residents' intense worry about methamphetamine use, previous research actually shows that prescription drug abuse is more prevalent in the region (Zhang, et al. 2008).

Overall, the health problems listed and discussed by community members and health providers show that both groups are aware of the common health problems in their community. In addition to demonstrating concern about drug abuse, interviews indicated specific worries about childhood obesity, cancer, and COPD, which are substantiated through research that

indicates elevated levels of these conditions in Appalachia (Hendryx 2009, McAlearney, et al. 2010, Crooks 2000)

One health concern that was not commonly discussed in this research, even though it has been shown to be a significant problem in the area, is mental health. As previously mentioned, studies show that Appalachian suffer from higher rates of mental illness like depression and anxiety (Zhang, et al. 2008). However, mental health was only listed as a concern by two community members and five health care providers. Unfortunately, the results of this research do not indicate *why* community members and many health providers did not include this in their list, but one could postulate that it has to do with a number of factors. It is possible that the stigma associated with mental illness kept it from being discussed. Also, since it is generally not a topic of conversation, community members may not realize how widespread a problem it really is. Bringing greater attention to the high rate of mental illness in the region could promote discussion and make people feel more comfortable seeking treatment.

Theory revisited

Political Economy

Political economy, which Morgan (1987) referred to as a "macroanalytic, critical, and historical perspective" through which to analyze health disparity, encompasses factors such as unemployment, affordability, and poverty that directly influence health care access. One quote from a community member succinctly describes the role that political economy plays in influencing health decision making: "If somebody has to put gas in the car to go to Lexington three times a week, what aren't they able to afford at home, food-wise or whatever?" Living in poverty can severely constrain people's ability to make decisions to take care of their health. As

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the above quote demonstrates, factors other than just the cost of health care can contribute to inaccessibility.

Therefore, cost and duration of travel and other personal financial obligations must also be considered when assessing the 'accessibility' of health services. Likewise, these same factors can influence the ability to maintain a healthy lifestyle. Making a service affordable means very little if a person does not have access to transportation to get there, or cannot afford healthy food or medications that would allow him or her to follow her doctor's orders.

Phenomenology

Even if the structural factors associated with health care access were mitigated, micro-level factors, such as individual experiences and interpretations, would still pose barriers to health care access. Community members' responses indicated several barriers to access that have little to do with social structure and more to do with experiential dynamics; the influence of these factors should not be underestimated. An example that illustrates this best is the woman who refused to see the gynecologist because she knew him personally. In a small town like Hyden, the influence of personal relationships is magnified because there may not be another option if one provider is ruled out.

Likewise, given the stigma surrounding mental illness and STDs, personal pride may influence health decisions more than physical necessity or financial access. Finally, providers' perceptions of their patients may influence the care that patients receive. Providers' interviews demonstrated that some of them blame patients for their own health problems. The role that this may play in how care is offered and how it is perceived merits further research. All of these "everyday experiences" and "dilemmas" (Desjarlais and Throop 2011:92-93) that influence

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patients' decision-making processes attest to the importance of understanding how phenomenology influences the usage of health resources.

Recommendations

Given the regional reliance on churches, religious institutions seem to be a logical place to discuss health concerns. Churches should make information available to their parishioners regarding health services, especially those related to mental health and drug treatment, since those were uniquely associated with religion in participants' discussions. Also, support groups for various health concerns could logically be successful additions to churches' outreach programs.

In addition, given the tightknit nature of the community, word of mouth is an effective way to recruit patients. Community fairs and social gatherings (like the weekly bluegrass show) would be great places to advertise services or outreach events like a health fair. Spreading the word about services that are available to the community would benefit providers, who would receive more clients, as well as patients, who would utilize services about which they had previously been unaware.

In order to promote awareness and usage of health resources, providers in the county should be forthcoming in recommending other services if they cannot meet patients' specific needs. Patients trust their nurses, whom they may have known since childhood, and might therefore be more likely to heed their suggestions. Providing concrete suggestions for where a patient can go for smoking cessation classes, or nutritional counseling, or reduced-price prescriptions can help patients understand their options and make use of services that are available to them.

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Finally, the fact that Mary Breckinridge Hospital does not accept all types of Medicaid is a significant barrier to health care access in the county. As the location of three of the only doctors who are regularly in the county, this hospital could be an even stronger asset to the community if there were some way to contract with the two other MCO providers so that the needs of all patients, not just those with a particular MCO, could be met. Making patients with the wrong MCO travel to another hospital for diagnostic tests or treatment is a significant barrier to healthcare access and could presumably reduce fulfillment of referrals. Additional research into the legal constraints of contracting with different MCOs, including what strategies allow other clinics to accept all three forms of Medicaid, would help elucidate the possibility of Mary Breckinridge expanding its coverage.

These recommendations, along with the constructed assets map of health resources in the county, will be returned to the health providers who participated in this study. Ultimately, the data gathered in this research should promote knowledge of available health services among health care providers who can, in turn, distribute this information to their patients.

Limitations

The predominant limitation of this study was its sample size. Accessing participants from outlying regions of the county proved to be difficult, and including a wider range of participants may have revealed more health resources and differing opinions regarding health problems. The use of snowball sampling might also have influence the results of this research, as illustrated by participants' higher-than-average level of education.

In addition, time proved to be a limitation because, although every effort was made to contact as many health care providers in the county as possible, these individuals had very busy

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schedules and some were not available to meet despite repeated requests. This also led to two abbreviated interviews that were not particularly productive. Therefore, the sentiments and services of a large proportion, though not all, health care providers in the region are included in this study.

Finally, it is vital to acknowledge that I am an outsider to this community, which made me a conspicuous addition to the tiny town. Despite my efforts to blend in, my accent clearly set me apart from the community members. By the second week of my being in the county, several people I approached for interviews had already heard about me, what I was researching, and who I was staying with. Interestingly, one woman expressed distrust in outsiders coming in to do research because a doctor from New York came to work there a few decades ago and wrote a scathing article about how 'backwards' and 'lazy' people were in Eastern Kentucky. The participant said that this was a shock to the area and made people distrustful of outsiders coming in and studying health care.

That being said, I did not perceive community members holding back but it is possible that they would have been more candid with someone from their own community. However, my living with a local woman did improve my trustworthiness, as the she was a venerated member of the community. Living with that individual may have also influenced who I was able to recruit and what details they confided in me.

Future Research

Given that this research is exploratory in nature, it leads to many opportunities for further research. First, further research could be done to investigate health providers' and patients' interactions during health appointments. This research did not specifically address the

patient/provider relationship, but this is an integral aspect of the efficacy of an appointment. Given the opinions providers had about patients' personal responsibility and decision-making capabilities, it would be interesting to see if or how these attitudes are perceived by patients.

Another possible topic for further research is investigating what factors contribute to a patients' decision to seek follow-up care or fulfill referrals. The results of this research indicate multifaceted and complex factors that include both financial and personal reasoning, but further research is necessary to elucidate specific reasons. This was an area of great concern for the health care providers, and would be important to understand in order to improve care in the area.

Finally, several interesting topics arose during this research that would merit their own investigation beyond the scope of this current project. Topics like the stigma associated with mental illness, the use of folk remedies, and the role of religion in coping with and recovering from illness are fascinating topics that could not be adequately investigated within the scope of this research.

Conclusion

This study corroborated previous research by demonstrating that community members are cognizant of the health problems that affect their community. These health problems, including drug abuse, cancer, heart disease, obesity, smoking, and diabetes, were likewise acknowledged by health care providers and supported by epidemiological data. This research contributes to research related to health concerns in rural Appalachia by including health providers' perceptions of not only the common health problems, but also the social and personal concerns related to their patients' health. Recognizing providers' perceptions of their patients' behaviors and

decision-making reveals an aspect of health care accessibility that moves beyond structural barriers.

Additionally, this research answers a call for analysis of local health resources that was posed by researchers from the Appalachian Regional Commission by providing a list of services available to residents of Leslie County (Halverson and Bischak 2008). Through an assets map of the county, it is clear that the county has ample primary care facilities that provide reasonably accessible care for many residents in the county. Given the preponderance of primary care services, Leslie County has the infrastructure to reduce several of the common health concerns acknowledged by participants.

However, the county is seriously lacking in specialist care, including OB/GYN, drug abuse rehabilitation, and mental health services to address the health concerns raised by participants. As an exploratory study, this research provides a platform for future research related to health decision-making and patient/provider interactions. Ultimately, the data gathered in this research should be used to inform community members and health care providers about the services that are available in the community in order to promote usage of available services and, ideally, improved health outcomes for residents of the county.

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Appendices

Appendix A: Selected Qualifications for Federal Rural Health Clinic Designation

From The National Association of Rural Health Clinics (n.d.)

1. Location
Rural Health Clinics must be located in communities that are both "rural" and "underserved". For purposes of the Rural Health Clinics Act, the following definitions apply to these terms:
- Rural Areas – Census Bureau designation as "Non-urbanized"
- Shortage Area – a federally designated Health Professional Shortage Area, a federally designated Medically Underserved Area or an Area designation by the state's Governor as underserved.

2. Physical Plant
- May be permanent or mobile
- Has a preventive maintenance program
- Has non-medical emergency procedures

3. Staffing
- One or more physicians
- One or more PAs, NPs or CNMs
- PA, NP or CNM must on-site and available to see patients 50% of the time the clinic open for patients.

4. Provision of Services

Each Rural Health Clinic must be capable of delivering out-patient primary care services. The Clinic must:
- Maintain written patient care policies:
  - Developed by a physician, physician assistant or nurse practitioner, and one health practitioner who is not a member of the clinic staff.
  - Describes the services provided directly by the clinic's staff or through arrangement
  - Provide guidelines for medical management of health problems;
  - Provide for annual review of the policies
- Direct Services (must be provided by clinic staff)
  - Provide diagnostic and therapeutic services commonly furnished in a physician's office
  - Basic laboratory services (6 tests)
    - Chemical examinations of urine
    - Hemoglobin or Hematocrit
    - Blood sugar
    - Examination of stool specimens for occult blood
    - Pregnancy tests
    - Primary culturing for transmittal
  - Emergency Services
    - First response to common life-threatening injuries and acute illnesses
    - Has available drugs used commonly in life-saving procedures
  - Services Provided through Arrangement (may be provided by individuals other than clinic staff)
    - In-patient hospital care
    - Specialized physician services
    - Specialized diagnostic and laboratory services
    - Interpreter for foreign language if indicated
    - Interpreter for deaf and devices to assist communication with blind

What is the closest town to where you live?

About how far of a drive from that town do you live (in minutes)?

What are the biggest health concerns in your community?

Rank these in order from the most severe problem to the least severe.

[Presented with Map Tool]

Where would you go for a check-up?

What would you do / where would you go if you thought you had a broken arm?

What if your child had a broken arm?

What if your child had a bad rash like chicken pox?

If you had a friend who was depressed or anxious, what would you suggest they do?

If you knew someone who had a problem with drugs, what would you suggest they do?

What would you do if your family member got too old to care for themselves?

If a woman you know were being injured by her husband, what would you tell her to do?

Where do kids go to get check-ups? Do you have to make special arrangements to get there? (Kids out of school, off work)

Who would you talk to if you had questions about eating health or losing weight?

If a woman in your community is pregnant, or thinks she might be pregnant?
    Do people commonly use midwives?

Do you go to the dentist? Where? What keeps you from going?

If you need glasses, who do you talk to?

If a family has a child with a disability, where do they go to get care for that child?

Where do people go for specialty doctors?
    Allergies?

    Heart problems?

    Diabetes?

    Cancer?

    Stomach problems?

    Headaches?

    Joint pain?

Who do you talk to other than a doctor or nurse to ask health questions?
Friends from work? Family members? Friends from church?

Do you know of anywhere that has support groups for conditions like cancer, diabetes, etc.?

What additional services would you like to have in your community?

Appendix C: Home Remedies and Folk Medicine

Remedy	Use	Notes
Garlic	Antibiotic/immunity	
Yellow root	Antibiotic/immunity	
Ginseng	Energy	Can be found naturally growing in the mountains. "Hunting for ginseng"
Vinegar on paper bag	Sun burn	
Chewing tobacco	Bee sting	
Sassafras tea	Head cold	Grows wild in area
Fat back	Boils	
Raw sauer kraut	Nausea	
Ginger root	Nausea	
Blackberry tea	Heavy bleeding (pregnancy, menstruation)	
Boiled white oak bark	Tooth pain	
Hot toddy (moonshine, water, honey, lemon)	Head cold	
Blackberries with flour	Diarrhea	
Buying (pay a nickel, have to save the nickel)	Wart	
Blowing in mouth	Thrush	7th son of a 7th son can blow in mouth Person who has never seen their father can blow in mouth
Bible verse: Ezekiel 16:6 And when I passed by thee, and saw thee polluted in thine own blood, I said unto thee thou wast in thy blood, Live; yea, I said unto thee when thou wast in thy blood, Live.	Bleeding	Reading the Bible verse stops bleeding. Anecdote: Woman's mother's nose was "pouring the blood" and a man came and said the verse to her and it stopped right away.
Gentian violet	Thrush	
Potato	Boils	
Clove	Toothache	
Hickory stick over door	Asthma	When child outgrows stick, he or she will outgrow asthma
Kerosene rubbed on belly	Worms	