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Running the Health Care Marathon: An Ethnography of a Charitable Clinic in a Rural Appalachian Community

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by

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ABSTRACT

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Appalachia is characterized as being a place of health inequalities, including substandard health care access. Health disparities in access to health care persist in the region, and many Tennessee residents are unable to afford premiums, if they can afford insurance at all. Uninsured individuals rely on community based free clinics, which serve as health care safety nets and allowing people to obtain limited health care. This ethnographic investigation, involving semi-structured interviews and participant-observation of the Blackberry Spruce Free Clinic, provides insight into the continued need of health care safety net resources. This research provides a patient's perspective on the barriers to care for the uninsured, the difficulties in managing chronic illnesses and other medical needs when relying on charity care, and the problems of clinic management in its role as a temporary solution for the uninsured population.

DEDICATION

This thesis and experience is dedicated to honor my grandfather, Richard Wayne Walker. Thank you for introducing to me a sense of compassion and pride in my heritage. I hope my work would make you proud.

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Graduate school has been a thrilling journey. I would like to first express gratitude to the patients and staff of the Blackberry Spruce Free Clinic who were welcoming and so willing to participate in this study. I feel honored to share their stories and appreciate their openness with me. These individuals taught me more than they will ever know during my summer in Blackberry Spruce.

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To my parents, thank you for always supporting my every whim and dream. You believed I could make a change before I did. Lastly, I give thanks to my friends and family for encouraging me, feeding me, and keeping me sane during this process. Without all of you and the Lord's blessings, this feat would not have been possible.

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> We meet the needs of the people that need it. There are a lot of people that aren't getting the care they need. That's what we are; we're there for people when they really need it. – Taylor (Interview 11)

The Blackberry Spruce Free Clinic opened in 2000 to address the medical needs of uninsured patients in Flat Top County, Tennessee.[1] As a free clinic, they offer an affordable health care option to the residents of this county who are without health insurance and fall below a certain economic level. While access to health care as a health disparity is profoundly experienced by many in Flat Top, the issue of access to affordable health care is a problem for many individuals and families across Appalachia and the United States. The problem is most profoundly felt by those without health insurance. Access to health care, as a health disparity, is complicated owing to the multitude of issues that can lead to access barriers. Healthy People 2020 defines a health disparity as:

> a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion (2016).

The health care provided by the Blackberry Spruce Free Clinic attempts to address the health inequalities of the uninsured residents in its community. The patients' stories collected at this clinic reflect multiple economic and social factors that contribute to their experience of health care access barriers, particularly their socioeconomic and

[1] To protect the identities of subjects in this project, all individuals and places involved in this study were provided pseudonyms.

employment status which leads to difficulty maintaining an insurance provider. These clinics are the main provider of medical treatment for the uninsured in this county. The complexities and the issues seen within this clinic act as a microcosm of the problems at traditional private-pay treatment sources and display the holes present in our current health care system. The patients in the "gap" of being uninsured in a health care system designed around health insurance payment systems are left to seek out care through free clinics like the Blackberry Spruce Free Clinic. To remain open in their community, clinics like this rely on fundraisers. Blackberry Spruce Clinic hosts an annual 5K run to raise money to support the clinic's operations. This fundraiser inspired my title, *Running the Health Care Marathon,* since accessing care as an uninsured patient invokes the metaphor of a long, arduous journey- a marathon- to receive any type of health care. Although the Blackberry Spruce Free Clinic is a stop gap for health care for many, it is not a substitute for private pay access, since they can typically only provide routine follow-up care and prescriptions for chronic diseases.

This study offers a patient-centered perspective of health care received in a free clinic. Through interviews and participant observation in the clinic, this research provides insight into the inner workings of a free clinic, describes the struggles to access health care for uninsured individuals in Flat Top County, and provides insight into broader issues of our nation's fractured health care system.

Following the passage of the Affordable Care Act (Obamacare), many assumed that free and charitable clinics would no longer be needed, since the main goal of the policy was to make health insurance and affordable health care more accessible to citizens. However,

as we shall see, many individuals remain uninsured, and some physicians attempt to assist in combating the problem by providing charity care through safety net clinics. Free and charitable clinics remain present in our society, providing necessary health care to those who are without health insurance. This study is not an overview of the Affordable Care Act as a health policy, but the details of these patients' situations and the clinic's organization must be understood as existing in a post-ACA context. An evaluation of this free clinic will provide understanding of what occurred after the Affordable Care Act in a safety net, non-profit setting. Lastly, this research discusses the importance of this rural clinic's presence and the existing health that contribute to this community's continued need for affordable health care.

CHAPTER 1

LITERATURE REVIEW

Introduction to Appalachia

The Appalachian Regional Commission defines the Appalachian region as covering 420 counties in thirteen states, which run from New York to Mississippi. The region contains various geographical features, including ridges, valleys, and plateaus that are nearly half a billion years old. Though historically important for providing fuel sources, such as timber and coal, today the region is the center of intense economic and extractive industry debates regarding the decline of coal and the rise of natural gas extraction or "fracking." While the region hosts several industries, academic institutions and various professional services, many communities continue to experience economic decline and are seeking employment and economic alternatives. The Appalachian region still supports a lower income average and post-secondary education levels, higher poverty and unemployment rates than the national averages (ARC 2017). These socio-economic factors pay an integral part in health disparities in the region.

Appalachia has a long-standing association as a place of distinctive health disparities, including the lack of access to quality health care for many individuals. This perception of Appalachia is attributed to its excessive morbidity and mortality rates and disease risk factors higher than the national averages (Halverson, Ma, and Harner 2004). Healthy People 2000's goal was to reduce the presence of health disparities, while Healthy People 2010's goal was to eliminate health disparities overall (Halverson, Ma, and Harner 2004). Healthy People is an initiative that sets up national ten-year goals each decade in an

attempt to improve the nation's overall health. (Healthy People 2020). These have clearly not been met in Appalachia, as today the region has higher mortality rates than the nation for heart disease, cancer, chronic obstructive pulmonary disease, stroke and diabetes (ARC 2017). The issue of Appalachia's persistent disparity narrative is not centrally due to the lacking infrastructure of health care services in the region but rather due to multiple factors. For example, the people of the region are often unfairly portrayed as being fatalistic, having a suspicion of outsiders, and of being weary of formalized medical systems (McGarvey et al. 2017). Appalachia has a history of limited access to health care providers, largely due to proximity and affordability. Prior to industrialization, many physicians participated in the barter system for payment and held a second job (Starr 1982). Small town populations in Appalachia and the long distance between many homes resulted in low availability of physicians (Barney 2000). The standards for training physicians were also lower than today's recommended schooling, and some physicians made their way to the hills had only trained for as little as a year at a medical school (Caudill 1960). The rise of industrialization in Appalachia, particularly due to coal and timber extraction, led to the introduction of professionalized medicine based on scientific principles into the region (Barney 2000). Medicine's transformation was not completely based on the advancement of scientific techniques or the satisfaction of met needs (Starr 1982). Professionalized medicine, entrenched in a capitalistic economic system, enforced the idea of needing a cash-based health care system. Although traditionally a position of little economic significance, medicine transitioned to an encompassing system of health insurance, hospitals, and an unparalleled labor force (Starr 1982). Today, the U.S. health care system is firmly entrenched within the national economy. Indeed, healthcare accounts for nearly

18 percent of the U.S. Gross Domestic Product (GDP), with health care spending totaling $3.3 trillion or $10,348 per person in2016 (Centers for Medicaid and Medicare Services 2018). While many nations throughout the world with capitalistic economies embrace a type of universal health care as a right, the United States does not. While universal health care is defined as representing an equal opportunity to quality health services no matter your insurance status (World Health Organization), the American health care system does not reflect this, and individuals experience differentials in access and quality of care based on their means of payment. For many Appalachians, finding affordable health care remains difficult due to the barrier of cost for some individuals and families.

In studying health care in Appalachia, we see the prevalence of health disparities is not solely attributed to poor choices, fatalism, or lack of health knowledge. Rather, Appalachian health disparities highlight broader regional and national issues of economics, employment opportunities, and the organization of the U.S. health care system. The supply of primary care physicians is twelve percent lower than the national average in the region, and within rural communities there is a twenty percent lower presence than the region's metropolitan areas (ARC 2017). The J-1 Visa Waiver Program offered by the Appalachian Regional Commission attempts to address the growing need for physicians in rural areas of the region by placing recent graduates in these communities (Rural Health Information Hub 2018). Overall in the region, health care utilization is low even when it is available to an individual, and those who reside in rural communities are less likely to seek medical care or to receive special treatments (McGarvey et al. 2017). To understand the issues regarding quality and access of rural health care, the term rurality must be defined.

Defining Rurality

Defining a concise distinction for a rural community is difficult due to the multiple definitions used throughout literature and by the United States government. For example, the United States Census bureau classifies populations as being rural by population size, the population density, and the relationship of an area to a city but does not differentiate at the county level (Vanderboom and Madigan 2007). In contrast, the United States Office of Management and Budget classifies rurality based on county population size and the areas relationship to a large city (Vanderboom and Madigan 2007). Recently, Dr. Waldorf at the Purdue Center for Regional Development developed the Index of Relative Rurality (Roehrich-Patrick and Moreo 2016). This index works off a continuous scale to rank how rural a county is in comparison to all the counties in the state, rather than simply assigning the county as either urban or rural (Roehrich-Patrick and Moreo 2016). This index ranges from 0, meaning most urban, and 1, meaning most rural (Roehrich-Patrick and Moreo 2016). Health care access is less accessible in rural communities and could lead to a lack of care for individuals in these communities. Central Appalachia is identified for having lack of access to care due to factors such as: lack of specialty care, long distances to service, limited public transportation, lack of health insurance, cost and shortage of health care (Gardener et al. 2012). Furthermore, rural areas often have little or no access to free clinics. This lack of access to health care for both insured and uninsured individuals in rural communities leaves the entire population vulnerable to adverse health outcomes.

Rural Health Care

Isolation has long been a descriptor for the Appalachian region due to the mountainous terrain. Rural communities in Appalachia have never completely been set apart from American life outside the mountain region, despite how they have been depicted in literature (Straw and Blethen 2004). Appalachian residents have been linked to regional, national, and global markets before the industrial transformation of the region (Barney 2000). However, much of modern Appalachia remains rural. A total of over 2.5 million individuals reside within the Appalachian Mountains, based on the Appalachian Regional Commission definition, in areas which are defined as rural, non-metropolitan and not adjacent to a metropolitan area, as of 2010 (Pollard, Jacobsen, and Population Reference Bureau 2011). However, per the Appalachian Regional Commission (2016), forty-two percent of these individuals live within rural communities compared to the nation's twenty percent. Previous studies associate a higher risk of rural residents being uninsured, when compared to individuals who reside in urban areas (Ziller, Coburn, Loux, Hoffman, and McBride 2003). However, all mention of care providers in the study highlight informal safety net services, excluding free clinics as providers of care (Ziller, Lenardson, and Coburn 2012). In Appalachian rural communities, the issues of economic, cultural, and social discrimination are still present in these healthcare systems (Carmack 2010). Carmack (2010) calls for the need for tailored care for rural patients to meet their needs for health facilities. For example, in East Tennessee there are a total of fourteen clinics which offer services for free or at a reduced fee, and only six of these clinics operate in town limits measuring below a population of 20,000 ("Clinic list for Tennessee" 2016). In comparison, the state of Tennessee has a total of 300 free or sliding-scale clinics ("Clinic list

for Tennessee" 2016). Since East Tennessee contains less than five percent of the clinics in the state, there is a lack of availability of resources for individuals in the communities of this region of the state. These free and charitable clinics play a significant role in the health care system by providing care to the uninsured of the state.

The Uninsured Accessing Health Care

Access to care for uninsured individuals in Tennessee is limited. For example, Bristol Regional Medical Center's (2016) Community Health Needs Assessment claims that due to Tennessee refusing to expand their Medicaid programs in conjunction with the Patient Protection and Affordable Care Act (Affordable Care Act or ACA), many individuals in the state remain unable to afford premiums or to meet deductibles. This report further describes the increased health risk for these underinsured or uninsured individuals, as their inability to pay leads to their reluctance to seek out medical care and their inability to build a relationship with a primary care physician (Wellmont Health System). Through the Affordable Care Act, states were provided the option of expanding their Medicaid coverage to individuals with earnings less than 400 percent of the federal poverty level (McGeehan et al. 2017). However, not all states expanded their coverage provided by Medicaid, leaving such individuals who would have qualified dependent upon receiving insurance through the online marketplace created. Those who remain uninsured for various reasons became dependent upon safety net clinics, such as mobile or RAM clinics and free-standing clinics, or self-pay through physicians' offices.

Mobile clinics are a type of safety net clinic and a form of alternative health services attempting to address the issues of economic insufficiencies and unequal access to care.

Mobile clinics, sometimes referred to as health wagons, are often vehicles or busses, which were renovated to appear like a doctor's office inside. Such clinics occur throughout rural Appalachian communities as an attempt to compensate for the geographic disproportion to access (Carmack 2010). However, in settings such as mobile clinics, even when providers attempt to avoid the issue of poverty, the factor of inadequate financial support must be considered, especially when related to a health issue of an individual. Additionally, in rural communities with high rates of individuals with low incomes, issues such as expense of medication and transportation to follow-up appointments remain largely unaddressed by mobile clinics.

Another popular form of free medical care in Appalachia are remote area medical (RAM) clinics. While RAM clinics occur worldwide, approximately sixty percent of their work occurs within the United States, including sites in the Appalachian region (Ludke and Obermiller 2012). In comparison to mobile clinics, these remote area medical clinics are often set up at available convention centers or at county fairgrounds to provide medical, dental, and vision care to underinsured and uninsured individuals at no cost (Watson 2011). These clinics also largely depend upon volunteer physicians, nurses, and students from the area to provide care to the patients. The dependency upon free medical care provided by RAM clinics is apparent by the multiple individuals who are treated at these temporary clinics. RAM clinics, however, are not permanent solutions for care since they only operate every six to twelve months in a community and can only treat one complaint per visit (Watson 2011). These clinics cannot provide routine follow-up care for an issue to an individual or consistent medication to treat their illness. The apparent need for temporary clinic care in Appalachia is also a clear sign for the need of an improved health

care system within the region. Yet, many without insurance access routine care through community based free clinics.

Free Health Care Clinics

Although the United States has more academic medical centers and a prolific amount of life saving technology available compared to other nations, it also boasts the highest percentage of individuals in the population without health insurance than any other developed nation (Watson 2011). Those who are uninsured are less likely to seek medical care resulting in higher mortality rates and higher adverse health outcomes (Lane et al. 2012). Often adults without coverage will have fewer visits to sources of care and practice less use of preventative medicine techniques than those with health insurance (Ziller, Lenardson, and Coburn 2012). Additionally, many will forego care due to expense even when their health requires it (Ziller, Lenardson, and Coburn 2012). This behavior in the uninsured has been found to result in preventable hospitalizations (Ziller, Lenardson, and Coburn 2012). Uninsured individuals also tend to use the emergency department as a source of primary care with a non-urgent complaint since they often cannot access care through any other source (Bicki et al. 2013). This use of emergency rooms can cause a financial burden on individuals and the health care organizations due to the use of services (Halverson, Ma and Harner 2004). Free clinics assist in decreasing the number of non-urgent emergency department visits and expand the access of some health care to the uninsured without having to worry about expensive medical costs (Bicki et al. 2013; Darnell 2010).

Free clinics are an important piece of the health care system because they provide needed health care, have strong connections within their communities, and smaller clinics are viewed positively by their patients based on the care received (Watson 2011; Becker 2004). Darnell's study (2010) defined a free clinic to be considered free by the following:

> the establishment must be a private, nonprofit organization or the program component of a non-profit; provide medical, dental or mental health care and/or fill prescription medications to the patients directly; serve a majority of uninsured patients; having no fee or nominal fees which exceed a sum of twenty dollars; not billing, denying care, or rescheduling appointments due to a patient's inability to pay the requested fee; and the establishment is not to be recognized as a federally qualified health centers or Title X family planning clinic.

Today, throughout Appalachia and the United States, community based free clinics serve as healthcare safety nets providing limited health care services to individuals who fall in between the gaps of the health insurance system. Free clinics are defined by the services they provide to the uninsured, including racial minorities and the homeless, and those who do not qualify for government assistance but still lack an ability to pay for health services (Darnell 2010). With the recent changes by the Affordable Care Act there was a belief that free clinics would no longer be needed. The creation of online insurance marketplaces and expansion of Medicaid eligibility attempted to increase the number of insured in the nation to allow access to and affordability of health care for everyone (Sessions et al. 2017). Despite these efforts, the 2015 US Census reports that 29 million Americans remain without health insurance. Currently, there is limited research on free clinics and even fewer studies examine free clinics after the Affordable Care Act implementation.

A better understanding of the implications of health care reform can provide additional comprehension of why individuals remain uninsured and how free clinics were affected.

Free clinics are the subject in several studies examining the clientele who utilize free clinics and where funding sources for free clinics originate. Kamimura, Ashby, Myers, Nourian, and Christensen (2015) examined the satisfaction of patients from the care received at a free clinic. This study found that a patient's satisfaction increased with the improvement of services offered and the larger presence of a patient-provider relationship (Kamimura et al. 2015). To ensure that satisfactory care is being provided at free clinics, this study recommends meeting requirements for language interpreter services if needed, providing social support help, and delivering health education (Kamimura et al. 2015).

Studies have investigated the role free clinics play in the "safety net" of America. According to Schroeder (1996), the safety net is a type of charity medical care. The existence of these clinics allows them to be viewed as a substitute for health insurance by policy makers (Becker 2004). As Taylor (2001) stated, health care is going to only be available to those who have the means to afford the payment of it. For others without the means to afford insurance and remain uninsured, the complexity of health care access becomes largely focused on affordability rather than medical need (Fletcher 2014). Free clinics, though designed to provide episodic treatment until patients can find standardized care, appear to provide care to individuals over a semi-permanent period as they are usually the only accessible care source for this population (Reynolds 2009).

The idea of cash-free medical treatment is not new to Appalachia for meeting individual healthcare needs. In 1918, Dr. Karl von Ruck of Asheville, North Carolina established a sanatorium for the free treatment of tuberculosis (Asheville Citizen 1918). Prior to this establishment, von Ruck noticed the tragedies occurring to the local population who were unable to afford the treatments available to wealthy travelers seeking

treatment (Asheville Citizen 1918). The Frontier Nursing Service, founded in 1925 by Mary Breckinridge, attempted to provide better care to expecting mothers and newborn infants in Eastern Kentucky at an affordable rate (Goan 2008). Nurse midwives provided home health care which resulted in improved conditions for child birth and decreased mortality rates in the Appalachian region (Barney 2000). Free medical clinics have since increased throughout the country, and are prevalent in the Appalachian region. Many of these clinics are the product of activism by an individual or the work of community organizations such as, the Mud Creek Clinic in Kentucky founded by local resident Eula Hall (Bhatraju 2013). Johnson (2010) discusses the origin of free clinics but also highlights the instability of such care due to financial reasons. Though often faced with inconsistent funding, the number of free clinics in the United States continues to grow, but some have closed their doors due to lack of available financing. The Blackberry Spruce Free Clinic in Flat Top County, Tennessee is an important resource for individuals in the community for routine and follow-up care for chronic diseases, especially diabetes.

Research Field Site- Flat Top County, TN

The Blackberry Spruce Free Clinic is a local medical clinic in Flat Top County dedicated to providing routine care to residents of Flat Top and two surrounding counties. The clinic hosts an evening primary care clinic on Tuesdays starting at 5:45 p.m. The clinic also provides diabetes treatment through a day clinic on Tuesdays from 10:00 a.m. to 3:30 p.m., to assist in addressing a state-wide initiative against obesity from the Tennessee Department of Public Health.

Based on the Index of Relative Rurality, Flat Top County is identified as 0.400 on the index, meaning it is closer to being considered rural than urban (Roehrich-Patrick and Moreo 2016). In comparison to all ninety-five counties in Tennessee, Flat Top County is relatively in the twenty-fifth percentile of all ninety-five counties in the state, making it closer to being classified as rural rather than urban (Roehrich-Patrick and Moreo 2016). Its association of being considered primarily rural makes Flat Top County an ideal research site in further understanding the effects free clinics in rural communities.

Approximately 14.2 percent of the town is below the poverty line (American Community Survey 2015). The average household income for the county of Flat Top is slightly above 45,000 dollars (American Community Survey 2015). Additionally, a total of over 6,000 out of the 55,000 individuals of the county have no health insurance, leaving approximately 10 percent of the county without the ability to afford adequate health care access (American Community Survey 2015).

Project Rationale

Following Watson's (2011) study discussing the effectiveness of and continued need for remote area medical free clinics, this study is a qualitative investigation to understand the importance of continuous care clinics. Watson acknowledges the early effects of the Patient Protection and Affordable Care Act in Appalachia. However, seven years have passed since Watson's observation of health care needs. During the present discussion of health care reform, understanding the implications of the Affordable Care Act on the uninsured and the possible result of reform are important to consider during this period of health care instability. The research completed at Blackberry Spruce Free Clinic is a clinic-

based ethnography that evaluates the functionality of this clinic and captures the stories of the patients and workers at the clinic. This method will avoid the process of dehumanizing the participants of this study, which often occurs in quantitative data. To protect the identities of these individuals and to follow HIPAA guidelines, pseudonyms replaced all places and interviewees in this study.

Using semi-structured interviews and participant observation, this project qualitatively investigates the Blackberry Spruce Free Clinic. This thesis project contributes to the current research on access to health care, free health clinics, and rural Appalachian health care by answering these research questions:

1) What is the daily operating structure and issues facing the Blackberry Spruce Free Clinic and its' patients since the passage of the Affordable Care Act health policy?

2) What health care services are offered by the free clinic and how do they address health care needs in the community?

3) What importance do free clinic patients place on the clinic for necessary health care?

4) What can be inferred about disparities in access to health care by the daily operations of a free clinic?

Currently, the research on free clinics is limited, particularly in rural Appalachia. This study contributes to our knowledge of the daily workings and effectiveness of care provided through free clinics in rural communities. Additionally, this study's conclusions will assist in understanding why certain individuals fall into the "gaps" by being uninsured through examining the economic parameters influencing health insurance and health care access in a rural community. In conclusion, this study provides additional exploration into the importance of free clinics, the role which these clinics play in their communities, and a

better understanding of the continued need of such entities for consistent care in rural areas.

CHAPTER 2
METHODOLOGY BEHIND AN ETHNOGRAPHY

Project Design

Free clinics are identified as an important part of the health care "safety net" in America and are investigated for their role in providing care (Geller, Taylor, and Scott 2004). The health care safety net is defined as the health services which provide routine care and emergent care at no cost or a reduced fee (Taylor 2001; Becker 2004). However, the extended definition for the safety net includes health services that provide care for free or at a reduced cost (Taylor 2001; Becker 2004). In modern society, health care is only available to those who have the means to afford the payment of treatment and to those receiving free or reduced-cost charitable care. As some have argued, the existence of charitable or free clinics enables policy makers to support a few free clinics in lieu of health insurance reform (Taylor 2001; Becker 2004). Since the enactment of the Affordable Care Act in 2012, many have been able to access health care coverage but some remain uninsured (Kamimura et al. 2016). The number of individuals uninsured is especially high in states that rejected the option of Medicaid expansion (Kamimura et al. 2016). In the Appalachian region, free clinics have a long-standing history of being popular based on news articles discussing Remote Area Medical clinics and mobile clinics. The enactment of the Patient Protection and Affordable Care Act spurred the belief that free clinics would no longer be needed as a source of health care. The continued presence of free clinics in the region displays the remaining need for safety net medical clinics in Appalachian communities. As the executive director of the Vermont based Volunteers in Medicine

explains, “free health care clinics have long been a crucial part of the health care safety net system, and they will continue to be in demand to serve the uninsured for many years to come,” (VIM 2014). The continued need for care for uninsured or underinsured individuals, has led to the continuance of the care provided by free or charitable clinics to underserved individuals (Kamimura et al. 2016). There has been limited discussion of how the Affordable Care Act affected charitable or free clinics.

To best examine the experience of an uninsured individual at a free clinic and the effects of the Affordable Care Act on a free clinic, I completed an ethnographic study to examine access to care, health insurance and policy change. An increase of ethnographic studies since the 1970s has allowed this writing technique to be viewed as recommended qualitative method (Emerson, Fretz, and Shaw 2011). Ethnographies consider the importance of human behavior and observe the interactions of participants to understand their lifestyle or culture (O’Reilly 2005). Described as involving the observation of individuals as they go about their daily interactions, ethnographers participate in these daily interactions, create relationships with the observed, and record what they see and experience at their research site (Emerson, Fretz, and Shaw 2011). My previous understanding of medical techniques played a key role in deciding on the method used to complete this research study about free clinics.

For two years, I worked as a medical scribe and personal assistant to emergency room physicians. This experience developed my interest in studying access to health care in rural communities and examining the issue of “frequent flyers” or reoccurring visits to emergency rooms. A study concluded that uninsured individuals tend to treat emergency

departments as a source of primary care visiting with complaints for non-urgent symptoms (Bicki et al. 2013). Working with physicians in the emergency department allowed me the opportunity to learn the correct protocol based on an individual's complaints and symptoms. For example, an individual who is complaining of abdominal pain typically receives some type of imaging such as an ultrasound or a CT scan. Through observing reoccurring patients at the clinic who utilized the emergency department for their primary care and overhearing the multiple discussions about insurance coding, I became interested in understanding health care access for the uninsured and the underinsured. I also became interested in focusing on rural communities since many of the individuals who utilized the emergency department drove thirty to sixty minutes or had to be flown in due to their remote location.

Based on my interest in rural health care access, the Blackberry Spruce Free Clinic was the ideal choice to focus on for my research project. Though free clinics are popular in the state of Tennessee due to the lack of Medicaid expansion in the state, there are limited free clinics in rural communities with populations below 20,000 ("Clinic list for Tennessee" 2016). The Blackberry Spruce Free Clinic is approximately seven minutes from the closest Interstate but is in a county defined by the Appalachian Regional Commission as being at-risk (ARC 2018). The Appalachian Regional Commission defines at-risk counties as economically distressed. Such counties typically have few employment opportunities, job types, or limited numbers of industry options.

Researching the Blackberry Spruce Free Clinic

Flat Top County, Tennessee houses a population over 50,000 with its largest town in Blackberry Spruce which accommodates approximately 7,000. Blackberry Spruce Free Clinic is located in downtown Blackberry Spruce. The town contains two regional grocery stores but has a limited number of local businesses, including a hair salon, florist, thrift store and a family owned pharmacy. The town is also home to several different churches and a post office. This clinic is housed in a small corner of a run-down shopping center off a main road in town, which also contains a bakery, a thrift store, two antique stores, a boutique, a flower shop, a moving company, a snow-cone stand and a laundromat. Two regional food chains, a bank, the local library, and a primary physician's office are also located in the shopping center. Past the physician's office are a community garden and a senior center that offers free lunch to individuals on Fridays. This shopping center also houses the local food pantry maintained by the same group as the clinic. The parking lot of the shopping center appears older than the center itself, with faded parking lines and potholes. Despite this, once a week a town farmer's market sets up in the lot during the summer months. Situated in the corner of the flower shop and the thrift store sits a row of benches and a sign that points to the Blackberry Spruce Free Clinic. However, the banner still sports the clinic's old name. The door to the clinic displays a sign saying there are no narcotics on the scene. A long hallway of chairs leads to a lobby, containing more chairs before a glass window and a door. In the lobby a bulletin board posts local events and offers in the area and displays the cookbook the clinic staff made as a form of fundraising.

Methodology

Prior to starting my field research, I had several introductory conversations with the office manager at the clinic and compiled secondary sources discussing rural health care, free clinics and health in Appalachia. Once I received IRB approval for my project, I spent twenty-one days during the summer of 2017 between June and August at the clinic completing participant-observation. While at the clinic I called patients to remind them of their upcoming appointment, signed in patients as they arrived at the clinic, and assisted staff with various computer issues. This opportunity of observing and being an active participant, or in this case volunteer, allowed me to comprehend the inner workings of the office staff, pharmacy, and physicians at the clinic that I would otherwise not understand.

After each day at the clinic, I wrote field-notes detailing my first impressions of the conversations heard and the observations made each day (Emerson, Fretz and Shaw 2011). In addition to field notes, I completed sixteen interviews using IRB approved interview questions. There were two different question sets for this research, a set for patients of the clinic and a set for volunteers or staff at the clinic. These questions avoided any of the eighteen identifiers categorized by HIPAA as being able to identify an individual. By following these guidelines the project is HIPAA compliant. The set of questions for patients focuses on addressing why they are utilizing the clinic as a source of health care, their previous experience with health insurance and their understanding of the health care reform acts. The questions asked to clinic volunteers and staff focus on addressing the history, services and needs of the clinic, their knowledge of health care reform and the effects of the Affordable Care Act on the clinic operation, and their prediction of why health

care access is a disparity in Appalachia. The criteria for interviewing patients was broad in nature. The individuals who were interviewed needed to be a patient or needed to work at the clinic, needed to be eighteen years of age or over, and needed to speak English fluently. I hung a flyer advertising the opportunity to be a part of the research study in the lobby of the clinic, but all patient interviewees were identified by me asking them of their interest. For example, one patient remembered me from a previous visit at the clinic and willingly volunteered to be an interviewee after he inquired about the progress of the study. Some individuals were identified based on office staff recommending them as knowledgeable and long-standing patients at the clinic. Interviewees included three providers; the male medical director who was interviewed twice, a female diabetes educator and nurse, and a female physician who volunteers once a month at the clinic. Other interviewers included eight patients, four female and four male. For two of my male patient interviews, their wives also acted as interviewees and provided additional insight. I attempted to interview a diverse selection of individuals to reflect county demographics, and my participants included African-American and Hispanic patients. I interviewed three office staff members, including the office manager, the clinic assistant, and the pharmacy technician. Additionally, I interviewed a community member who worked for another local non-profit to provide a further outlook of the community of Blackberry Spruce. Once my research in the field was completed, I transcribed all sixteen of the semi-structured interviews.

For each transcript, I completed pattern coding to identify major themes in the data. I also completed line by line coding on the daily field notes written for each day I spent at the clinic. The process of coding, or open coding, entails reading field notes closely, line by line, to search for all themes and concepts suggested from the data sets (Emerson, Fretz

and Shaw 2011). These codes or identified themes were written in the margins of field notes and transcripts. The themes present in my field notes coincided with the discussion present in my interviews and provided additional insight for the conclusions drawn in this study. Themes were then constructed into a codebook which was used to focus on which topics to discuss as main points in my research data chapters. The themes identified included: missing care, ailments present, needs of the community (including finances), health care policy discussion (including the Affordable Care Act and current reform possibilities), and lack of knowledge on a variety of topics (including the Affordable Care Act and the clinics operations). After identifying the original themes, I further elaborated these topics by re-analyzing the transcripts for statements that address these motifs. I then collected all quotations to use as supporting statements for conclusions derived from my research.

Since all my data is based on primary research and sources, the possibility of bias must be addressed prior to the composition of my conclusions from my experience at the clinic. Defining an ethnography is difficult due to its versatility as a research method but involves the continued contact with a group in the context of their life for a sustained amount of time with the use of participant observation and conversation (O'Reilly 2005). Ethnography is also considered the gathering of stories to understand a concept or issue present in society (Fletcher 2017). Completing an ethnography involves overt and covert participation for an extended time in the everyday life of a community, examining social life interaction, and observing the context of the community while recognizing one's own role in the construction of everyday interactions (O'Reilly 2005). Since the key to an ethnography involves sharing interactions with the group of people you are studying,

relationships are often developed in this experience (Emerson, Fretz and Shaw 2011). This experience of spending the summer volunteering and observing the clinic allowed me to see the negative and positive aspects. I also must contextualize my own judgement and bias based on being a woman who has previous experience working in the medical field and an understanding of medical procedures. . This bias and natural judgement can be portrayed through my experience at the clinic. However, I have attempted to support all statements and conclusions with quotes, literature and observations in my field notes.

This study explores the ability of patients at the Blackberry Spruce Free Clinic to receive health care at this source and through other services of care. My research further notes the presence of chronic illness in the community of Blackberry Spruce. This study will also examine the demographics and health behaviors of individuals at the clinic and the community of Blackberry Spruce and Flat Top County. Such research will provide additional information into the current status of free clinics. I have compiled the conclusions and quotes from these data sets in the following chapters which detail the perspectives of patients receiving care at the Blackberry Spruce Clinic and the daily workings of the clinic. Finally, I reflect on the effects of the Affordable Care Act on an Appalachian free clinic.

Chapter two and three will discuss the data compiled during this research study. *Chapter Three: A Day in the Clinic* will examine the everyday operations at the clinic and the services provided on site. Here I will detail the inception of the clinic, both the diabetes and primary care clinics hosted. This chapter discusses the patients' viewpoints of the clinic and gives an overview of their need for health care access, including specialty care and medication access. Overall, Chapter three will highlight the structure of the Blackberry

Spruce Free Clinic and the services provided to address the health care needs in their community.

Chapter Four: Understanding Health Care Reform in a Free Clinic will provide insight into the insurance history for those who now utilize the free clinic for health care and assist in understanding why they are now uninsured. This chapter will define the Affordable Care Act and the implications of this bill on free clinics. Lastly, this chapter will discuss the current health care changes being discussed and the potential implications of policy changes to the uninsured population and free clinics.

The concluding chapter will discuss the need for affordable care in this community, in Appalachia, and nationwide. Such insight into the discussion of the Affordable Care Act and its implications on free clinics fills a void in current literature regarding safety net care.

CHAPTER 3

A DAY IN THE CLINIC

Blackberry Spruce Free Clinic

Every Tuesday, the Blackberry Spruce Free Clinic opens its doors to its community of patients to provide them with free healthcare and medications. The morning clinic, which mostly treats individuals with diabetes, has two nurses who are certified diabetes instructors who start seeing patients at 10:00 a.m. and work until the last appointment at 3:30 p.m. The clinic closes its doors at 4:30 p.m. in preparation for its evening clinic. As patients enter the clinic, they sign in and go back to the examination room based on the order each arrived. Prior to seeing patients, the clinic bustles with chatting providers while the pharmacy preps the administered medications. Meanwhile, the spiritual counselors prepare for the heartbreaking stories they will soon hear. The evening clinic begins with a prayer at 5:45 p.m. and then begins drawing in patients. Patients drive anywhere from five minutes to as far as two hours to receive affordable care through the clinic. The clinic attempts to address medical, spiritual, and social issues which each of these patients bring to them.

Free clinics provide episodic care rather than promoting ongoing care but are instead operating to provide consistent health care access to individuals (Mouton 2013). Clinics, such as the Blackberry Spruce Free Clinic, attempt to offset cost and access problems for individuals who find themselves uninsured and in need of health care (Darnell 2010). The Blackberry Spruce Free Clinic treats multiple individuals on a monthly routine to provide management of various diseases and ailments. Demographically, most of

the patients are Caucasian, with a few minorities present, mostly Hispanic and African American. Patients are between the ages of forty to sixty years of age but do not have affordable insurance options. Dr. Cash, a physician who volunteers for the clinic, describes the clientele as being "gap people" stating:

> They're in a gap between having employment and insurances and waiting for a disability determination. They are living minute to minute, dollar to dollar however, they can get it and all their hopes are pinned on this disability determination. The others that I see are folks that are either uninsured or underinsured and work a type of job that they can't afford any type of insurance but don't qualify for Medicare, the working poor, the very poor. And then I see a few that appear to have exhausted all other safety nets; they've been fired from different doctors, they've been fired from their jobs for whatever mental health addiction issue they've had. And they're usually not very old, thirty, forties and fifties we don't see anyone older than that really. A lot of bad mental health problems, criminals, folks that have been incarcerated (Interview 10).

The lack of Medicaid expansion in many Appalachian states widened the gap of accessing insurance for such patients and has left many with the inability to afford premiums or to meet deductibles, if they can afford to obtain insurance at all (Wellmont Health System 2016).

Flat Top County

The Blackberry Spruce Free Clinic attempts to serve the individuals in Flat Top County and two of the surrounding counties. As a clinic, they try to provide care to the low-income and the uninsured within certain rural counties in Tennessee and the neighboring state. The Appalachian Regional Commission lists Flat Top County as at-risk economically. Housing a population below 60,000, the county is closer to rural than urban when compared to this region's largest county with a population of over 120,000 (Roehrich-Patrick and Moreo 2016). Located approximately eight miles from the interstate, the

majority of residents in Flat Top County reside in rural areas of the state (Roehrich-Patrick and Moreo 2016). This clinic is in the largest town in the county and home to over 6,500 individuals (U.S. Census Bureau 2010). As of 2017, this county houses an uninsured rate of thirteen percent (County Health Rankings and Roadmaps 2017). Situated in the mountains, Flat Top County boasts beautiful skyline views and several hiking trails. A largely undeveloped area, little industry exists in the county with only two major towns. Blackberry Spruce and Nash are the two major towns in the area and Nash is one of the oldest towns in Tennessee. Blackberry Spruce contains a population of approximately 6,000, making it the largest town within the county. Once an area with a bustling tobacco industry, the area now boasts limited available manufacturing positions. One individual described the economic status of the county as, "struggling" (Interview 12). The presence of multiple food pantries and this free clinic exhibit the economically struggling status of this county.

From Food to Health Care: Origins of the Clinic

Blackberry Spruce Free Clinic's first home was in the food pantry that opened over twenty-five years ago. It assists in meeting, "the needs of a lot of people, of low income people," as the director describes (Interview 12). Dorothy Golden, the director of the food pantry in Blackberry Spruce, admits that the county contains at least an additional two other pantries. In her early seventies, Dorothy is a native of Flat Top county and remained in the area most of her life. She explains many of the recipients who receive assistance: "A lot of them are older, elderly people who do not draw as much social security as they do today," (Interview 12). Families receive food boxes once a month that provide

supplemental food for at least a week. All the food provided through donations from local churches, a local community senior garden, and two grocery stores supporting over 350 families a month. Dorothy, a longtime volunteer with her husband and now director, recalls the clinic starting in the pantry. "They were in here with us and the back room was shared and they had two examining rooms back there," (Interview 12). Like the clinic, Dorothy and the volunteers at the food pantry attempt to address the needs in their community. The director explains:

> I try to fill this one need if I can help anybody in need that's what we do. Our need is, I see it growing and there's not a lot offered in Flat Top County. I don't feel like we have the means like the other counties do," (Interview 12).

In small, rural communities an individual faces potentially limited resources for various issues faced.

Clinic Operations

Diabetes Clinic

Diabetes is a staggering issue in the nation, in the Appalachian region, and in the state of Tennessee. The diabetes prevalence in the region is approximately twelve percent, higher than the national average of ten percent (ARC 2017). In 2016, America's Health Rankings listed the state of Tennessee as 45th out of the 50 states for overall health. Furthermore, residents in rural counties have a higher prevalence of diabetes than those in metropolitan areas (ARC 2017). There is a frequency of diabetes in Flat Top County due to obesity and poor diets. The medical director, who works at a local primary care office, describes this issue stating, "[we] see a lot of diabetes…. [For] some reason in our society an unhealthy diet [is] a lot cheaper than a healthy diet," (Interview 14). Dr. Jackson, the

medical director, and Dr. Cash place a great deal of emphasis on a patient's diet as being the contributing factor to developing diabetes. Dr. Jackson further explains:

> Most of our patients, like a Hispanic patient we saw last night, they're a little overweight and they eat tortillas with beans because it's cheap and that's the same with a lot of poor in our county. They can't afford salads and fruits and stuff like that, so they eat can food, bread and pasta, (Interview 14).

As Dr. Cash discusses, however, many of the individuals who enter the clinic need medical intervention for treatment of their complaints.

> They already experienced a lot of those end stage diseases of those; they have kidney failure, they've had a stroke, they've had a heart attack and they're living with the consequences that if I intervened, if I found a way to intervene with diet and exercise and healthy living and support it's too late to reverse anything, there already at this point where we're maintaining them, (Intervention 10).

Teaching the importance of diet and exercise must also accompany medication for an individual to have a prolonged life.

In attempting to address the issue of diabetes for the uninsured in this community, Blackberry Spruce Free Clinic hosts a diabetes clinic during Tuesday mornings. The diabetes clinic has two registered nurses acting as certified diabetes educators. An intricate part of the diabetes clinic appointment is education on diet. June, one of the diabetes educator nurses, explains:

> [the biggest health risk factor is] obesity since carbohydrates are the cheapest food source. When I'm teaching people about meal planning I always say as the first thing that I realize you have to eat what you have to eat, my job is to teach you how much of that you can eat so you can count carbs and keep your diabetes under control. If beans and potatoes and cornbread are what you have then that is what we have to work with. I would try to get you to throw in a piece of chicken or an egg or a piece of cheese or if it is soup beans throw in some greens," (Interview 16).

After a diabetes diagnosis at the evening clinic, the diabetes clinic sees these individuals. Patients receive care once a month for five dollars each visit, unless they are having

difficulty regulating their blood sugar levels. Appointments are scheduled in thirty-minute intervals from 10:00 a.m. to 3:30 p.m. Some appointments, such as those for newer patients, can last as long as an hour. On rare occasions, appointments last even longer. For example, the office manager also receives care at the clinic and her diabetes appointment once lasted over an hour. The inclusion of diabetes education attributes to the lengthy appointment times. However, these lengthier appointments can leave some patients waiting for thirty minutes or more for their scheduled appointment, like in a typical physician's office. Patients receive their prescriptions after each appointment. New patients often receive diabetes meters and strips to begin monitoring their blood glucose levels.

Diabetes Prescriptions

Several patients also receive brand name diabetes medication through patient assistance programs. Patient assistance programs provide medications to individuals unable to afford the medication. Through these programs an individual can apply to receive the prescription at no cost or at a reduced cost from the pharmaceutical company. The clinic receives delivered prescription medications, and patients pay a five-dollar processing fee to the clinic to obtain these medications. During my time at the clinic, there were several discussions about the process of applying for prescription assistance programs. Patients could have these prescriptions delivered to their door. However, the clinic receives the prescriptions and charge an in-house processing fee. The medical director explains the rationale behind this process:

> That started really when money was so tight that we were about ready to close. So, we thought that would help a little bit, and it is a minimal fee and plus people appreciate a service more if they must pay something for it. In most clinics patients pay a little bit just so they have a stake in it, and they don't. The problem with a lot

> of welfare programs is that you get a sense of entitlement. We don't get any money from the government, and people were upset that they can't get what they wanted but we weren't given any funding, so the government doesn't have any control. I think people have more stake and are more willing to follow the medical advice and take the medicine if they pay a little for it." (Interview 15).

Dr. Jackson's discussion of paying a fee for the service plays into the concept of moral hazard, which is a common term in health insurance policy discussions regarding payment for health care services acquired. Following Fletcher (2014), the clinic's fees to ensure patients take their care seriously is an example of moral hazard. While the purpose here is not to explicitly deter use of health care but to ensure patients "have a stake in it," the issue with this charge is that some individuals struggle with the additional expense. Taylor, the pharmacy technician, explains it thus: "Money [is an] issue, a lot of them feel like they have to pay the five dollars so they won't show up because they don't have the five dollars [for their appointment]," (Interview 11). Therefore, this additional fee can prevent marginalized patients from receiving care.

Another issue with prescription assistance programs medications is that several of them need to be stored in a refrigerator. During my time at the clinic, the refrigerator door was left open over a weekend leading to an early expiration date on all the stored prescriptions. Since many of these medications are on guidelines for when refills are available for reorder, this mistake left multiple patients of the clinic in jeopardy of being without their medication for several days. While at the clinic, patients would receive a part of another patient's medication to compensate for a shortage of their required amount. Patients rely on the medications the clinic provides or those they can afford to purchase over the counter. The pharmacy's supply at the clinic is impressive, as Dr. Cash explains:

> They [the clinic] have a lot of pharmacy, a good pharmacy. It has some problems, but they have quite a big supply and it surprises me the things they can give away. And I

> like that they have relationship with the in-town pharmacy so we can send someone over there to get a prescription if we don't carry it and it not cost them much or anything which is great." (Interview 10).

This relationship with another pharmacy means that patients may have access to prescriptions that are not in stock at the clinic pharmacy at no cost to the patient. June, a diabetes nurse with the clinic, explains that the pharmacy has provided a miracle for the clinic several times:

> Again, it is that assessment of how great is the need. God expects us to be wise stewards of what He gives us, and there have been many times we've needed a very costly medicine we've never had and suddenly, we go in and move a few pill bottles and find it. Or someone gave a physician a nebulizer machine with treatments and that night a guy came in having an asthma attack." (Interview 16).

The clinic attempts to provide various treatments to their patients through their available pharmacy. Limited funding is available to the clinic, but their extensive community of support assists them in providing access to various medication that might not be accessible otherwise.

Evening Clinic

While the day clinic provides care only for diabetes, the evening clinic operates like a regular primary care physician's office. The medical director, Dr. Jackson details providing care for, "heartburn, ulcers, hernias, and cancer," (Interview 15). According to the clinic's pharmacy technician:

> most of [the patients] are on just general blood pressure, cholesterol, thyroid, I mean that's what most of our patients take diabetic medications, blood pressure, cholesterol and thyroid medications and allergy," (Interview 11).

The clinic also treats patients suffering from chronic obstructive pulmonary disease (COPD), anxiety, depression and sleep apnea. Patients arrive at the earliest possible time,

pay five dollars, and sign in at 5:15 p.m. for the evening clinic. Physicians see patients in the order of arrival at the clinic. The providers usually include the medical director, Dr. Jackson, and one or two volunteering physicians or nurse practitioners. The clinic has approximately five individuals who volunteer at the clinic as providers, one nurse practitioner, three physicians, and the medical director. Volunteer nurses call back two to three patients at the start of the evening clinic to have their vitals taken and then place them in one of the three examination rooms to be seen by a provider. After seeing patients, the physician places the patients chart in the in the holder on the pharmacy's door so the volunteers in the pharmacy can assemble the patient's medications. Patients then visit the front desk to receive an appointment card, scheduling their next visit in either a monthly or a three-month basis. Patients further have the option of seeing a spiritual counselor or waiting for their medication in the waiting room. While some patients talk with a spiritual counselor, other patients sit outside of the clinic on the bench and talk to each other while smoking cigarettes and waiting for their medication. Once they have received their medications and have scheduled a day for their next routine appointment, patients are free to leave.

Patients have either monthly or seasonal appointments (every three months) based on their treatment regimen and the amount of medications received at the previous visit. Some of these issues patients face are the result of forgoing care in the past and the consequences of not having the health insurance required to receive routine check-ups or to maintain treatment. Faith, a patient in her fifties at the clinic, is disabled and unable to work due to her health but has been denied disability. Her health issues were related to a previous accident. She explains:

> Originally what started all this mess is I was in a very bad horseback riding accident and broke my ribs and punctured my lung and waited forty-eight hours to go to the hospital because I didn't have the money to go and then by that time I had pneumonia in both lungs and was in the hospital for fourteen days," (Interview 2).

Faith further explains why she waited to seek care:

> I couldn't afford it. I couldn't afford to go to the doctor. I couldn't afford the prescriptions. And then I wait until I was like on deaths door and wind up in the emergency room," (Interview 2).

Because she still cannot afford health care from a typical doctor's office, Faith relies on the free clinic to help her manage her condition. Several other patients also need the clinic to maintain the treatment of their diseases. However, since many do not have regular check-ups, diagnosing these chronic illnesses are often by chance. A long-time patient at the clinic explains how he was diagnosed with diabetes:

> When I found out I was a diabetic, I was at a health fair at a Baptist church. I took my daughter and she was little and we saw a lot of people so we stopped there. There was like a lot of inflatables for kids and we stopped there and they asked if I wanted to check my blood sugar. My glucose and everything was messed up. I knew I was feeling bad, but I try to be tough most of the time. I don't cry, I try to be real strong, but at that point I felt real tired and I didn't tell anybody but thank God I found out," (Interview 5).

By not having access to routine care, this patient's story could have been a dangerous reminder what happens when one does not have yearly examinations. He could have found out too late, and his continued lack of care might have resulted in vision problems, stroke, or neuropathy issues, all of which could affect his quality of life.

Many patients visit the clinic based on their need for a family physician and their inability to afford health insurance. Naomi, a longtime patient at the clinic who suffers from a gastrointestinal disease, explains she is uninsured because, "I don't have the financial means right now to pay for health insurance," though she previously had health insurance

through her employer before retiring (Interview 3). Dolly, a transplant patient at the clinic, also states her inability to afford insurance claiming,

> It is very unaffordable for me. My husband is now covered through his disability and social security, but I can't afford it myself now and prescription coverage for a transplant patient can run about 3,000 dollars a month just for the anti-rejection medications. I don't know what person could afford treatment, let alone prescriptions." (Interview 6).

Dolly owns a business in a nearby town and admits this affects her access to insurance stating,

> I can't afford [insurance]. I own my own business, and they think I make more money than I actually do. And a lot of times my husband's disability helps to pay for my store, because some months it's better than other months when it's just not there," (Interview 6).

Dolly's predicament of owning a store and having a husband enrolled in disability makes it difficult for her to receive her own insurance plan. As a small business owner, Dolly struggles to maintain a profit for her livelihood in addition to worrying over finding adequate health care for her health needs.

Hank and Georgie are a married couple in their early thirties. Hank recently began visiting the clinic for his anxiety and hypertension. Hank explains that their need for the clinic relates to the finances of affording insurance: "We never had any kind of insurance… [We] could never afford it. We [are] just a poor boy and a poor girl." (Interview 9). Though they are unable to afford their insurance, the couple has found innovative ways of procuring their care. Hank has suffered from anxiety since he was in his twenties, which he associates with his best friend's passing. Since his friend's death, Hank has been unable to work in the public sector and finds it difficult being in large crowds without suffering an anxiety attack. Hank explains that he had to cancel his visit to the clinic one evening after arriving and realizing the considerable number of individuals in the waiting room. Hank

previously worked for the government maintaining landscape throughout the county; he now works as a mechanic at their home. His wife, Georgie, is the assistant manager at a local diner in the area. She previously worked in a factory but was unable to receive benefits from either of these positions. She explained that her job with the factory was on contract basis that did not require insurance being provided. She also informed me that her job with the local diner would soon be offering health insurance however, has not yet installed this into their contracts. Georgie believed that though she may have access to health insurance soon through her job, did not believe that she would be able to afford the plans of coverage offered. The couple desires to start a family and receives counseling from the local hospital's obstetric physician through a financial assistance program. Hank, due to his work as a mechanic, has had several accidents resulting in the need for stitches. He states, "I've had so many stitches and everything we couldn't pay for that…I've used glue before." Georgie recommended the idea of "have[ing] to sew him up thread and needle, I guess. You do what you've got to do" (Interview 9). Georgie explains, "He's had to go for a lot of things, and even if I had insurance, I couldn't afford everything that he has to go for. Even with just the upgrade in my job, we're just breaking even." (Interview 9). Their lack of insurance has led to negligence in the care they have received. For example, Hank informed me he went to various emergency rooms over eighty times over the course of a year and a half before he received an ultrasound for his reoccurring abdominal pain, which turned out to be associated with gallbladder complications. He states, "Yeah, and she told them to do an ultrasound, and they did the ultrasound and they said you're having surgery tomorrow" (Interview 9). His wife explains that prior to the visit where he received an ultrasound, "they always said it's probably ulcers, stomach acid. I don't know how many times they

gave him stomach acid medicine," (Interview 9). The couple explained that though they could not afford the bill from the hospital, and have been unable to receive assistance from the hospital, they pay a small amount each month. Georgie explains,

> They won't help him with assistance, we've got a bill and we've asked them for any kind of help so I just pay them five dollars a month because they won't give you any kind of assistance" (Interview 9).

Hank also explains that since his surgery he has received no follow-up care. This lack of follow-up could have placed this patient at risk for infection or other such issues after his surgery. This follow-up routine is not the expected behavior for post-surgical patients and individuals with insurance would not be placed in such a risk. Such an atypical follow-up pattern leads to questioning the reliability of the health care system for uninsured individuals. Additionally, at the clinic, Hank explained some issues in his care stating, "they just ignored how extreme my anxiety was" (Interview 9), resulting in him having to continually wait in the crowded waiting room each month for his hypertension medication and to see a psychiatrist out of pocket for his anxiety medication. The clinic attempts to provide care to the citizens of Flat Top County. However, Hank's story shows the lack of acknowledgement or treatment of mental health problems that affect him and other people in this county. This lack of care could be the result of their limited time to spend with patients or be one of the missing resources this clinic cannot provide its patients. However, it may also reflect broader problems within the community that dismisses or undervalues mental health issues.

Patients appeared to be grateful for the care they receive, based on its affordability. However, several missed the intimacy with their original physician and did not feel as though the clinic was as thorough as they could be. Walker is a single father in his forties

who works as a mechanic. He was previously insured and had an affordable insurance plan prior to the Affordable Care Act, but he could no longer afford his insurance after the policy changes took place. He explains what he felt was missing in his care stating:

> They're really not treating everything. Right now they're just looking at my diabetes and my high blood pressure. I never get asked about anything else, whereas my old doctor would come in and sit down and ask about the overall picture. She would ask how family was, would attempt to figure out if I was under stress, why my blood pressure was up, you know that kind of stuff. That was when I had insurance though," (Interview 8).

Walker's experience of seeing a primary physician through his insurance coverage has provided him a comfortable experience of building a relationship with his provider. His experience at the free clinic however, does not mirror his previous history with this provider. The limited time availability for appointments and the high demand for care has made his experience at the free clinic to appear less holistic than his experience with his previous provider. This less holistic approach could result in a missing part in their care for the patients of this clinic.

Quality of Care

Patients were seen anywhere from ten minutes to an hour during the evening clinic. However, the clinic operates on rotating physicians. These physicians' different styles of interacting with patients could be causing tension between the patient and the physicians of the clinic. By not discussing lifestyle, a part of the patient's care is missing. The clinic addresses certain (but limited) medical needs. However, as the patients describe, the clinic does not provide complete care and is not a direct substitute for being able to visit a standard physician's office. This inability to provide holistic treatment is a quality of care issue that is a problem for the patients that could have broader implications on their health

and well-being. Walker also stated that since he had been seeing his previous primary physician for over a decade, "I felt more comfortable at my primary care doctors" (Interview 8). Wyatt also had similar thoughts about his care process. He commented:

> They kind of seem like last time I was there I had problems with my left knee and when I told them about it they said well when you come back if you're still having problems we'll look into it. I felt like I was just being put off because I was having a problem with the knee at that time and [had] to wait another month," (Interview 7).

Wyatt's wife also commented on her husband's care at the clinic remarking,

> The free clinic treats the symptoms with medication but they [do not] look or help for the underlying cause. Which could…shorten a life, you can treat high blood pressure with medication but if you don't find the underlying cause of it and do something alleviate it, your symptoms are only going to progressively get worse. So, I feel like the free clinic, they just treat the symptoms like if you have a cold you take Tylenol and they're treating his symptoms but they're not helping. They didn't suggest to us that sleep apnea could be the cause [for his high blood pressure]" (Interview 7).

Dr. Cash recognizes the inattention to patients that occurs in the clinic. The physician spoke of her experience as a provider in the clinic setting, stating:

> A lot of times I can't read the person that saw them before me [in the paper charts], and I'm sure they can't read mine because your rushing and your scribbling and there's no impetus except you own conscious to do a good note. And when the place is a disorganized messed, you kind of get to where, why I would try, I'll just write refill meds see you in four weeks. Instead of [asking] what is the status of their heart failure, when's the last time they had an echo…You're hopeless when you're there because, yes you can spend ten minutes writing a detailed chart or you can spend two and get home because nothing is going to change anyways and the patients quote unquote like their doctors there but is that important? They're not getting better. I'm glad they like me and they want to come see me because I'm not mean to them and I listen to their horrible problems, but I can't do anything for them and that makes me feel like a crap doctor. What am I going there for? Anyone can refill their meds or just don't refill them; you're just giving them out anyway. You don't need my prescription power" (Interview 10).

Dr. Cash acknowledges the inconsistency of care that is occurring through paper charts that are not well protected. Dr. Cash recognizes the difficulty of providing consistent care to address a patient's overall health, especially considering the lack of financial resources held

by the patients and the clinic. Dr. Cash previously discussed their reason for working at the clinic, stating that it was their attempt to remember why they became involved in medicine. However, beyond the clinic's disorganization and lack of resources, Dr. Cash reveals the cynical attitude and feeling of hopelessness that even the health care providers' experience. While fatalism is too often ascribed to noncompliant patients, we see through this clinic the discouragement in the doctor's failure to follow charting protocol due to a feeling of hopelessness and time constraints. Here we see the difficulty in assisting patients' overall medical needs when they have little monetary means to afford medical care. The Blackberry Spruce Free Clinic is providing individuals with a basic maintenance and follow-up discussion and medication for their certain diagnosed diseases. However, the clinic fails to provide holistic or complete patient care and is often unable to secure specialty care for acute complaints. Furthermore, the disorganization at the clinic through the multiple providers rotating each week could be interfering with a patient's health improving. The organization of the evening clinic could be a barrier for providing adequate care to the patients at the free clinic, along with the need for an electronic medical record to better track their progress.

Specialty Care

Providers struggle with keeping a positive outlook when there are limited resources to provide additional care to patients. An issue for providers is referrals, since many specialists refuse to accept individuals without insurance unless they can provide approximately a hundred dollars up front.

> We can usually call around and find someone to do what we need, [but they're] not getting everything they need. Sometimes I feel like we have to make sacrifices because we are the free clinic. So sometimes with their blood work we may not

> [order] all the bloodwork that we'd like to do or we do just the bare minimum… Just access to what they need and kind of with the medicines maybe not having the best medicines, but being responsible for their own health I think is a challenge for some of them," Taylor (Interview 11).

The clinic places a lot of emphasis on the patients' staying in control of their health and health plan though the clinic is unable to provide the maximum availability of care to these individuals. Dolly, a woman who is a patient in the evening clinic, had transplant surgery prior to losing her insurance with the enactment of the Affordable Care Act, a bill which attempted to provide health insurance coverage to all citizens (Interview 6). Dolly is one of the few who can see her specialists without a charge, even after losing her insurance. A business owner in nearby Nash, Dolly struggles with obtaining health insurance. As a transplant patient, Dolly explains her relationship with her specialist:

> I've been a patient of his since 2005. I've been at the clinic for about three to four years, and he has been seeing me free of charge for three to four years. And actually I had cancelled like one or two of my appointments with him because I had lost my insurance, and then I had gotten sick and started running a fever, which is a first sign of rejection so I was like okay I have to break down and go even if it will cost me a hundred dollars to see the doctor and then when I got in there he asked me where I had been going to the doctor and I told him and he said since you're going to that clinic well then I'm not going to charge you anything but do no miss an appointment with me. I just wanted to hug him. That was a load off me (Interview 6).

Dolly's situation is unique compared to the other patients at the clinic. Her physician's willingness to see her without charge offers her access to specialty care that she needs to maintain her health with her transplant that the clinic cannot provide. The clinic provides access to pulmonologists, dermatologists, and optometrists through various grants. However, many patients are unable to receive referral to specialists like, gastrologist and

orthopedics. Dr. Jackson, the medical director of the clinic, describes the process of getting such services for the clinic:

> a lot of time I try to acquire providers without too much luck, but usually I talk to people personally and a lot of times people hear about the clinic and are interested in getting involved…he [the dermatologist] just heard about the clinic and was interested (Interview 15).

However, Dr. Cash acknowledges the need for further specialists, explaining:

> What if I could treat their pain in some appropriate way [since the clinic does not provide narcotics]? What if I could have an orthopedist come and do knee injections so people could work their construction jobs instead of not working any job at all. That would be cool, but I've never seen an orthopedist darken that door. And when we try to send them to anybody in the area, they tell them no they're not going to see a free clinic patient… I'm trusting the front office staff to make these liaisons for me (Interview 10).

Because the clinic cannot provide total care, patients may not be able to improve their health status. If a patient is continuously out of work, they will never be able to afford access to medical insurance. Though the clinic can provide patients with free lab work, through an arrangement with a local laboratory, and x-rays at the medical director's private office, they do not have access to specialty providers, such as orthopedists. This lack of specialty providers impedes patient's overall health and well-being, and clearly demonstrates one of the many holes in health care offered at this clinic and in the access to care for uninsured patients.

Medication Access

Taylor Wynette is the pharmacy technician employed by the clinic and has lived in Flat Top County all her life. Taylor began volunteering at the clinic several years ago after seeing a post advertising the clinic's need for volunteers. She was hired as the clinic's main

pharmacy technician a year later. Taylor describes the financial problems facing the pharmacy's ability to provide services:

> We order drugs, but we don't always have what would be preferred, we usually have a second-best alternative but we have to be careful what we order. We don't necessarily have the best medicine out there, but we have the old trusties because they're cheap and know they work. We don't try patients on weird things, and we use things we know work and don't cost a fortune, but sometimes we don't have something we need like test strips or sometimes we don't have pen needles. I mean we have three boxes now so we will be out soon, if we don't have any then we just don't have any…money is our biggest obstacle. There is no generic insulin, they're all brand name. That's costly, and if we can't get them on a patient assistance program then we have to hunt it, samples or charge it. Sometimes I don't feel like the patients get the best care that they need or the best medication that they need just because of money. Every now and then there is some type of oversight, in the medications prescribed (Interview 11).

Taylor also explains educational deficiencies in the clinic's pharmacy:

> I'm not a pharmacist so education, I have a doctor and two nurses to rely on and I have a lot of friends who I can call but just, I can only use the knowledge that I have access to sometimes I have to look things up. I've been doing it long enough to see interactions or duplication of therapy (Interview 11).

Taylor's candor on this issue is important because this issue is a major problem in the pharmacy service of the clinic. There is a lack of quality control in the pharmacy, since there is no licensed pharmacist on site at the clinic. Taylor is a trained pharmacy technician; however, she usually has access to a pharmacist who can assist with any complications or issues that occur. Additionally, as Taylor discussed her lack of technology access at the clinic makes it difficult when compared to the availability of computer systems she has at her position at a large pharmacy. This means that the clinic pharmacy does not have the same ability to identify and avoid a complication between two prescriptions. Though Taylor performed competently during my time at the clinic, other individuals who volunteered in the pharmacy during the night clinic often did not know what each medication was supposed to treat or possess awareness of potential

complications between two medications. Additionally, volunteers would not always acknowledge the change in dosage in a patient's prescription, which could lead to a complications or failure of the drug to perform as needed.

Spiritual Counseling

When asked what the clinic does well, the medical director's first comment was about the spiritual counseling, which he describes as his favorite job in the clinic. Utilized as a service provided by the clinic to speak and pray with an individual about certain issues occurring in your life at the time. Dr. Jackson describes the spiritual counselors' role thus:

> It's to meet their spiritual needs and one of the important things is to find their relationship with Jesus, if they've been to church if they have accepted Jesus as their savior. Besides that, we ask them if there is anything we can pray with them about. In spiritual counseling sometimes, people unburden something that they haven't' told the doctors. The main purpose is praying and witnessing to patients and we don't force our faith on anybody because Jesus didn't do that and we have had people who did not want to talk to the spiritual counselor and that's fine, we have to ask permission before we witness. My wife will ask where they are going when they die and if they would like to know then she will show them the verses and stuff. That's the only thing that is going to make a difference in people's life, eternity and we all know the benefit besides Jesus is being in community with other believers who will support and pray for you. A lot of people don't have that and a lot of them like because there is no one else to talk to who cares about them like that and who will pray with them," (Interview 15).

Though some see it as an opportunity to simply listen to another's problems, certain spiritual counselors are known for being aggressive about their perspective of Christian faith and have made some patients uncomfortable. Wyatt is a patient at the clinic and a practicing Jehovah's Witness; he speaks of his experience with the Christian counseling stating:

> There was one time I went there and somehow, I ended up sitting and talking to somebody and I think he asked me do I believe in Jesus and I said yeah and somehow it came to the belief of hell fires and I said I don't exactly believe that and

> from that point on then he kind of pounded to me that if you don't believe this then you're going to burn and this and that (Interview 7).

Dr. Cash explained that the spiritual counseling is controversial based on its denominationally focused discussions and an aspect that should not be a mandatory component of the care. This physician further describes a discomfort with the current managing of the spiritual counseling aspect of the clinic. Dr. Cash states:

> [The clinic] would need to lose the faith based counseling, if it were me remaking it, I wouldn't have that part of it there as a semi-mandatory part of it. Sometimes I think it is actually mandatory, you know the way certain people present it. I think counseling would be an absolute part of it, but it's not a now you're going to come over here and pray because you got free meds. That seems like a quid pro quo kind of thing, and I don't like that. And 9 times out of 10, and maybe it's my attitude and how I present it, but most patients that I see refuse it now. I'm probably swaying them, because I say you can go wait in the waiting room or you can go pray with the spiritual counselor, and I don't care which one you do. And I don't think that's what Dr. Jackson does. I think it's more now you're going to go over here and pray (Interview 10).

Counseling is a key aspect of an individual's well-being. Providing a counseling aspect is important to encompassing total care in a free clinic. However, the faith based aspect of this counseling could be deterring individuals from receiving this aspect of their care. Though spiritual counseling could potentially be comforting to patients, if used in an uncaring method as exhibited above, it could be harmful if it discourages patients from returning to the clinic or from seeking mental health care.

Currently, the clinic has no access to mental health services. This spiritual component of counseling is instead an opportunity to determine the "saved" standing of a patient. While one spiritual counselor saw it as an opportunity to allow patients to discuss their burdens, the majority of counselors were interested in the patient's spiritual walk. This aspect of determining one's status as a Christian could be correlated with determining a patient's worthiness of care through this free health care source. As Katz discusses the

worthiness between the deserving and the undeserving poor, this concept of a patient's spiritual position being discussed openly at a clinic could be a classifier of worthiness for care (1989). Keefe's research portrays the current issue behind limited mental health avenues as "mountain people" observing mental illness symptoms as being a component of spiritual weakness rather than a sign of a possible disease (Casey 2016). Spiritual counseling through this clinic is not a substitute for mental health treatment.

The medical director's point of view that spiritual counseling is the best quality of the clinic causes concerns about the standard of medical care provided to patients. As a free medical clinic, the first step to be successful should be considering how to provide the most complete care as possible rather than simply attempting to prophesize one's belief on the patients. A Christian aspect as a motivator to complete the work occurring at the clinic is important but should not be a mandatory aspect of receiving care simply because this is their only access to care.

Assessing the Clinic

When analyzing the clinic, the providers and staff of the clinic viewed the needs of the clinic as externally focused on services the clinic lacks. Several mentioned the need for dental volunteers to provide for their patients. The needs listed also included donations, specialty care, and pharmacy volunteers. An issue that was often discussed at the clinic was the long waiting period which occurs for an appointment and for a patient to receive their medications. Dolly represents the sentiment of many of their patients stating, ""I'm satisfied. I'm just grateful that they're here, and I do whatever I can to make sure I'm here when I need to be" (Interview 6). However, even some of the physicians note the issue of

the long waiting period. Dr. Cash details the sentiment of the need for structured appointments as a minor change in the clinic, explaining:

> The place is so unorganized, none of these changes can go into effect at all without an organized chartering system, transparency by the staff, structured appointments. I don't know why we don't make appointments. I mean I come there on a consistent basis. You know what hours I will be there, I should know when I get there how many patients I'm going to see. I don't know why it's a big guess. Some days I'll go in there and there's five, and somedays I'll go and there will be 25 and that's overwhelming. And it seems they go well come in, come in. I understand that. I want to help as many people as possible, but everyone who works there as a provider was at work all day. I would like to know what to expect, and the patients should be treated respectfully enough to say your appointment is at 6:15, the doctor will be here at 6:15. They're just sitting there for hours. Why? I don't get it. They require them to come early, right? Why not just assign them an appointment time when they get there, it's arbitrary anyways? You'll be seen at 7:30, if things go early she may see you sooner but this is your appointment time. I don't get it (Interview 10).

June however, explains the rationale behind this clinic structure.

> I do know at night time they do not like to come and sit here and wait. They have complained about that multiple times in the past. Our push back on that is that anyone with insurance who goes to the doctor waits 20 to 30 minutes to be seen by the doctor yourself, you get a prescription and then drop it off at the pharmacy where you wait 45 minutes to an hour unless it has been the next day to get it all and of that is combined into 2.5 to 3-4 hours versus maybe 1 hour and 45 minutes you wait here maximum time. So, but they haven't had health insurance so they don't know the health end of the side (Interview 16).

The providers at the clinic have various viewpoints on the clinic's appointment. However, the most important question to consider is which of these options is most respectful of their patients' time. The belief that the inconsistency of appointment times is acceptable due to a lack of experience at a traditional physician's office is inconsistent with the patients' view. Many of the patients I interviewed had previously been insured at some point. The provider assuming that a wait is acceptable simply because of their uninsured status is disrespectful to the patients who attempt to receive care through this available and affordable source. A long appointment wait could interfere with the patients' time

spent with family or effect the hours one can work at their job. The pharmacy technician would typically prepare the routine night patients medication during the day clinic to prevent a long wait in the pharmacy. If changes such as filling their medications before and scheduling an appointment when they come in were made at the clinic, there could be a further increase in patient satisfaction and efficiency in overall clinic services. These few changes could better organize the clinic and further reinforce clinic's concern about the patients' well-being. One man who came into the clinic was frustrated because he had driven almost three hours to make his monthly appointment. However, he had been provided with three months' worth of medication during his last visit, making this monthly appointment unnecessary. Better communication and procedures could prevent miscommunication and show further regard to patients of the clinics concern for their health and respect for their time and other obligations. Individuals should not have an inconsiderate wait for the appointment simply because they are uninsured. By providing an appointment time, the patients can experience a typical appointment model which could improve their overall experience with the clinic.

Clinic Sustainability

Health insurance does not appear to have become more accessible to patients who are treated at the Blackberry Spruce Free Clinic. Due to the present unrest in the nation as health care policy debates occurs, a solution does not appear to be on the horizon. The sustainability of the Blackberry Spruce Free Clinic is also unknown, as acknowledged by Dr. Cash. The physician explains the need for a

> Top down review of who does what with written job descriptions, hours they work and what is expected of them. That could also give us an idea of what gaps need to

> be filled in staffing because I don't even know…I don't know if the clinic will make it, I really don't. That requires a lot of time and someone really being retentive about did this happen, did that happen. Nobody is doing that right now that I know of (Interview 10).

As my research encompasses an overview of my observations and experiences at the clinic and the inclusion of their patients' stories, this could be a first step into understanding the discrepancies of the clinic. When I discussed the sustainability of the clinic with the medical director, Dr. Jackson, he responded:

> I don't really know, it's kind of all in God's hands and we will just have to see. Eventually we will have to find someone else to be medical director…It would be nice if we were a lot more financially stable now than we have been, but it would be good to get the clinic on a good financial footing with more reliable sources of support and fundraisers and whatever so we don't have to always worry about money or running out of money (Interview 15).

Overall, the clinic has no sustainability plan for ensuring its doors will remain open in the future for its patients and the community, though the continued need for access to free medical care is apparent.

Conclusion

The Blackberry Spruce Free Clinic provides care to the uninsured population of Flat Top County, Tennessee. This clinic provides thorough diabetes education and treatment through its diabetes clinic. However, care of other issues is often lacking because it is unavailable (e.g. specialty care) or seemingly unacknowledged (mental health). Some patients, while thankful for the care they were receiving, felt as though the quality was not the same as at other doctor's offices and was not fully including all aspects of their health. Mental health acknowledgement appeared to be lacking, and issues such as knee pain seemed too often be ignored, according to patients (Interview 7; Interview 9). Additionally,

the lack of comprehensive, quality health care provided to the patients at the free clinic could be resulting in the inability to work, keeping patients in the position of remaining sick and unable to work (in some cases) to better their economic situation.

Despite these concerns, the clinic does have strong qualities. The clinic offers access to some types of health care, the management of certain chronic diseases (hypertension and diabetes) and provides access to some prescription medication. This does not completely compensate for other concerning issues, including the organization of the pharmacy, lack of trained pharmacists, and large reliance on volunteers in the pharmacy with no formal pharmaceutical training. The clinic's spiritual counseling is also a controversial offering with patients of the clinic, occasionally making some of them uncomfortable.

Uninsured individuals usually have access health care through free clinics, such as the Blackberry Spruce Free Clinic. However, their uninsured status also places them at risk of receiving care that is less holistic and, in some instances, lesser quality when compared to traditional pay-for-service offices and hospital settings. This was apparent in Hank's story. Free clinics allow patients to avoid forgoing some health care needs, which allows for the opportunity to maintain health or prevent further deterioration of specific conditions. Because the Blackberry Spruce Free Clinic has no sustainability plan to remain open for its community, the continues access to care for these patients is in jeopardy, as it is the only source of health care for many community members. The Affordable Care Act, enacted in 2010, brought about change to the health insurance policy and impacted patients and providers in both positive and negative ways. Any change to the Affordable Care Act could

greatly affect the recently insured and the Blackberry Spruce Free Clinic. The next chapter will more directly address health insurance issues among the clinic patients.

CHAPTER 4

UNDERSTANDING HEALTH CARE REFORM IN A FREE CLINIC

The Patient Protection and Affordable Care Act, henceforth referred to as the Affordable Care Act (ACA), was introduced in 2010, drawing America into a new era of health care through multiple reform measures and an online insurance marketplace. Health care access possesses the ability to pay for this service and to maintain insurance that opens the gate to receiving care. However, cost of health insurance is a major complication (Vladeck 2008). The Affordable Care Act, popularly called Obamacare, was an attempt to provide affordable health care and increase health insurance coverage to all American citizens. However, not all individuals received insurance or access to health care through this bill and must find alternatives, such as the Blackberry Spruce Clinic, to meet health care needs.

Patients' Insurance History

Health care access in the U.S. is largely dependent upon maintaining health insurance, since it is a measure of one's ability to pay for services, (Fletcher 2017). Free clinics are an important aspect of the health care system because they provide needed health care, have strong connections within their communities, and smaller clinics are viewed positively by their patients based on the care received (Watson 2011; Becker 2004). There are several reasons why individuals seek care from a free clinic whether they are uninsured, or unable to pay for health care which can increase the chance of poor

health outcomes (Darnell 2010). Ten percent of the working-age uninsured receive a range of care through a free clinic now (Darnell 2010).

Walker is a single father who works as a mechanic in the county of Flat Top. Walker previously had health insurance through his employment. However, with the enactment of the Affordable Care Act, he had to drop his insurance plan due to the high premium. Until this spike in his premium for insurance, Walker had maintained insurance since he was discharged from the military. He discusses his attempt at receiving care as an uninsured individual prior to utilizing a free clinic, stating:

> For the most part I'm doing this right now [using the clinic to overcome health barriers] but before it was just all out of pocket. I'll be honest, before Obamacare came around my insurance was 25 dollars a week for health, dental and vision with Blue Cross and Blue Shield and as soon as Obamacare went into effect I was screwed. My insurance just sky rocketed, everybody's did. It was the worst thing that ever happened… The price just got so high [from the marketplace] I couldn't afford it anymore. I was paying out of pocket for four years. Doctor's visits were anywhere from 75 to 125 dollars, my medicine was just unreal, that's why I didn't take a lot of it. I mean just too expensive to get so just kind of done with that. [Doctors] just told me to go to the marketplace all the time and then if you don't have insurance and you go to file your taxes and they charge you for not having it, so you can't afford insurance but then fine you for not having it. I went to my tax guy and I told him I'll pay the fine because it's the same price as one month of insurance. I'll do without it and pay the fine (Interview 8).

The high price of a monthly premium was a barrier for Walker to maintain health insurance for himself, and he had further difficulty when considering how to ensure his young son maintained his own health insurance through Medicaid stating, "He comes first. If he needs something, I'll do without" (Interview 8). Individuals who remained uninsured after the Affordable Care Act often blame the inability to afford health insurance premiums (McGeehan et al. 2017). Though the care provided at the Blackberry Spruce Free Clinic is affordable for Walker, there is a discrepancy in quality, and the hours of operation can

sometimes be challenging for him to fit in to his schedule. Since he is a diabetic, he must schedule his diabetes appointments during the clinics day clinic that overlaps into his work time. This interruption affects both his relationship with his employer and his income, since he must come to the diabetes clinic once a month for routine follow-up. For his six-month follow-up appointments to the evening clinic, Walker explains that the wait time during the evening clinic results in the need to pay for a caregiver for his young son during that time or having his son come to the appointment with him to wait until he receives care. He remarks, "I've been here at 8:30 at night," (Interview 8). Walker, having experience with primary care physicians, questions the quality of his health care received at the clinic stating, "Down here [at the clinic] it's just here's you medicine, what's your sugar level and go" (Interview 8). He addresses his need for the partial care he obtains remarking, "I'm a hundred percent satisfied with everything they've done for me" (Interview 8). Walker has explored the health care marketplace and is unable to afford insurance premiums or self-pay medical services. Because of this Walker understands the importance of the minimal care this clinic provides him.

Dolly was another individual who was insured prior to the enactment of the Affordable Care Act. She explains:

> When they revamped Medicaid was when I lost it [insurance]. I don't really understand why I lost mine, but I did. I'm sure they gave me a reason, but I had no idea what the quotes meant [jargon]. They told me if I got back on organ failure, if I lose my organ, they will pick me back up. Isn't that nice? I don't know much about Obamacare other than I got cut off, but that's about all I know about it" (Interview 6).

As a transplant patient, maintaining health care is pertinent for Dolly to ensure she does not reject the organ or return to organ failure. For unknown reasons to the patient, Dolly

lost her insurance and her health care became jeopardized[2]. Faith is also a patient at the clinic who previously maintained health insurance. She explains:

> I have had health insurance when I worked for a hospital in Florida as a phlebotomist. That was twenty years ago, I was in my thirties…I don't have the financial resources to have health insurance [now]. I'm fighting for my disability (Interview 2).

For individuals who remain uninsured, this leads to a postponement of care or partial care received through safety net clinics. For seriously ill patients, like Dolly and Faith, this leaves them vulnerable as they live with serious health issues.

Lucille is a patient at the clinic in need of affordable, consistent care. She previously maintained work insurance through her job with her mother but remarks, "It's been a long time ago, but like I said I haven't been sick until now so I really didn't press on the issue," (Interview 3). She was previously self-paying to see physicians but states:

> It's a hundred and fifty dollars [to see the doctor], and I can't go there. I would have never known about this place if it weren't for [the physician she was seeing]. She set me up over here [at the clinic] … [I use the clinic because] I can't afford over at my regular doctor and I will not run to the emergency room (Interview 3).

The uninsured often utilize emergency rooms as a source of health care. However this method of care can also be pricey. Clinics have been shown to decrease the use of emergency room visits though they are often not seen as being a sufficient replacement for primary care (Sessions et al. 2017). These clinics are an important source of care for those who remain uninsured or underinsured. Naomi is a patient at the clinic who previously had

[2] For transplants that involve an organ that is not life-threatening, there is limited time period where the patient receives Medicare coverage. This discrepancy in coverage leaves patients responsible for covering their anti-rejection medications, which are taken every day after the transplant, once this initial period ends. Without these anti-rejection medications, a patient could begin to show signs of rejection, such as a fever like Dolly experienced. Limited insurance coverage with a transplant places the patient in further harm once unenrolled in Medicare if the patient is unable to afford insurance coverage to maintain their post-transplant regimen.

insurance through her work but was unable to access any local physicians with the plan. She discusses this issue stating, "They said I had insurance but never could get an appointment with anybody. They didn't accept my insurance. So, I came here," (Interview 4). Naomi further explains that she had to unenroll in her insurance program due to the expense. She explains:

> I'm diabetic. I got my diabetes under control. Got a decent job and couldn't afford my deductible and I had a nephew who needed help going to college. So, it was between my health and his college and it was his college (Interview 4).

Naomi is now a retiree who is uninsured and explains her health insurance status, stating: "I don't have insurance. I can't afford it on my retirement" (Interview 4). Wyatt was another patient at the clinic who had a similar experience of being unable to access care through his work insurance. Wyatt's wife explains his insurance plan remarking:

> His company offers insurance and he signed up for it, but it payed for only one doctor's visit a year with an in-network doctor which was not in this area. The closest were two hours away, and it would not cover follow-up. You only got one well visit a year and it was constantly 26 dollars a week. They have another plan which he can apply to in November however; it's going to take about a third of his paycheck just for insurance for him. They give a list of ten doctors but every doctor we called said they would no longer work with them (Interview 7).

Though Wyatt can enroll in an insurance plan, he will still find barriers in accessing health care. Importantly, Wyatt is an example of an insured person not having health care access because the local doctors did not accept the plan his employer offered. Indeed, this correlates to Fletcher's (2014) findings, where having health insurance is only part of the process for accessing quality, affordable health care. Clearly, people can have insurance and be unable to access the health care system.

Pat, a patient at the clinic since 2006, works for a local small construction group and is not offered the opportunity to buy health insurance though his work. As a diabetic

though, he needs access to medication and health care to keep his diabetes under control. Pat explains, "I try to live healthy, but I can't avoid the diabetes because it's in the family. So, I try to just come here for my medicine and follow their instructions about eating habits" (Interview 5). However, since he does not have health insurance, Pat has limited understanding of the Affordable Care Act explaining, "I know absolutely nothing [about Obamacare]" (Interview 5). Patients at the free clinic had differing experiences with attempting to maintain and receive health insurance. As patients at a free clinic, these individuals display the demand for affordable health insurance and accessible care.

Defining the Affordable Care Act

The Patient Protection and Affordable Care Act, also referred to as the Affordable Care Act and popularly termed Obamacare, attempted to guarantee coverage to all individuals including those with pre-existing conditions and individually shared responsibility provision (Kaiser Family Foundation). This concept of individually shared responsibility encouraged all individuals to enroll in a health insurance plan and enforced a tax penalty on those without coverage. The idea of having health insurance is a key factor into being able to obtain health care, and this is a founding concept used to formulate the Affordable Care Act. Having health care equates to having health insurance however, obtaining insurance does not guarantee care to some individuals. Wyatt has been a patient at the clinic for approximately a year and at one point left the clinic to enroll in his work's offered insurance. Once enrolled in this insurance though, Wyatt found difficulty accessing care with a local physician since none accepted his insurance type. Wyatt's wife explains the health care situation stating, "I look at it as almost a discrimination [in access] because

of no health insurance vs. health insurance" (Interview 7). Wyatt has attempted multiple ways of navigating health care access, including utilizing the Blackberry Spruce Free Clinic and trying to maintain insurance. Wyatt has difficulty accessing health care coverage because his wife has insurance through her deceased husband's military career. She explains her desire for Wyatt to receive care for his health stating,

> I've thought how can I go to my doctor and say I need more blood pressure pills to be able to help treat him, this was before he was going to the clinic. I'd actually thought of ways to do that, but then the medication that's right for me might not be right for him. I've never done that but the thought was there, I have to get him some care" (Interview 7).

Marriage is often a means for individuals to receive health insurance coverage for themselves by accessing their spouses' insurance plan. However, both Wyatt and Dolly have spouses with separate insurance policies leaving them in need of individual health insurance plans. Wyatt has a history of not having access to care explaining:

> Occasionally [I] qualified for Medicaid…There was a lot of times I ended up doing without medication. I guess that's how I ended up getting Medicaid at times, I'd get into a situation where I'd end up in the hospital and somehow that would qualify me because I didn't have my medication and ended up in the hospital. Then I'd be on medication for a while and they'd be like okay you're okay now so you don't qualify anymore, then [I'd] lose my medication [and insurance] (Interview 7).

Wyatt has a personal understanding of the consequences of forgoing care based on the unexpected deaths of his late wife and his daughter who both passed away due to complications with Diabetes Mellitus Type 1. Furthermore, Wyatt attempted to receive insurance through the marketplace after the enactment of the Affordable Care Act. He explains this attempt stating:

> I remember the first year when they said if you don't have health insurance you'll be penalized. I had tried to get care, I went through all kinds of appointments until they reviewed my income and they said that I don't make enough to qualify to get anything so your exempt from the penalization (Interview 7).

This lack of access with insurance resulted in the patient giving up his insurance to remain uninsured. However, Wyatt explained that after dropping his insurance he struggled receiving care at the free clinic again, since he had informed them that he was maintaining insurance now. He had to wait to be seen back at the clinic and was almost out of his medications before his return appointment.

The Affordable Care Act was an attempt to reframe the relationship between individuals and the health care system (Rosenbaum 2011). This policy attempted to set federal standards for health insurance coverage and guarantee insurance for all, including those with pre-existing conditions (Rosenbaum 2011; Kaiser Family Foundation). The expanded health coverage through the Affordable Care Act overall improved population level health outcomes and reduced the presence of the uninsured in emergency departments, since these individuals could now access primary care physicians (McGeehan et al. 2017). The addition of this policy also included the coverage of preventative services, acknowledging the importance of public health initiatives and reduced the financial burden of the uninsured on the health care system (Rosenbaum 2011; McGeehan et al. 2017).

The Affordable Care Act increased peoples' opportunity to obtain insurance through: expanding Medicaid eligibility, creating insurance exchanges, subsidizing premiums, and requiring minimum insurance coverage (Sessions et al. 2017). States were offered the opportunity to expand Medicaid for low-income individuals and were incentivized to expand their Medicaid coverage (Rosenbaum 2011; McGeehan et al. 2017). All states were incentivized by covering costs for newly eligible Medicaid recipients by federal spending up until 2016 (McGeehan et al. 2017). By 2014, twenty-seven states and Washington D.C. had implemented Medicaid expansion, and today thirty-two of the fifty

states have expanded their Medicaid coverage (Swan and Foley 2016; McGeehan et al. 2017). Nationwide, many new insurance enrollments in states that expanded their Medicaid were through new Medicaid accounts (McGeehan et al. 2017). In states that expanded their Medicaid coverage, there was a forty percent decrease in visits of uninsured to free clinics in comparison to non-expansion states with a sixteen percent decrease (Sessions et al. 2017). Twenty million people received medical insurance through the Affordable Care Act, however as a bill that was promoted as providing all with health insurance, those who remain uninsured have been left wondering why this promise was not achieved (Sessions et al. 2017). The lack of Medicaid expansion in many Appalachian states including Tennessee, left many individuals without affordable insurance because of high premiums once the Affordable Care Act was placed into effect. This is clearly apparent, as revealed in the stories of patients at Blackberry Spruce Clinic. If the expansion for Medicaid had occurred in the state of Tennessee, these individuals might be able to access more sufficient care if the state had expanded Medicaid coverage. This lack of expansion appears to be a primary reason why these patients continue to seek care at a free clinic and the continued need for affordable care through a free clinic.

The Affordable Care Act and the Clinic

The Blackberry Spruce Free Clinic was established to care for the low income and uninsured in the Flat Top county area. Established by the lead physician, Dr. Jackson, the clinic attempts to address the county's present financial needs of the patients to guarantee care to those who are low income (Interview 1). As the clinic assistant, Clementine, established, when discussing the need for free health care in this community, "of course

these days a lot of people are uninsured" (Interview 1). These individuals who utilize such safety net clinics are typically uninsured or underinsured, and though millions of Americans became insured through this bill, there is still a present need for free clinics for those without insurance and unable to access other health facilities. As of 2010, in the U.S. there were approximately 1200 free clinics providing more than 3 million medical visits to uninsured individuals (Swan and Foley 2016).

Free clinics remain overlooked when considering the United States health care system, since they do not receive government reimbursement, are operated by volunteers, and serve normally exclusively individuals without insurance (Swan and Foley 2016). Free clinics, which are typically listed as non-profits, provide services for little or no cost to the patients, which differentiates them from Federally Qualified Health Centers (FQHC). These FQHCs offer sliding-scale fees for services to those who are uninsured, receive proceeds from federal funds, bill services to Medicare and Medicaid, and offer a sliding-scale fee to those who are uninsured (Swan and Foley 2016). Free clinics have been identified as providing care to over 1.8 million individuals a year in the United States alone (Sessions et al. 2017).

The Affordable Care Act had limited discussion of free clinics but did introduce medical malpractice insurance coverage to include the non-medical personnel, such as the governing board of directors, employees, or contractors at a free clinic through the Federal Tort Claims Act (Patient Protection and Affordable Care Act 2010). During my time at the clinic and multiple discussions with the staff and volunteers, there was no discussion of the effects of this aspect of the health care reform bill. This aspect of the bill would assist in liability coverage for retired physicians, who often assist at free clinics (Swan and Foley

2016). Since the medical director, Dr. Jackson, of the Blackberry Spruce Free Clinic is approaching retirement, it is concerning that this clinic may not have applied for coverage under the Federal Tort Claims Act. Recently, a study of North Carolina free clinics found that only half of the medical clinic directors in the state knew of the expanded medical malpractice insurance (Swan and Foley 2016). Based on the lack of discussion with the staff and volunteers at the Blackberry Spruce Free Clinic, it can be assumed that this was not put into effect at this clinic and that the staff may not have known of this possibility of protection for their clinic.

The Affordable Care Act had a little impact on the Blackberry Spruce Free Clinic, excluding the possibility of increased patient enrollment. In a study observing North Carolina clinics, a similar pattern of increased number of patients was reported for the past three years (Swan and Foley 2016). June, a nurse who provides diabetes education at the clinic, explains the impact of the Affordable Care Act on the clinic and its patients stating,

> Well, we saw a few more patients when the ACA came through because patients could not afford the high deductibles. Three to five to seven thousand-dollar deductibles and the high premiums. They decided they would take a hit on their income tax rather than pay for the insurance, personal choice. They knew they would take a hit and made the decision not to buy the insurance (Interview 16).

Certain patients at the Blackberry Spruce Free Clinic, such as Walker decided to make this decision of paying the penalty rather than paying monthly for insurance because the insurance was unaffordable for him. The office manager, Iris, further explained the demand on the clinic since the enactment of the Affordable Care Act:

> Yes, by far. When I started here we had our patient number was much lower than it is right now, and now it seems like it's doubled. Matter of fact I've cut off eligibility until December. As it is right now, we were seeing 25-30 patients in the night clinic and we were here till 10 at night, and it's made a notable difference (Interview 13).

The clinic can only provide routine thorough care to a limited number of individuals at the community due to only being opened one night a week for their primary care evening clinic. There is still a prominent number of uninsured individuals in this community based on the discussion from patients, volunteers, and staff of this clinic. Some patients could not afford their insurance or the tax penalty, which leads to more complications with receiving and affording access to care.

The perception of the Affordable Care Act among uninsured individuals varies based on their insurance status prior to the policy enactment and their experience with the bill. Patricia is a long-standing patient at the clinic and explains that her experience with the Affordable Care Act stems from helping a friend receive insurance through the marketplace. She explains:

> I know I can't afford it. That's about it, and Trump's going to repeal it, so I don't really know anything about it. I mean I helped a friend of mine get Obamacare but he can afford it, he was paying 700 dollars a month for health insurance for one single male, but with the Obama tax credit for what he brings in a year, he's only paying 212 and they give him a credit of 500 a month. I think Obamacare is a good thing for those who can access it (Interview 2).

The unstable climate of the health care insurance field has left many individuals worried about the potential upcoming changes.

During my time at the Blackberry Spruce Free Clinic, there was an abundant discussion in the news of President Trump potentially repealing or replacing the Affordable Care Act. In May 2017, the House of Representatives passed the American health Care Act of 2017 that would repeal and replace the Patient Protection and Affordable Care Act (Kaplan and Pear 2017). The Senate denied this act which would withdraw Medicaid expansion (Kaplan and Pear 2017). However, several other bills have since been submitted and denied, including the Graham-Cassidy-Heller-Johnson Amendment (Kaiser Family

Foundation). The proposed discussion includes decreasing the amount of federal aid for Medicaid coverage and decreasing the number of Medicaid recipients (Levey and Kim 2017). This lack of funding for Medicaid will mostly affect the same population that the clinic treats, the low-to moderate income population. This could increase the number of individuals seeking care at free clinics because fewer individuals would qualify for insurance assistance, including Medicaid. Thus, repeal of the ACA is likely to increase the need for the available sources of health care through this free clinic. Lucille, another patient at the clinic, explains further worry about the possible health care changes: "I know it's not going to be beneficial to me. To be honest with you, I can't give you an answer" (Interview 3). Like many others, individuals at the clinic had limited knowledge of the political debate regarding potential changes to the Affordable Care Act discussed throughout the summer in the news. Limited knowledge of health care changes, as seen with the Affordable Care Act, could lead to a decrease of volunteers and donors for free clinics (Swan and Foley 2016). June explains the expectation of change in the clinic and the uncertainty of what this change will cause:

> We don't know enough about the new healthcare law that is coming to make any decisions. I don't know enough about it to make any decision on that. I know the democrats are proposing a single payer system where people can buy into Medicare, buy into Medicaid. That is going to have the same impact; these people have no money to buy into anything. So, same boat again. So, in the end it may be of no impact (Interview 16).

The office manager of the clinic, Iris, further explained that the community around Blackberry Spruce has begun to also express concern about the upcoming prospective health care reform changes. Iris explains:

> I'm not real sure what the changes are, but I've already seen I mean we've had a lot of calls wanting to see what they need to do to become a patient here and like I said right now we've cut off eligibility because 15 patients a night is about all we can see

> and we were seeing 25-30 so that was putting a big strain on the doctors because they put in 8-10-hour days before they even get over here. So, we had to stop it for a while, I mean it may be September it may be December but we've had a lot of phone calls already wanting to come. I know the Medicaid that they cancelled for a lot of patients that have it we've had lot of calls (Interview 13).

While individuals may lack detailed information about the Affordable Care Act or the potential changes that would repeal the Act, it seems that the possibility of policy changes regarding health insurance have some people seeking alternatives to health care just in case. It is also clear that the clinic is not able to handle an increase in patient volume. In addition to the possible increase in the number of patients at the clinic, a volunteer provider at the clinic also assumes that the clientele who use the clinic could change as an effect of the proposed health care reform. Dr. Cash explains this situation thus:

> I think you'll see a lot of insured patients coming in, and were not equipped to handle that. Not administratively, not staffing wise. We don't know what to do. I don't know if it's legal, that's a big term, I don't know if it's appropriate to see patients who have insurance. How do we handle that? Do we bill for, we have no one who understands that or who could bill anything? We might even get paid to see them we don't know that, we don't know how to do it. So, we could be throwing away funding that is available. Who knows? So, it's going to be a big problem. It's not just, oh poor Johnny doesn't have any money, will see him at the free clinic. No, it's much more complicated than that (Interview 10).

The changing demographics of patients in the Blackberry Spruce Free Clinic could create a cumbersome situation for finding resources for these new individuals who may have limited coverage through insurance. Additionally, this change in clientele could usher the clinic into more extensive care offerings that could take advantage of additional funding sources.

Many individuals at the clinic also had recommendations about the upcoming health care changes. Lucille explains the issues surrounding health care and her assessment of ways for it to improvise:

> The financial part [is the issue]. You know make it to where everyone can afford it. You know, I feel that we should be able to get the same kind of insurance that congress people get. I mean they get everything, you know, everything and a lot of us who are working are the ones who make the payments to keep it, that's the way I feel about it. Or you know just get it somewhere reasonable that we can afford it. That it isn't going to hurt us, especially living on one income right now. My husband's disabled; he's had a heart attack and a stroke and all. Thank God, he's fine right now but you know living on one income is hard and trying to pay health insurance so I have to come here and then I feel bad coming here when there's somebody else out there who needs to come here more than I do. But it's not an option, you know? (Interview 3).

Dr. Cash further explains the issues surrounding the health care reform changes detailing:

> It upsets me greatly that the people making decisions about healthcare appear to have never interacted with a sick person or a person who has chronic pain or disabilities. Which is kind of bizarre to me. None of those republicans have anybody in their family who depends on Medicare/Medicaid for daily needs and all of them are rich, they don't remember what it's like to wonder whether you can fix your insurance premium or can I fix my car or pay my doctor bill, which am I going to choose to do this quarter. So, nothing good can come out of a decision made by one class of people about another class of people. It's just going to fail. It's going to be much, much worse (Interview 10).

Affordable health care is still an apparent need in our nation, and a key aspect of affordable care is reasonably priced insurance coverage. Currently, the financial aspect of insurance coverage contributes to the strain of obtaining insurance and is why these patients seek care at a free clinic. The lack of consideration of free clinics in the health care system could cause such individuals to be overlooked in any upcoming changes. Their lack of representation could lead to remaining uninsured or a larger population of uninsured, increasing health disparities linked to health insurance coverage and access to health care.

The unstable situation of health care reform in our country leaves many patients and volunteers at the Blackberry Spruce Free Clinic questioning their future role in the health field as a partial provider of care for uninsured individuals.

Health Care Changes

As Trump's administration has proposed multiple changes to the health care reform bill, the Affordable Care Act, uninsured patients have become concerned about these possible upcoming changes. Faith, a long-standing patient at the clinic, explains the impact health care changes could have stating, "I can't afford insurance now, but if Trump repeals Obamacare, and that's maybe the only insurance I could afford once I get my disability, it's going to be negative I can tell you that" (Interview 2). Patients at the clinic see the option of insurance provided through the marketplace as the only affordable insurance which they could one day possibly afford. However, if repealed, they worry they will never be able to access health insurance. Another individual at the clinic viewed the proposed health changes as only being suitable for a younger generation. As a clinic that assists in treating majority of patients between the ages of thirty to sixty, these changes could eliminate the hope of ever finding an affordable insurance for individuals with pre-existing conditions.

The majority of individuals at the clinic had limited interest or time to explore the health care changes being discussed in the news. Dolly explains, "I haven't [been following the changes]. I don't have time to even hardly read my Facebook page or watch TV. I'm always doing something at the house for the business or for our singing business or just something I'm always busy with that stuff" (Interview 6). Hank, a newer patient at the clinic, had a similar comment stating, "We don't even turn the news on," (Interview 9).

Patients are not alone in remaining uninformed. Individuals who work or volunteer at the clinic had limited knowledge of the proposed changes being discussed. Clementine, the office assistant at the clinic remarked, "Well, I'm not sure I'm informed enough to answer that," when questioned on her knowledge of the discussion around health reform. Similarly, Paula – the pharmacy technician at the clinic – laughed when presented about the question of the health care reform changes and made no additional comment. The multiple discussions around health reform that appears in the news repeatedly can be difficult to maintain consistently up to date on the discussions occurring within the national level. This lack of knowledge, however, could also make this population of uninsured more susceptible to negative results of the possible changes presented with no steps of protecting the clinic or the patients who utilize the clinic.

Congress continues to deliberate over a possible health care reform bill. In the North Carolina free clinics, eleven of the fifty medical directors of these clinics wanted a complete repeal of the affordable care act while eighteen wanted certain parts of the bill repealed (Swan and Foley 2016). A resulting change that would decrease the coverage provided through the Affordable Care Act would lead to an influx of need for these free clinics and result in a further strain on the safety net system (McGeehan et al. 2017). Any bill put into place to repeal or change the Affordable Care Act as it is today will influence the uninsured (Sessions et al. 2017). It was expected that by 2016, a total of only nine percent of the population would be uninsured with a successful enactment of the Affordable Care Act compared to twenty percent without this legislation (Swan and Foley 2016). There is a crucial need for advocating for the vulnerable and medically underserved individuals in our nation during this time (McGeehan et al. 2017). As Congress debates the changes to this

nation's health care, considering both the insured and uninsured could be imperative to bringing about full medical access for all individuals.

Conclusion

The Affordable Care Act was put into place as an attempt to increase medical coverage nationwide. The remaining presence and persistent need for free clinics such as, the Blackberry Spruce Free Clinic shows the lack of access to health insurance coverage that is needed in our country. Medicaid expansion was a key factor that increased health insurance coverage. In states like Tennessee, individuals who could have been covered by the expansion did not receive health care coverage due to the lack of expansion.

Patients have various views of the Affordable Care Clinic. Some consider the Affordable Care Act to provide the most affordable health care insurance options through the insurance marketplace such as, Faith. Those who may have previously had insurance and the bill resulted in an increase in their insurance such as, Walker have a negative association to the Affordable Care Act. The model of this bill resulted in various responses based on the structure. The Affordable Care Act discussed Medicaid expansion however, left this option open to the states to decide (Sessions et al. 2017). As a result, the medical insurance coverage in states across the nation varies based on the status of expansion and the functionality of their online insurance marketplace. Most newly insured individuals were insured on Medicaid (McGeehan 2017). There are still barriers to receiving health care access for individuals though especially in states that chose to not expand their Medicaid coverage such as, Tennessee. Some of these barriers include the high cost of insurance, lack of knowledge of eligibility criteria, language barriers and difficulty with

navigating enrollment logistics (Sessions et al. 2017). These barriers have left individuals with limited access to health care and dependent upon safety net clinics like the Blackberry Spruce Free Clinic.

Free clinics provide access for individuals to enter the health care system however, are not an adequate replacement for primary care (Sessions et al. 2017). The use of free clinics may not result in thorough quality of care. Patients at the Blackberry Spruce Free Clinic are grateful for the care they receive however, recognize that their access is lacking based on what is missing in their care. Some examples include specialty care, consistent care for acute issues, and choice in care. As patients at a clinic, the lack the opportunity to have choice in the providers they see and have limited options for their treatment choices based on their affordability.

The Affordable Care Act had limited impact on the Blackberry Spruce Free Clinic except in an apparent shift of an increased clinic population. This population could be related to better advertising or on an increased need for affordable care though. The clinic could have also received medical malpractice coverage but based on the lack of discussion of this at the clinic, I assume the clinic did not apply for medical malpractice coverage of non-medical personnel. The decreased understanding of the Affordable Care Act among the staff of the free clinic questions the lack of advantages that the clinic could be missing out on receiving.

In conclusion, as the debate for health care reform continues to be discussed in Congress, health continues to be presented as a fight about whether health care access is a human right. If the Affordable Care Act is repealed, the number of uninsured could increase by twenty-two million uninsured by 2026, from 28 million to 50 million (Dobson et al.

2016). If the Affordable Care Act is repealed the need for safety net clinics will become further prominent based on the assumption that many individuals will lose their health care coverage.

CHAPTER 5

CONCLUSION

Free clinics remain an important access point to care for uninsured individuals. These safety net sources provide chronic care management, episodic care, and are the gatekeepers for patients to access the traditional health care system. Understanding their importance cannot be inferred without being displayed in the context of the Patient Protection and Affordable Care Act. The Affordable Care Act ushered in a new age of medical coverage through the online marketplace and Medicaid expansion. This policy led to many individuals receiving care, either through Medicaid or private sector insurance and the nation's rate for uninsured adults dropped from eighteen percent in 2013 to twelve percent in 2017 (Auter 2018). However, there remains an uninsured population and the lack of Medicaid expansion in the state of Tennessee left many individuals with the inability to afford insurance premiums (Wellmont Health System 2016). Those who remain uninsured, in the region and in the nation, are left to seek care from federally qualified health centers who offer sliding-scale fees, free clinics or emergency rooms (Darnell 2011). Though identified as originating in the 1960s, the concept of a free clinic has been present since the early twentieth century in the Appalachian Mountains (Reynolds 2009).

This research study, through qualitative methods, provides a patient-based critique of care received through a free clinic from analyzing the Blackberry Spruce Free Clinic. Depicting the struggles of health care access for uninsured individuals, this thesis details the obstacles of attempting to acquire specialty appointments, procedures, medications and treatments needed for those with severe illnesses. The lack of universal care for those

without insurance leads to inadequate care. Stemming from this are missed diagnoses, as seen with Hank's need for a cholecystectomy. Others who are uninsured simply forgo care; this was described in terms of Pat's coincidental diabetes diagnosis and Faith's development of life-long lung issues. This research also describes the importance of health care sources like the Blackberry Spruce Free Clinic and discusses the organizational issues that arise in the absence of adequate resources. The Blackberry Spruce Free Clinic is the only source of health care for the uninsured individuals of Flat Top County today. The clinic provides care through a diabetes clinic and an evening primary care clinic. Patients receive access to their medications but struggle to receive care through a specialty provider if needed. This clinic is still unable to meet all the medical needs of the county due to its limited availability (open hours), enrollment, and its lack of certain specialty aspects, like dental care. The clinic attempts to combat the rising presence of diabetes in the region and treats other diseases, such as cancer, hypertension and others. However, the brief period the clinic is open to see patients, only one night a week and on a one or three-month period, could lead to a lack of quality care for the patients at this clinic. This lack of total treatment could result in a patient's inability to return to work or could deter the possible relationship that forms between a physician at the clinic and the patient.

Lack of quality care is a type of health disparity in addition to the limited access which the patients at this clinic experience. In a field such as non-profit work, the possibility of compassion fatigue is plausible, and clinic Dr. Cash is no exception. He explains:

> "It's tempting to think… I can change things. It seems like that at first, it's kind of intoxicating but you're not affecting any major change. You're a part of the system that is broken. And you do the best that you can to not burn completely out," (Interview 10).

Without the adequate means to provide care, it is possible for staff and providers to become numb over the issues their patients are experiencing in a free clinic environment. My findings discovered that the workload in the Blackberry Spruce Free Clinic was uneven and appeared mismanaged. Furthermore, the benefits received by staff appear to outweigh those for the patients, since the clinic allows the staff to maintain their status as the gatekeeper for all the available health services that these patients can receive. In a fractured system, where individuals fall in the "gaps" of health care, it is important for free clinics to remain present in their communities. To continue treating the uninsured though, clinics must be well organized and have the resources needed for holistic care. Otherwise, the minimal care being provided will change little in this all-encompassing health care issue.

The patients at this clinic place a significant importance on the clinic for providing medical care and acknowledge this care as a blessing. This view point from the patients could cloud their statements, as they are less likely to complain to the staff or providers of the clinic, for fear of being denied care. Many patients who were interviewed admitted that, at this moment, the only care they can afford is that provided through this free clinic. The assumption is that if patients did have an issue with the quality of care they were receiving, they would remain quiet over such an issue to ensure they can continue to access clinic resources for their medical care. Though there is a possible lack of quality care, the clinic is providing some type of medical care to those who have access to none.

Being situated in the Appalachian region draws some significant influences into this clinic and its patients. This clinic's placement relates to different issues than those that

might be faced in other areas in the country. For example, the region's declining industrial presence leads to higher unemployment rates than seen in other areas. Geographically, the Appalachian region is associated with maintaining the largest regional religious traditions within our country (McCauley 2004). This clinic's association with a local Christian ministry has an impact in the structure of this free clinic that varies from others. Though I am a Christian, the possible worthiness of care that could develop around these issues leads to concerns for the future of patients who continue to need affordable treatment. Similarly, the clinic reports a high prevalence of hypertension (high blood pressure) and diabetes that could be associated with the traditional foods consumed in the southern part of the nation and the Appalachian region, as well as the low-quality, processed foods that become staples for economically marginalized families. The clinic attempts to provide education on eating healthier to patients, however not all follow the mandated diet due to assorted reasons, including finances. This behavior could place a patient in jeopardy of being dropped from the clinic. These factors play into the variances of this clinic from others and reflect local and regional differences. Though patients were not unenrolled for such reasons during my time working there, the present structure could lead to this possibility in the future.

The Affordable Care Act had a limited impact on the Blackberry Spruce Free Clinic. According to staff, the only result was an increase in the number of patients. Furthermore, they predict a similar occurrence if a new health care reform bill is passed. The Affordable Care Act offers a larger impact on free clinics by providing expanded medical malpractice insurance through the Federal Tort Claims Act. This extended coverage would allow for free clinics to have additional protection against malpractice lawsuits and the possibility to

attract more doctors to the clinic. There was no mention of this increased coverage during my time at the clinic, and I was unable to complete follow-up with the staff to inquire of their knowledge of this Tort Claims Act or if they had applied for this coverage. In this way, the clinic staff's lack of understanding of the Affordable Care Act could place it in jeopardy with the ongoing health reform discussions occurring in Congress. It is notable that several patients at the clinic attributed their uninsured status to the Affordable Care Ac while others believed Obamacare to be the only available insurance to them once they have access to such funds to afford insurance.

Free clinics serve as indicators of policy implementation (Sessions et al. 2017). The apparent theme discussed was that individuals could not afford the premiums for the "affordable care" provided by the Act. The observed patient increase in the Blackberry Spruce Free Clinic as reported by staff and the patients' inability to afford insurance signifies the issues surrounding the Affordable Care Act as a health policy. In the state of Tennessee, due to the decision to not expand Medicaid coverage, many of the state's poorest citizens did not receive access to insurance or affordable care. Since the states were left to decide their Medicaid expansion policy, many of the uninsured individuals today and at the Blackberry Spruce Free Clinic could have qualified for the new Medicaid guidelines.

Though Tennessee decided to not expand Medicaid, the neighboring state of Kentucky did accept the expansion. Through its decision, Kentucky experienced the largest coverage gain of any state and maintained an uninsured rate of five percent in 2016 compared to twenty percent in 2013 (Cross-Call 2016; Farmer 2017). Kentucky's choice to expand Medicaid allowed for the number of emergency department visits to drop by thirty

percent and an additional thirteen percent of individuals are receiving routine follow-up care for their chronic illnesses (Sommers et al. 2017). In comparison, nine percent of Tennessee's population were uninsured in 2016 (Farmer 2017). Though this rate has decreased, there is still a significant discrepancy of care in Tennessee due to this non-expansion.

Staff must become active and remain knowledgeable of discussed health care changes to ensure there is a clinic for their patients to continue to use. Free clinics, such as the Blackberry Spruce Free Clinic, are not long-term solutions to the uninsured issue in our region and nation. However, for now, these clinics are the only source of care for too many individuals. To improve the quality of care and available resources at the clinic, I recommend a collaboration with other local clinics to provide an equal opportunity of resources in a rural clinic such as, Blackberry Spruce Free Clinic. The North Carolina Association of Free and Charitable Clinic is a collaboration of free clinics in the state who attempt to provide affordable and quality medical care to the underserved (NCAFCC). This organization has partnerships with BlueCross Blue Shield, the National Association of Free and Charitable Clinics, AmeriCares, and multiple state agencies (NCAFCC). This model allows for a community of state free clinics to explore effective methods and resources to provide uninsured individuals further access to care. If the Blackberry Spruce Free Clinic was involved with a similar affiliation they would have additional resources such as, possible specialty providers. A standardization of care could provide improved services and a better quality of care until a health policy is enacted that provides a solution to the uninsured issue in our nation.

The Blackberry Spruce Free Clinic is a community of individuals who suffer from similar hardships; they struggle with finding adequate health care amid minimal finances. These similar burdens, routine visits, and extended utilization of the clinic has created a community of patients who know one another inside and outside the clinic and a staff who recognizes everyone by name and face. There are other unifiers in this community beyond finances, such as the resourcefulness to find care that is needed and to provide care where there is a need. This glimpse into the operations of the Blackberry Spruce Free Clinic and the care provided to the uninsured population of Flat Top County shows the continued hunt for affordable care in our state and region. As patients at a free clinic though, these individuals only have access to the available resources that can be provided to them through the resources of the clinic. Health care access is not just an Appalachian issue but is magnified in the central Appalachian region. The apparent continued need for affordable care and safety net clinics in the Appalachian region can provide insight into the issues with the current health care system and provide an expanded focus on what needs have not been met (Watson 2011). The present discussion of health care reform could jeopardize the clinic patients and the newly enrolled individuals on marketplace insurance. Understanding the individuals who access this clinic and their needs could change policy maker's discussion of health care access and coverage for the state, region and nation (Watson 2011).

This clinic is providing care to the various individuals who have found themselves in the gap of the health care system. The population of uninsured has changed and is today reflected in the low-income working families (Kaiser Family Foundation). Families in this clinic's clientele, such as Dolly, Walker, Wyatt and Pat are "gap" people who have found

themselves uninsured due to the high cost to maintain insurance (Kaiser Family Foundation). Pat, Walker and Wyatt are all employed but are not offered insurance through their work or are not offered affordable, accessible health care plans. Additionally, Dolly was previously insured and is a local business owner but can only gain access to specialty care based on the kindness of this physician to see her at no charge. Care provided through free clinics is not a sustainable solution to ensure these individuals are able to maintain routine health care. Furthermore, this source of care is not able to provide complete quality of care to these uninsured individuals based on the lack of available resources.

The furthering of health disparities through the creation of bad policy and the inaccessibility of insurance leaves too many relying on free clinics to maintain health care for the uninsured. The lack of Medicaid expansion in states such as Tennessee has led to a great disparity of access for individuals, as described by the patients in this clinic. Many of the participants in this study would have would have been provided access to health care through Medicaid coverage under the new guidelines. The limited consideration of free clinics by the Affordable Care Act did not cause a great deal of change to their structure, but it also did not assist them in supporting this nation's uninsured. Though the Affordable Care Act did decrease this nation's number of uninsured, it did not consider what avenues these individuals would have to take to receive care. Due to this lack of Medicaid expansion and consideration for supporting free clinics, patients who might have received care through the Medicaid expansion are now dependent upon a free clinic that remains open based on donations and revenue from fundraisers like a 5K marathon. Future policy measures should consider understanding their free clinic population to better access the needs to expand coverage. The expense of maintaining insurance is a major issue with the

patents at the Blackberry Spruce Free Clinic. Exploring why individuals remain uninsured and their issues with accessing insurance is a key aspect to making a major change in the policy surrounding health care access and health care insurance. Without this examination of the issues surrounding health care access, no improvements to policy can occur soon for the individuals who are currently uninsured.

This thesis attempts to understand and provide new insight into the importance of free clinics in this age of health reform through ethnographic research completed at the Blackberry Spruce Free Clinic. Themes acknowledged recognize the needs of this community, the missing aspects of care, and the impact of current health policy on this underrepresented population. My observations of this clinic through both patients' and staffs' perspectives conclude that this access point for affordable care is important but is not being managed in an efficient way. There is a discrepancy, with quality, holistic care missing from this clinic. This includes access to specialty care and mental health care. If staff worked to seek better relationships with providers or attempted to pursue new grants, patients could be further assisted with receiving specialty appointments and treatments. *Chapter Three: A Day in the Clinic* discusses the everyday operating structure and the health care services which is provided to the uninsured through this clinic. By highlighting the clinics diabetes, evening primary clinic and medication access, this chapter display how this clinic attempts to address the needs of their community. *Chapter Four: Understanding Health Care Reform in a Free Clinic* highlights the health disparities seen in the free clinic setting by discussing these patients' health insurance histories and why they currently find themselves uninsured. The uninsured find temporary affordable and accessible health care, until there is a change in policy that will allow them access to

receive insurance. The Blackberry Spruce Free Clinic continues to attempt fill in as a health care access source for those individuals who fall in the gap of health policy and find themselves on the marathon to affordable health care.

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APPENDICES

Appendix A

Primary (Patient) Interview Schedule

Primary interviews with patients seeking health care at the free clinic

Demographics:
How long lived in the area? _____
Are you from Flat Top County (other TN county, etc.?)_____
Where do you work? _____ How long there? _____
Gender_____ Age _____ Race/ethnicity _____
Married / long term partner? _____
Children? _____
Household members? _____
Education level or training? _____

A) Access to Health Care

1. How would you describe your health? (e.g. fair, poor, good, excellent)

2. Do you have specific health care concerns for yourself? For your household / family (e.g. children, parents)? Would you list those concerns?

3. Are there any barriers (problems) to health care for you or your household / family? What do you do to overcome these barriers (get health care)?

4. Is transportation or proximity to a health care facility a problem?

5. Do you have a usual source of health care / doctor (other than the clinic)?

6. How did you hear about the clinic?

7. Why do you come to the clinic?

8. How often do you visit the clinic?

9. What if anything would you change about the clinic? Can you get all the care you need here at the clinic? (what's missing?)

10. What do you do to try to be healthy? (Basically a question asking about positive health behaviors?)

11. Do you have anything you would like to change to help you be healthier? (smoking, weight, exercise, etc.?) (Basically a question asking about negative health behaviors.)

B) Health Insurance

7. Do you currently have health insurance?

[If has insurance]
-Are you insured through a private source (e.g. work, spouse) or public source (Medicaid, Medicare) or Insurance exchanges?
-How long have you had your current insurance?
-How many months insured previous year? Past two years?
-Have you had gaps in your health insurance coverage? When and why? Consequences?
-How do you feel about the proposed changes to health insurance?

[If no insurance]
-Why are you uninsured? (e.g. cannot afford, not offered, does not need, etc.)
-Have you ever had health insurance? When and where?
- What do you know about Obamacare? How do you feel about the proposed changes to health insurances? Do you think this will affect you?
-When were you last insured and for how long?

8. Are the members in your current household uninsured / insured? Do you know if they have problems accessing health care?

9. Have you ever had difficulty (or worry about) paying for health care services (e.g. high co-pays, prescriptions; procedures recommended by doctor but not covered by insurance plan; preventive care, follow-up care etc.) How do you handle these problems?

10. Do you or your household members ever forego (go without) or postpone health care? What are the reasons you might you go without health care?

[If so] What were the consequences of foregoing / postponing care?
- Problem caused pain or difficulties?
- Interfered with ability to work or care for others (work days lost?)
- Still have problem? Was the problem ever treated?
- Went without care more than once?

11. Do you ever have difficulty in making an appointment for health care (refusal, long waits, referrals, etc.)? Examples?

12. Do you have children? Do you ever have problems / concerns getting health care for your child(ren)? Examples? What did you do to get care?

13. Do you have parents or grandparents (elder family members) that have trouble getting health care? Examples? What do they do to get care?

14. How satisfied are you with your health care access overall? For your household / family?

15. What do you think is the most important issue with health care in this community / area?

D) Closing

1. Is there anything I haven't asked about that I should be aware of?
2. Would it be ok for me to contact you again later for a follow-up interview?

Appendix B

Secondary (Provider) Interview Schedule

Clinic staff, administration, and provider volunteers.

Demographics:
Are you from the Area? (where?) _____How long lived in the area? _____
Where do you work? _____ How long there? _____
Gender_____ Age _____ Race/ethnicity _____
Education level _____ Where received medical training?

1. Could you tell me about the history of the clinic? How did it start and what were the specific needs it sought to address? (community needs?)

2. Is the clinic partnered with any other health care service centers? Community groups?

3. What drew you to work/volunteer in a free clinic?
   a. Why this clinic?

4. What does the clinic do well?

5. Is there anything you would change about the clinic (structure, services)?

6. Who utilizes the clinic? Are there fees or other costs for using the clinic for patients?

7. What are the biggest health care needs of the patients at the clinic? Health risk factors? Health behavior concerns?

8. What are the biggest needs of this clinic?

9. What services are offered?

10. What is the biggest issue faced as being a provider in a free clinic?
    a. What is the biggest issue you believe faced by patients?
    b. How would you wish to improve access provided by the clinic? Access to care in the community?

11. How is the clinic funded? Originally? How has this changed over the years?

12. What do you know about the Affordable Care Act?
    a. Has funding changed since the Affordable Care Act?

b. Has patient enrollment changed since the Affordable Care Act?
c. Have available resources changed with the Affordable Care Act?

13. How do you feel about the proposed changes to health insurances?
    a. How do you think this will affect the clinic?
    b. How do you think this will affect the patients of the clinic?

12. Why do you think health care continues to be a disparity in Appalachia?

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