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# Cardiovascular Disease in Central Appalachia, an Exploratory Study of Behavioral, Community, and Patient-Centered Care Influences

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A dissertation
presented to
The faculty of the Department of Community and Behavioral Health
East Tennessee State University

In partial fulfillment
of the requirements for the degree
Doctor of Public Health, Community Health

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by
Kristy Gagnon
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Keywords: Cardiovascular disease, Central Appalachia, diet, physical activity, cardiac rehabilitation, multiple generation households, built environment, community organizations, mountainous topography, patient-centered care, lifestyle medicine, rural communities.

# ABSTRACT

## Cardiovascular Disease in Central Appalachia, an Exploratory Study of Behavioral, Community, and Patient-Centered Care Influences

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The Central Appalachian region of the United States disproportionately experiences higher rates of cardiovascular diseases (CVD) and associated risk factors. Primary risk factors for CVD include hypertension, hypercholesterolemia, and tobacco use, all of which have the potential to be mitigated through lifestyle behavior changes. Dietary and physical activity practices are the two main driving forces for the development of hypertension and hypercholesterolemia, while tobacco use is a behavioral choice on its own. Subsequentially, shifting lifestyle choices to emphasize healthier living has the potential to reduce CVDs within the Central Appalachian region. Considering behavioral choices are not made in isolation and are the result of internal and external influences, it is necessary to contemplate the multitude of factors driving these rates. Additionally, healthcare systems within this region ability to provide patient-centered care (PCC) is another consideration, as effective point of care also can address these rates from a disease treatment and management level. The purpose of this study was to explore the knowledge, perceptions, and influences among patients with cardiovascular diseases and non-licensed caregivers within these communities, at the behavioral and community levels, in addition to the perceptions of essential components of PCC among professional stakeholders.

Seven focus group discussions with CVD patients and non-licensed caregivers were conducted, with a total of 78 participants; additionally, 20 interviews were held with professional stakeholders within the healthcare field. At the behavioral level participants identified internal and external barriers to sustaining healthy diets, the impact of interpersonal relationships on diet and stress, and influential role of cardiac rehabilitation in physical activity following a major cardiac event. At the community level participants discussed the economic characteristics of communities, a need for community infrastructure expansion, and the role of community organizations. Professional stakeholders addressed PCC in the current healthcare system, constructs of effective patient-provider interactions and the role of community outreach. This research serves as a look into the challenges and opportunities within this region and provides insight to inform future research and interventions.

# ACKNOWLEDGEMENTS

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My family… I have some exceptional children. Each one of you (in order of appearance: Corduroy, Sayona, and Dayzie) have continuously supported me every step of the way, while demonstrating kindness and understanding while I attempted to juggle all my responsibilities and aspirations. If you each weren’t the amazing people you are, this endeavor would have been exponentially more difficult.

My husband, although you are a newer addition to the family and entered my life amid this process, your support has been monumental during all the late nights and long weekends.

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# ACRONYMS

AHA – American Heart Association

ARC – Appalachian Regional Commission

BMI – Body Mass Index

BP – Blood Pressure

CCA – Collective Central Appalachia

CCM – Chronic Care Model

CDC – Centers for Disease Control and Prevention

CHR – County Health Rankings

CHW – Community Health Worker

CMMS – Centers for Medicare & Medicaid Services

CVD – Cardiovascular Disease

DTC – Direct to Consumer

FDA – Food and Drug Administration

FGD – Focus Group Discussion

HBM – Health Belief Model

HC - Hypercholesterolemia

HCP – Healthcare Provider

HDL – High Density Lipoproteins

HHS – U.S. Department of Health and Human Services

HTN – Hypertension

IOM – Institute of Medicine

KY - Kentucky

LDL – Low Density Lipoproteins

NC – North Carolina

NLC – Non-licensed Caregiver

ODPHP – Office of Disease Prevention and Health Promotion

OH – Ohio

PA – Physical Activity

PCORI – Patient-Centered Outcomes Research Institute

PCC – Patient-Centered Care

RAM – Remote Medical Unit

SEM – Social Ecological Model

TN – Tennessee

U.S. – United States

VA - Virginia

WV – West Virginia

# Chapter 1. Introduction

Cardiovascular disease (CVD) has been the leading cause of mortality in the United States (U.S.) since 1921 (Sidney et al., 2016; Wall et al., 2018). While rates have been trending down over the last 40 years, and has reached a near plateau over the last 20 years, (Benjamin et al., 2019; Wall et al., 2018) it has continued to hold its ranking for over 100 years. CVD constitutes of all types of diseases that impact the heart and the blood vessels it serves. Under this umbrella, the leading cause of fatalities is coronary heart disease, accounting for 43.2% of deaths, followed by stroke at 16.9%, hypertension (HTN) at 9.8%, heart failure at 9.3%, diseases of the arteries at 3%, and all other CVD conditions at 17.7% (Benjamin et al., 2019).

While the reach of CVD is felt throughout the U.S., the Appalachian region is afflicted with disproportionately higher mortality and morbidity rates, with disparities even occurring between neighboring Appalachian and non-Appalachian counties within the same state. The infringement of CVD on Appalachian communities' quality of life, the factors driving these rates, and the perceptions of these communities is an underexplored area of research. Subsequently, it is apparent this is a public health issue requiring further exploration to inform and direct future population specific primary prevention efforts.

## Statement of the Problem

The Appalachian region is impacted by CVD with an overall mortality rate 17% higher than the rest of the U.S. (Marshall et al., 2017). However, this percentage greatly varies within the region, with the highest rates seen in Central Appalachia, at up to 42% higher than the national average (Marshall et al., 2017). Geographic and economic variations also drive mortality; rural counties rates are 27% higher than large metro counties; and distressed counties rates are 29% higher than non-distressed counties (Marshall et al., 2017). The variation of impact is a complex interplay of numerous driving factors within the unique constructs of the region, that requires examination within the environment they occur.

While mortality is the ultimate concern, nearly half of adults over the age of 20 currently live with, seek treatment for, and suffer from some form of CVD (Benjamin et al., 2019). Mitigating these disease processes is key for long term health, however, adults may not be aware that they have developed one of these conditions that puts them at high risk until it is identified by a healthcare provider (HCP). Once identified, HCPs can then determine appropriate treatment and education. Considering the potentially large role HCPs contribute to prevention and treatment, the relationship between providers and patients is an important component in the equation. The patient-centered care (PCC) model provides guidelines to optimize this relationship, and has been shown to increase treatment adherence, (Haskard Zolnierek & DiMatteo, 2009) recall, and satisfaction (Rao et al., 2007).

Research in the Appalachian region has provided the necessary informative data to identify disparities extensively impact the Central Appalachia region. However, deciphering which intervention designs are the most suitable to impact changes within these communities is an ongoing area of research. The purpose of this study was to contribute to the growing collection of qualitative research by exploring CVD behavioral risk factors, community determinants and the role of PCC to inform future prevention intervention strategies.

## PCORI

The Patient-Centered Outcomes Research Institute (PCORI) is an independent nonprofit, nongovernmental organization dedicated to improving patient-centered care through funding research initiatives. The Eugene Washington PCORI Engagement Awards program, an initiative of PCORI, awarded East Tennessee State University funding to develop a research agenda to prevent and control CVD in Central Appalachia. Part of this research involved gaining primary qualitative data from community and professional stakeholders in the Central Appalachia region. This dissertation investigates the region regarding CVD and patient-centered care, as well as presents findings from the PCORI funded research.

## Specific Aims

*Specific Aim #1*- To investigate barriers to primary prevention of CVD in Central Appalachia at the behavioral risk level through qualitative investigation.

*Specific Aim #2*- To investigate barriers to primary prevention of CVD in Central Appalachia at the community determinant level through qualitative investigation.

*Specific Aim #3*- To examine professional stakeholder perceptions concerning the definition and delivery of PCC in Central Appalachia in relation to CVD.

## Appalachian Region

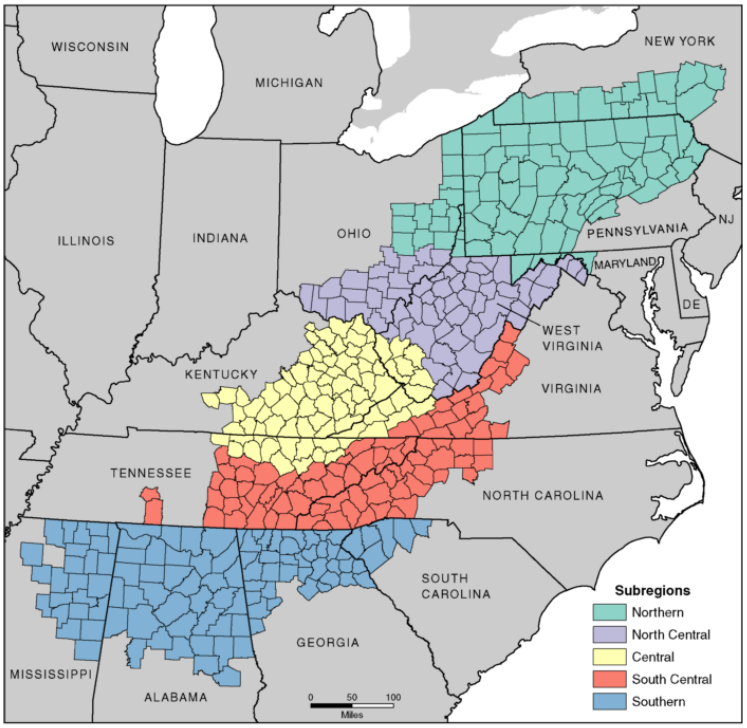
The Appalachian region of the U.S. is known for its rugged mountain range, rural communities, rich culture, and abundance of natural resources and beauty. This area encompasses approximately 205,000 square miles across 13 states and 423 counties, ranging from Mississippi to New York, with a total population of 26 million people (Appalachian Regional Commission [ARC], 2019). This large area is further divided into five subregions by the Appalachian Regional Commission (ARC), an organization dedicated to developing community capacity and economic growth in the region. The five subregions consist of: Northern, North Central, central, south Central, and Southern Appalachia (ARC, 2019). Figure 1.1 illustrates these subregions and the geographical areas they encompass.

The PCORI funded research that preceded this dissertation is based on primary data collected from the three central portions of the region, the North Central, Central, and South

Central. For purposes of this study, the three subregions will be referred to the Collective Central Appalachian region (CCA). CCA spans over six states: Kentucky (KY), North Carolina (NC), Ohio (OH), Tennessee (TN), Virginia (VA), and West Virginia (WV); and encompasses 228 counties and jurisdictions (ARC, 2019). This population of approximately 9 million is predominately homogenous, with over 90 percent being non-Hispanic white (Pollard & Jacobsen, 2020), and are dispersed into rural, urban, and metro communities, with the majority of 55 percent residing in rural areas or small communities (George et al., 2002).

**Figure 1.1**

*Appalachian Subregions*



Map by: Appalachian Regional Commission, November 2009.

*Note.* Image source: The Appalachian Regional Commission, About the Appalachian Region (ARC, 2019).

## Cardiovascular Disease

CVD is largely a progressive disease that is often the result of lifestyle factors. According to the American Heart Association (AHA), 80% of CVDs can be prevented through not smoking, eating a healthy diet, engaging in physical activity, maintaining a healthy weight, and controlling hypertension, diabetes mellitus, and elevated lipid levels (Benjamin et al., 2019). These factors, with the addition of getting healthy sleep, make up what the AHA has termed "Life's Essential 8," and serve as the most significant predictors of cardiovascular health (American Heart Association, 2023). Figure 1.2 below shows a graphic of the AHA key measures to health, which each factor being related to either behavior or health factors. has developed (American Heart Association, 2023). In the context of this graphic, the AHA has identified a healthy diet consists of whole grains, fruits, vegetables, plant-based protein, and lean animal protein, adults should aim for at least 150 minutes of aerobic activity each week, all individuals should abstain from smoking and vaping, adults should aim for seven to nine hours of sleep nightly, as well as manage weight by keeping track of calories, and manage cholesterol, blood sugar, and blood pressure (American Heart Association, 2023). The high rate of CVDs in the CCA region suggests this population may be disproportionally not engaging in those protective factors, thereby increasing their risk. Modification of individual behaviors would then have the potential to greatly reduce and alleviate the burden in CCA, through the adaptation of healthier lifestyles. However, individual behaviors are molded by a variety of outside influences experienced day to day and throughout the lifetime. Research has found community factors contribute to the burden, including health systems, built environment, community programs, and health policies (Joseph et al., 2017). Studying behavioral risk factors, and community risk factors will provide precursor knowledge necessary to then examine their relation to each other, and their combined impact on CVD.

**Figure 1.2**

*American Heart Association, Life's Essential 8*

*Note.* Life's Essential 8 includes the following components: diet, physical activity, tobacco use, sleep, weight, cholesterol, blood sugar, and blood pressure (American Heart Association, 2023).

## Theoretical Framework

Theoretical frameworks and models are used in public health to provide a systematic method of examining health behaviors and the key factors that these drive behaviors. This process provides an in-depth perspective of the influences the target population experiences, resulting in an informed view of the challenges and opportunities to influence healthier behaviors. High CVD rates in Central Appalachia is a complex issue that requires examination into the many factors that impact it, in order to identify potential areas to target prevention strategies and efforts. To guide this research and gain a comprehensive view of the unique characteristics of the Central Appalachian region, and how these factors contribute to CVD rates, the Social Ecological Model (SEM) will be adapted.

The SEM was developed in the late 1970s (University of Minnesota School of Public Health [UMN SPH], 2015) to understand the reciprocal influences between individuals, relationships, community, and society (Centers for Disease Control and Prevention Agency for Toxic Substances and Disease Registry [CDC ATSDR], 2011; Rimer & Glanz, 2005; University of Minnesota School of Public Health [UMN SPH], 2015). This model takes a holistic approach to health promotion and disease prevention strategies, by looking at the individual and their environment through five constructs: intrapersonal, interpersonal relationships, community, organizational, and society (Centers for Disease Control and Prevention Agency for Toxic Substances and Disease Registry [CDC ATSDR], 2011; Poux, 2017; Rimer & Glanz, 2005). It is acknowledged that individuals are influenced by the constructs, and the constructs are influenced by individuals. At the intrapersonal level, the SEM looks at what influences the individual, such as knowledge, attitudes, beliefs, and personality (Rimer & Glanz, 2005; Rural Health Information Hub, 2018a). The interpersonal level then examines the influence of interactions with other people, such as family and friends (Rimer & Glanz, 2005; Rural Health Information Hub, 2018a). Next, at the community level, factors such as social norms, built environment, and access to social amenities are examined (Rimer & Glanz, 2005; Rural Health Information Hub, 2018a). The organizational level looks at the policies and practices of organizations, such as work sites, healthcare, and schools (Poux, 2017). Finally, the societal levels takes into consideration policies and laws that regulate or support health action and practices for disease prevention, early detection, control, and management (Rimer & Glanz, 2005; Rural Health Information Hub, 2018a) at the local, state, and federal levels.

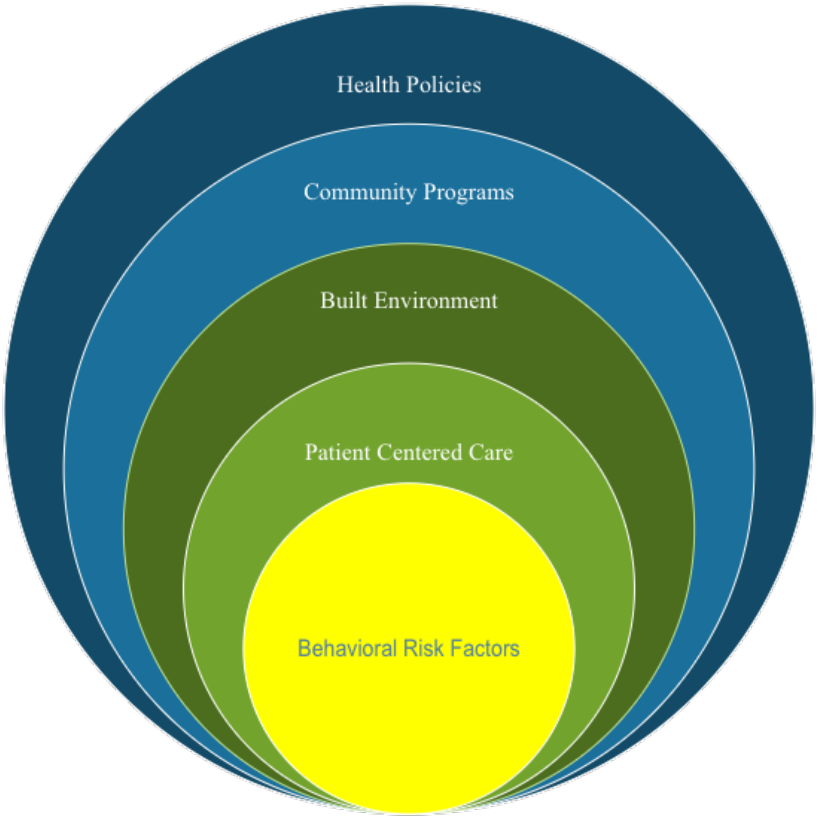
While the SEM addresses a range of factors and influences on health behaviors, it still has its limitations. It does not consider motivation to change, as well the difficulty to concurrently obtain resources across each level to effectively impact change. Nonetheless, it has been useful as the foundation of many health promotion and disease prevention strategies, such as Project HEART (Health Education Awareness Research Team) (Balcazar et al., 2012; Rural Health Information Hub, 2018a). This intervention targeted the risk factors associated with CVD in order to mitigate the high rates of CVD among Hispanics in two low-income communities in Texas (Balcazar et al., 2012). Using the SEM, researchers were able to design a culturally appropriate program specifically for their targeted population.

### ***Social-Ecological Model CVD Adaptation***

CVD rates are driven by a variety of factors, ranging from the interpersonal and intrapersonal constructs, as well as organizational, community and policy constructs. While risk factors can be significantly reduced through behavior change, it is also important to provide an environment conducive to facilitating and supporting healthy behaviors in order to obtain a sustainable healthy lifestyle for the population. For this study, as seen in Figure 1.3, the constructs of the SEM have been adapted to specifically address CVD in the CCA region, the framework is utilized to organize and examine the interplay of the multitude of influences that contribute to elevated CVD rates.

**Figure 1.3**

*CVD in CCA, an Adaptation of the SEM*



The behavioral risk factor level explores primary controllable risk factors for CVD and the health behaviors responsible for their development, while considering intrapersonal perceptions that guide behaviors. Next, the PCC level considers interpersonal relationships between patients and HCPs, and the subsequent impact on health. The built environment level explores the facilitators and barriers of the physical environment of communities, pertaining to promoting healthy lifestyles. While at the community level, the potential to levee local organizations to impact change through health programs and raising awareness is considered.

Finally, the opportunity for health policies to provide direction and support to create healthy communities is explored.

## Literature Review

### *Behavioral Risk Factors*

The first level of the SEM begins to examine CVD risk factors and the contributing lifestyle factors. According to the AHA, 47% of Americans have at least one of the following three primary controllable risk factors for CVD, HTN, hypercholesterolemia (HC), or cigarette smoking (Benjamin et al., 2019). Statistics show that the population of CCA suffer from increased rates of each of these risk factors, when compared to the national average.

**Hypertension.** Blood pressure level is the measurement of the force of blood circulating through arteries, using two measurements to determine the level. Systolic pressure is measured when the heart beats, and diastolic is measured between heart beats. Together they provide an overall measurement of blood pressure is at its highest and lowest. When these levels are too high, an individual may be diagnosed with HTN. HTN is the leading risk factor for developing CVD and is divided into two stages. HTN stage one is defined as a systolic mm Hg of 130-139, or a diastolic mm Hg of 80-89; and stage two is a systolic of 140 or higher or a diastolic of 90 or higher (American Heart Association [AHA], 2021). These numbers indicate an increased risk of mortality from a cardiovascular event, with each increment of 20 mm Hg systolic and 10 mm Hg diastolic higher doubling the risk (Carey et al., 2018).

Often, individuals do not present any signs or symptoms of HTN resulting in it going untreated, unless identified by a HCP. Leaving HTN uncontrolled for a prolonged amount of time results in the arteries that circulate vital blood throughout the body to become damaged, increasing the risk of heart attack, stroke, heart failure, kidney disease, peripheral artery disease, vision loss, and other conditions. There are serval risk factors for developing HTN, some of them can be controlled through lifestyle, and others cannot. Controllable risk factors include exposure to cigarette smoke (first and second hand), diabetes, obesity, hypercholesterolemia, unhealthy diet, and physical inactivity. Uncontrollable risk factors include family history, race/ethnicity, increasing age, chronic kidney disease, and obstructive sleep apnea (American Heart Association [AHA], 2021).

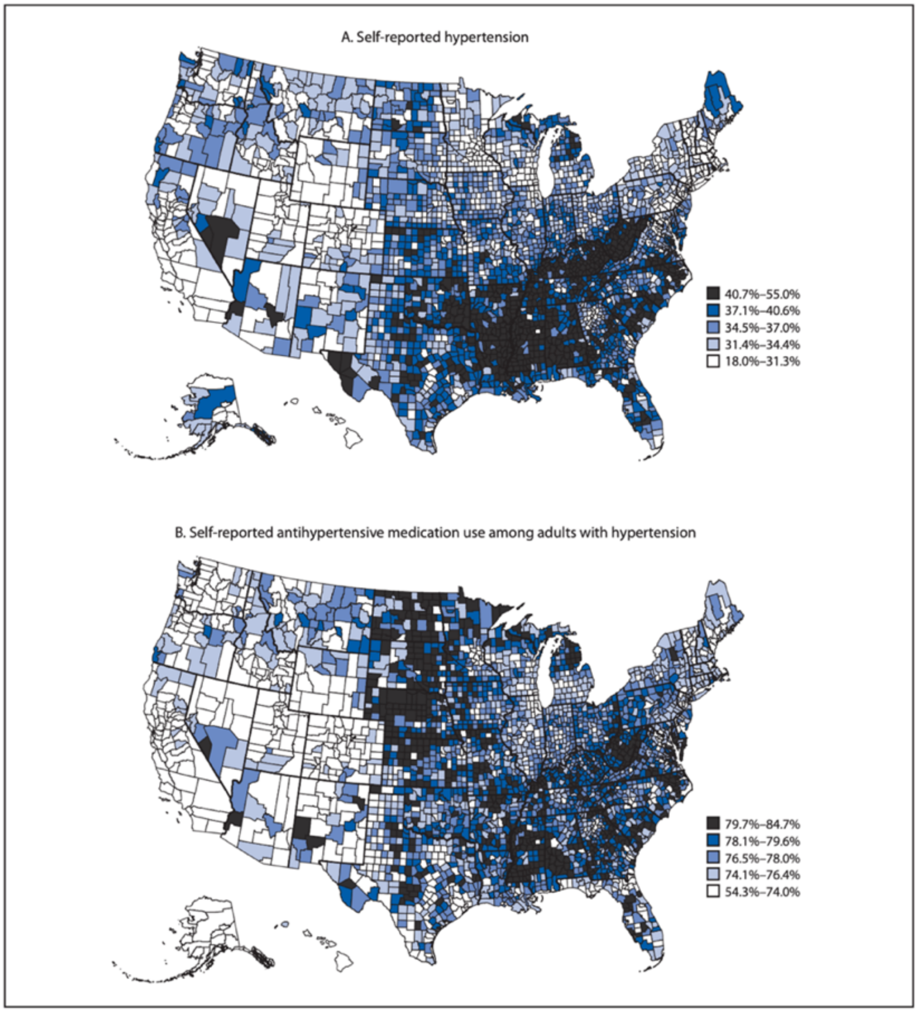
Approximately 32% of adults nationally suffer from stage two HTN (Carey et al., 2018), with rates higher in rural areas versus urban areas, at 40% and 29.4% respectively (Samanic et al., 2020). Figure 1.4, from the Centers for Disease Control and Prevention (CDC), provides a distinctive look of the nation from a county perspective versus statewide (Samanic et al., 2020). The breakdown on Map A illustrates how greatly CVD rates can vary between counties within the same state, while Map B shows the prevalence of antihypertensive medication use between counties.

It is evident that HTN in CCA region is disproportionately prevalent, with some rates doubled that of other regions of the U.S. Nationally, HTN rates have been on the rise with almost a 2% increase between 2011 and 2019 (United Health Foundation, 2022a). As seen in Figure 1.5, CCA rates have been rising along with the country, although at a more progressive rate in all CCA states except for TN. The greatest increase is seen in WV with an increase at almost 7% (United Health Foundation, 2022a). However, these are state level rates that include counties outside of CCA and do not provide a complete view of the variances within these states between Appalachian and Non-Appalachian counties. As shown with the breakdown of hypertension by county in the previous figure, there may be even greater temporal progression in CCA counties.

**Figure 1.4**

*Map of Self-Reported Hypertension*

**FIGURE. Model-based prevalence of self-reported hypertension (A) and antihypertensive medication use (B) among adults aged ≥18 years, by county — Behavioral Risk Factor Surveillance System, 2017***

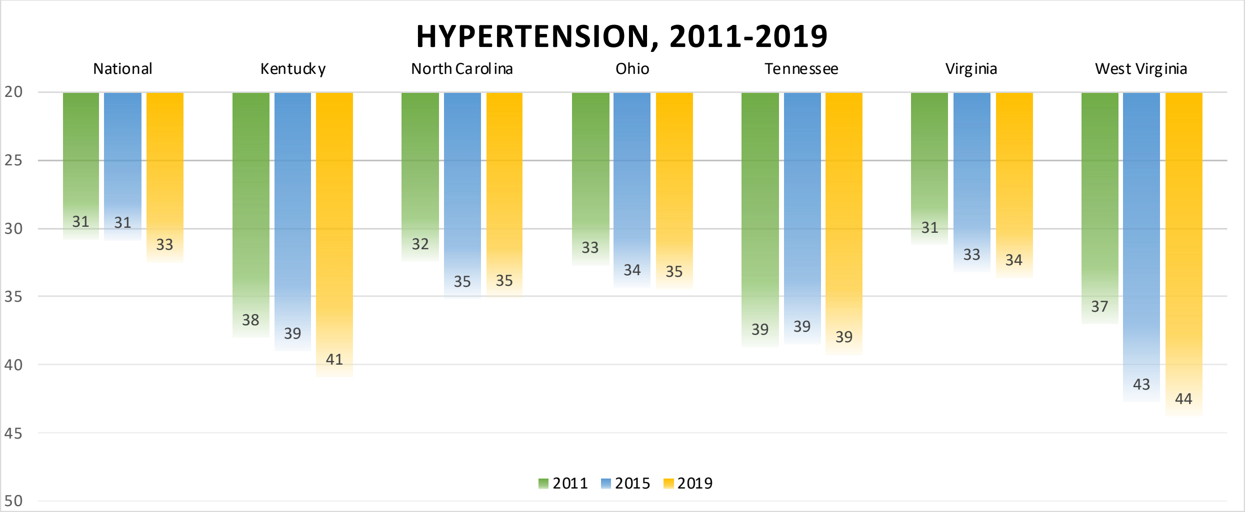


* Map A includes the 442,641 respondents to the 2017 Behavioral Risk Factor Surveillance System; Map B is limited to the 178,312 respondents with hypertension.

*Note.* Image source: Centers for Disease Control and Prevention Morbidity and Mortality Weekly Report, May 8, 2020 (Samanic et al., 2020).

**Figure 1.5**

*Percent of Adults with Hypertension by State and Year*

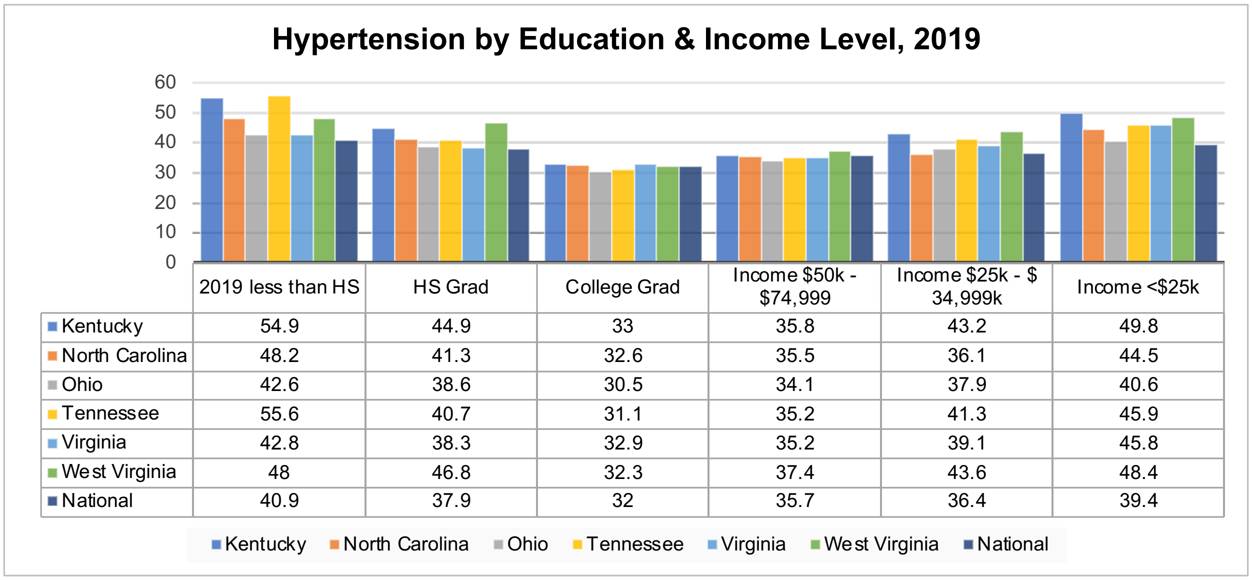


*Note.* Percent of adults, 18+, who reported being told by a health professional that they had high blood pressure. Data from America's Health Rankings analysis of CDC, Behavioral Risk Factor Surveillance System, 2011, 2015, and 2019 (United Health Foundation, 2022a).

Within the CCA region additional risk factors are present. Age plays a large role in these percentages, as the risk of HTN increases greatly with age, between the age groups of 18-44 and 44-64, the percent of those effected more than doubles (United Health Foundation, 2022a). Men are more likely to develop HTN, however rates vary from just a 0.3% difference in TN to a 5.5% difference in NC (United Health Foundation, 2022a). Disparities also exist between education and income levels, as education and income increase, the percentage of HTN decreases. Figure 1.6 exemplifies this inverse relationship, highlighting college graduates the least impacted (United Health Foundation, 2022a).

**Figure 1.6**

*Hypertension by Education and Income Level, 2019*



| | 2019 less than HS | HS Grad | College Grad | Income $50k - $74,999 | Income $25k - $ 34,999k | Income <$25k |
|---|---|---|---|---|---|---|
| ■ Kentucky | 54.9 | 44.9 | 33 | 35.8 | 43.2 | 49.8 |
| ■ North Carolina | 48.2 | 41.3 | 32.6 | 35.5 | 36.1 | 44.5 |
| ■ Ohio | 42.6 | 38.6 | 30.5 | 34.1 | 37.9 | 40.6 |
| ■ Tennessee | 55.6 | 40.7 | 31.1 | 35.2 | 41.3 | 45.9 |
| ■ Virginia | 42.8 | 38.3 | 32.9 | 35.2 | 39.1 | 45.8 |
| ■ West Virginia | 48 | 46.8 | 32.3 | 37.4 | 43.6 | 48.4 |
| ■ National | 40.9 | 37.9 | 32 | 35.7 | 36.4 | 39.4 |

*Note.* Percent of adults, 25+, who reported being told by a health professional that they had high blood pressure, by education and income level, 2019. Data from America's Health Rankings analysis of CDC, Behavioral Risk Factor Surveillance System, 2019 (United Health Foundation, 2022a).

**Hypercholesterolemia.** The next significant risk factor for developing CVD is HC, also known as high cholesterol. This condition occurs when cholesterol homeostasis processes in the body become disrupted. Examining the role of lipids in the body provides an understanding of why this condition occurs. Lipids come in several forms, such as fats, oils, phospholipids, waxes, and steroids, all which play essential roles by contributing to the creation of cell membranes, earwax, and hormones (Ahmed et al., 2021). Cholesterol also falls into this category as a type of steroid, which aides in the production of certain hormones, vitamin D, and substances for digestion (Ahmed et al., 2021; MedlinePlus, 2020a). Cholesterol is naturally produced in the liver and binds with proteins to make a form of lipoproteins, this combination makes travel through blood vessels possible (Ahmed et al., 2021; Ibrahim et al., 2022). Health issues arise when the quantity of “bad” cholesterol in the blood becomes elevated resulting in HC.

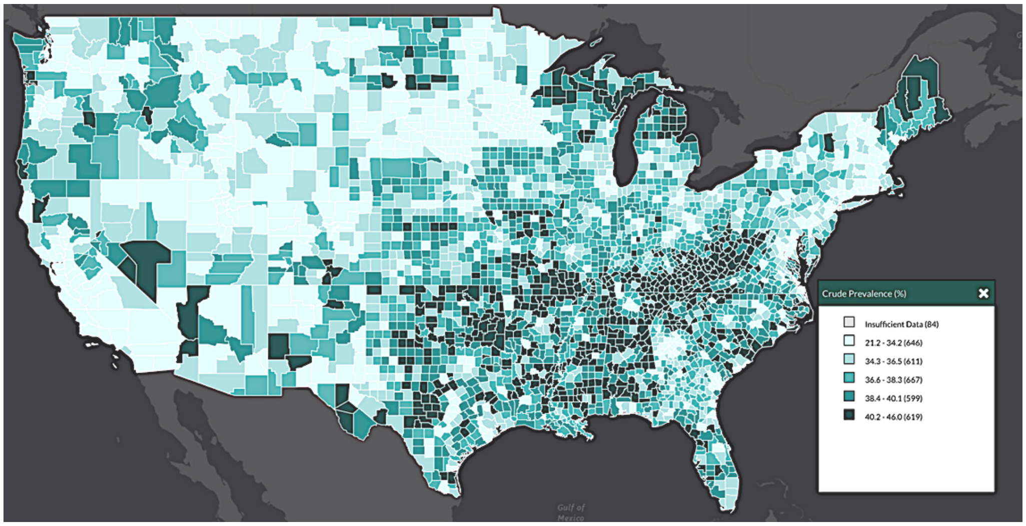
Two types of lipoproteins transport cholesterol through the body, low-density lipoprotein (LDL) and high-density lipoproteins (HDL) (MedlinePlus, 2020b). LDL is known as the “bad” cholesterol, high levels of LDL build up plaque in arteries, leading to coronary artery disease which restricts or blocks blood flow to the heart, potentially resulting in a stroke or heart attack (MedlinePlus, 2020a, 2020b). HDL is known as the “good” cholesterol, it transports cholesterol in the body back to the liver for disposal (MedlinePlus, 2020a, 2020b).

HC is often asymptomatic and requires a blood test to determine cholesterol levels. As with HTN, it has the potential to go untreated for long periods of time, until diagnosed by a HCP. Optimal LDL levels are less than 100 mg/dL, near/above optimal levels are 100-129 mg/dL, borderline high is 130-159 mg/dL, high is 160-189 mg/dL, and very high is 190 mg/dL and above (MedlinePlus, 2020b; Nelson, 2013). While high LDL is a health concern, the opposite is true with HDL. HDL levels below 40 mg/dL increases CVD risk, and levels above 60 mg/dL decrease the risk (Nelson, 2013; U.S. Department of Health and Human Services, 2005). Optimal total cholesterol levels are less than 200 mg/dL, borderline high is 200-239 mg/dL, and high is 240 mg/dL and above (U.S. Department of Health and Human Services, 2005).

The risk of CVD doubles when total cholesterol levels reach ≥240 mg/dL (Virani et al., 2020). In the U.S., it is estimated that approximately 28.5 million adults have a total cholesterol level within this range, accounting for 33.3% of the adult population (Virani et al., 2020). Figure 1.7 from the CDC provides insight on the percentage of adults with HC broken down by county. As with HTN, Figure 1.6 shows higher rates in the CCA region, and visible variances between counties in the same state. Rates have been trending downward decreasing nationally by 5.1% between 2011 and 2019 (America's Health Rankings, 2022a). However, with the exception of OH with a decrease of 6.1%, other states in the CCA region's downward trends are below average, WV has had the slowest decline at just 1% (America's Health Rankings, 2022a). Figure 1.8 displays this trend for each of the states that reside in CCA. However, these state level rates include counties outside of CCA and do not provide a complete view of the variances within these states between Appalachian and Non-Appalachian counties.

**Figure 1.7**

*Crude Prevalence of Hypercholesterolemia*

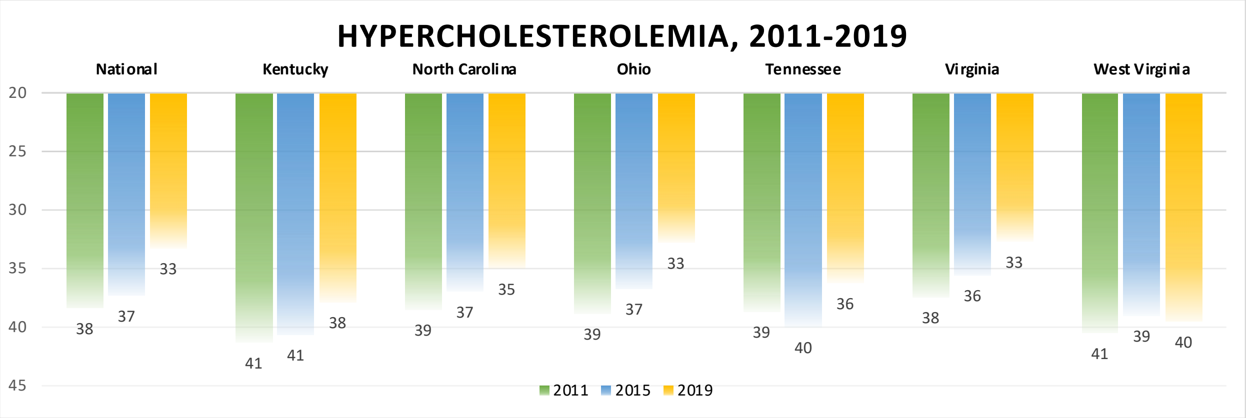


*Note.* Percentage of HC among adults 18+, screened in the past five years, by county, 2017. Image source: CDC, Interactive Atlas of Heart Disease and Stroke, US Map – County Level, Risk Factors, High Cholesterol Awareness (CDC Division for Heart Disease and Stroke Prevention, 2020).

HC can be caused by either genetic or lifestyle factors. However, most commonly, it is the result of controllable behaviors such as eating a diet that is high is saturated and trans fats, smoking, and lack of physical activity (PA) (MedlinePlus, 2020a, 2020b). The development of HC does not happen overnight, it is often the consequence of an unhealthy choices over years, subsequently the percent of adults between 45 to 64 have rates more than double of those between 18 to 44 (America's Health Rankings, 2022a). Higher education and income levels are shown to provide some protection as Figure 1.9 demonstrates, with college graduates accounting for the lowest rates (America's Health Rankings, 2022a).

**Figure 1.8**

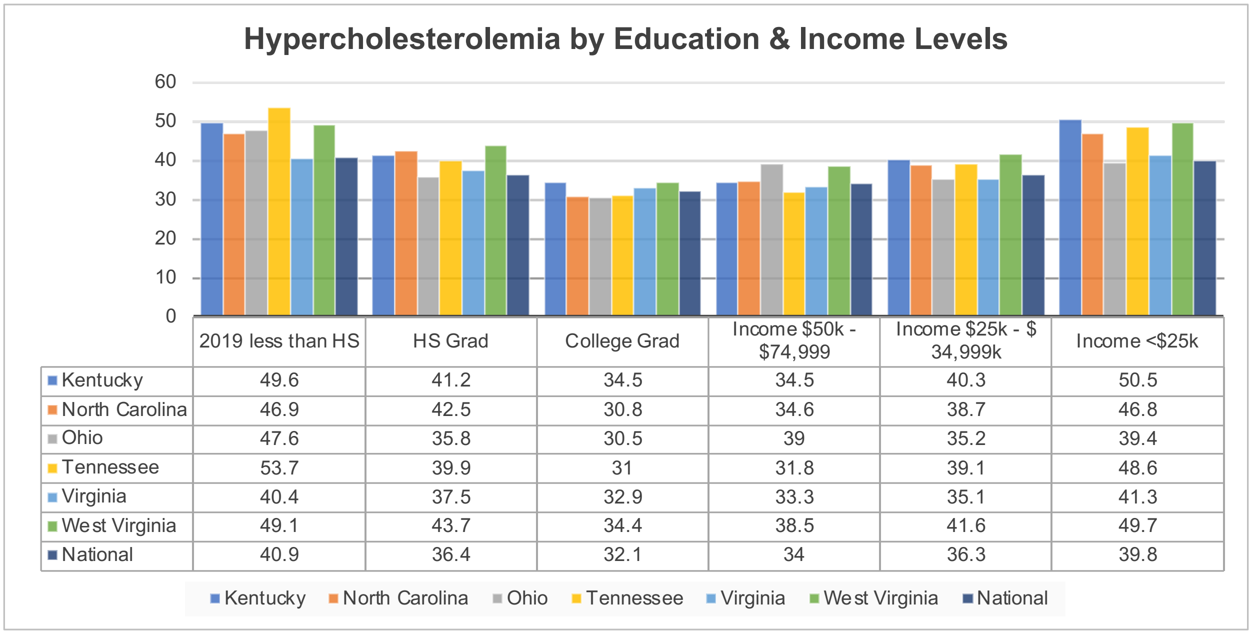
*Percent of Adults with Hypercholesterolemia by State and Year*



*Note.* Percent of adults, 18+, who reported being told by a health professional that they had high cholesterol. Data from America's Health Rankings analysis of CDC, Behavioral Risk Factor Surveillance System, 2011, 2015, and 2019 (America's Health Rankings, 2022a).

**Figure 1.9**

*Hypercholesterolemia by Education and Income Level, 2019*



| | 2019 less than HS | HS Grad | College Grad | Income $50k - $74,999 | Income $25k - $ 34,999k | Income <$25k |
|---|---|---|---|---|---|---|
| Kentucky | 49.6 | 41.2 | 34.5 | 34.5 | 40.3 | 50.5 |
| North Carolina | 46.9 | 42.5 | 30.8 | 34.6 | 38.7 | 46.8 |
| Ohio | 47.6 | 35.8 | 30.5 | 39 | 35.2 | 39.4 |
| Tennessee | 53.7 | 39.9 | 31 | 31.8 | 39.1 | 48.6 |
| Virginia | 40.4 | 37.5 | 32.9 | 33.3 | 35.1 | 41.3 |
| West Virginia | 49.1 | 43.7 | 34.4 | 38.5 | 41.6 | 49.7 |
| National | 40.9 | 36.4 | 32.1 | 34 | 36.3 | 39.8 |

*Note.* Percent of adults, 25+, who reported being told by a health professional that they had high cholesterol, by education and income level, 2019. Data from America's Health Rankings analysis of CDC, Behavioral Risk Factor Surveillance System, 2019 (America's Health Rankings, 2022a).

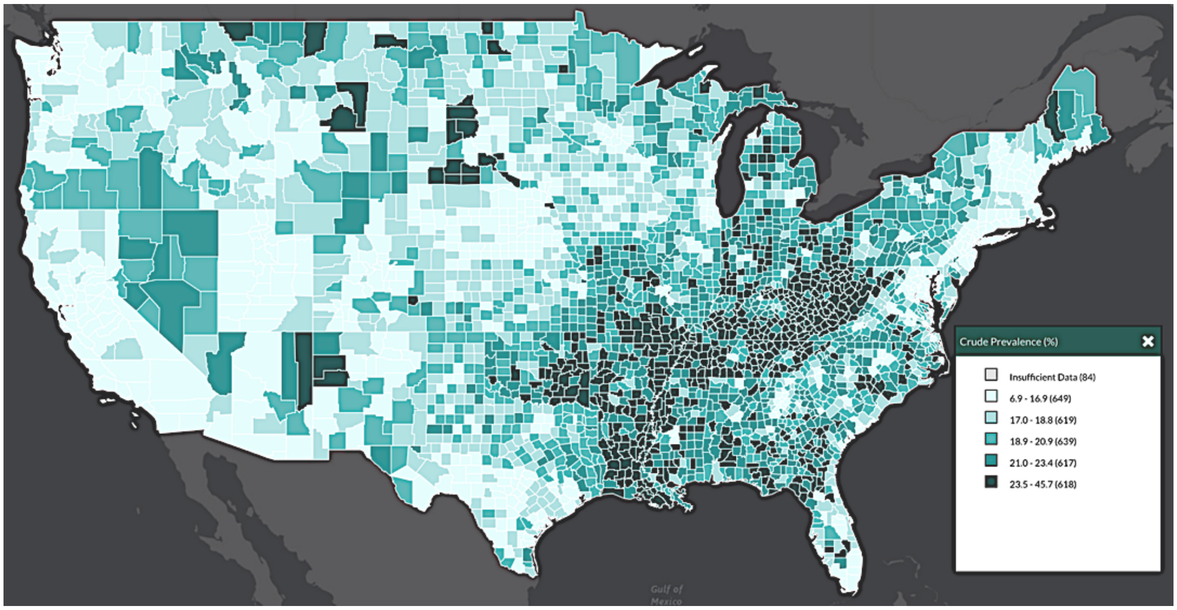
**Cigarette Smoking.** Cigarette smoking is the leading cause of preventable mortality and morbidity in the U.S., accounting for over 480,000 deaths every year (America's Health Rankings, 2022b). It's detrimental long term effects on the body result in the damage of almost every organ, and greatly increases an individual's susceptibility to respiratory diseases, diabetes, rheumatoid arthritis, and some forms of cancer (National Center for Chronic Disease Prevention and Health Promotion Office on Smoking and Health, 2020). As it impacts other organs in the body, it also has a profound impact on the development of CVD, causing one in four CVD related deaths (Centers for Disease Control and Prevention Office on Smoking and Health, 2022). The chemicals in cigarettes cause blood vessels to become inflamed, leading to narrowed arteries resulting in the buildup of plaque, which reduces the ability of oxygen carrying blood to circulate throughout the body (Centers for Disease Control and Prevention Office on Smoking and Health, 2022). Moreover, an individual does not have to be a smoker to suffer these consequences, second hand smoke also has damaging effects on the body with over 41,000 deaths a year contributed to this exposure (National Center for Chronic Disease Prevention and Health Promotion Office on Smoking and Health, 2021).

Smoking rates vary throughout the U.S., with areas seeing as low as 6.9%, and as high as 45.7% (CDC Division for Heart Disease and Stroke Prevention, 2020). Figure 1.10 provides a look at the percentage of smokers, by county throughout the nation highlighting higher use in CCA. Rates have been on the decline, dropping nationally by just over 5% between 2011 and 2019, averaging 15.9% in 2019 (America's Health Rankings, 2022b). As shown in Figure 1.11, rates in the CCA region, apart from VA, have also been decreasing, although at a slower rate and remain above the U.S. average. Further variance between counties is not accounted for in Figure 1.11, as it only provides state averages.

Adults who smoke in CCA are more likely to be younger, the percentage of those between ages 18 to 44 who smoke range from 16.1% in VA, to 37.9% in KY; those between 45 to 64 range from 16.3% in VA to 27.1% in WV; and from 65 and older range from 10.1% in VA to 13.8% in WV (America's Health Rankings, 2022b). Within the CCA area, it is evident that even wider gaps in rates are present among those with lower education and income levels. Figure 1.12 illustrates the influence of these two crucial factors compared to the average rates in CCA states, with the lowest rates among those with college degrees (America's Health Rankings, 2022b).

**Figure 1.10**

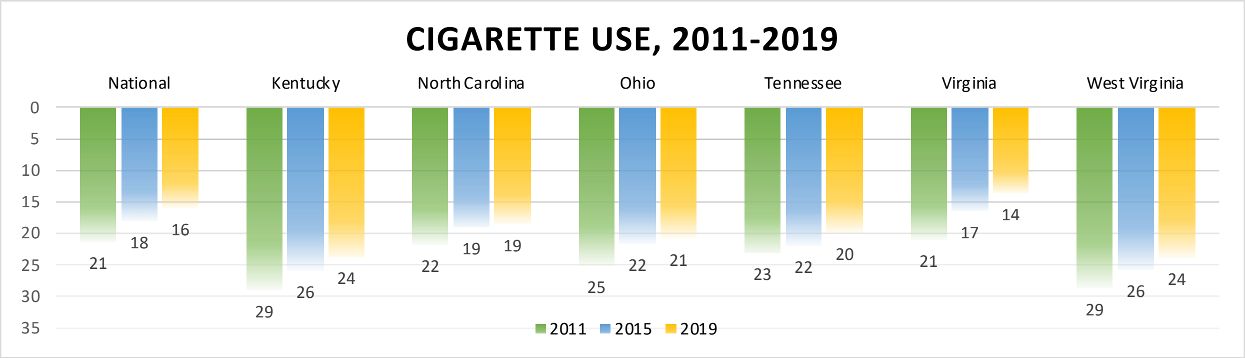
*Crude Prevalence of Smokers by County*



*Note.* Current smoker status percentages among adults 18+ by county, 2018. Image source: CDC, Interactive Atlas of Heart Disease and Stroke, US Map – County Level, Risk Factors, Current Smoker Status (CDC Division for Heart Disease and Stroke Prevention, 2020).

**Figure 1.11**

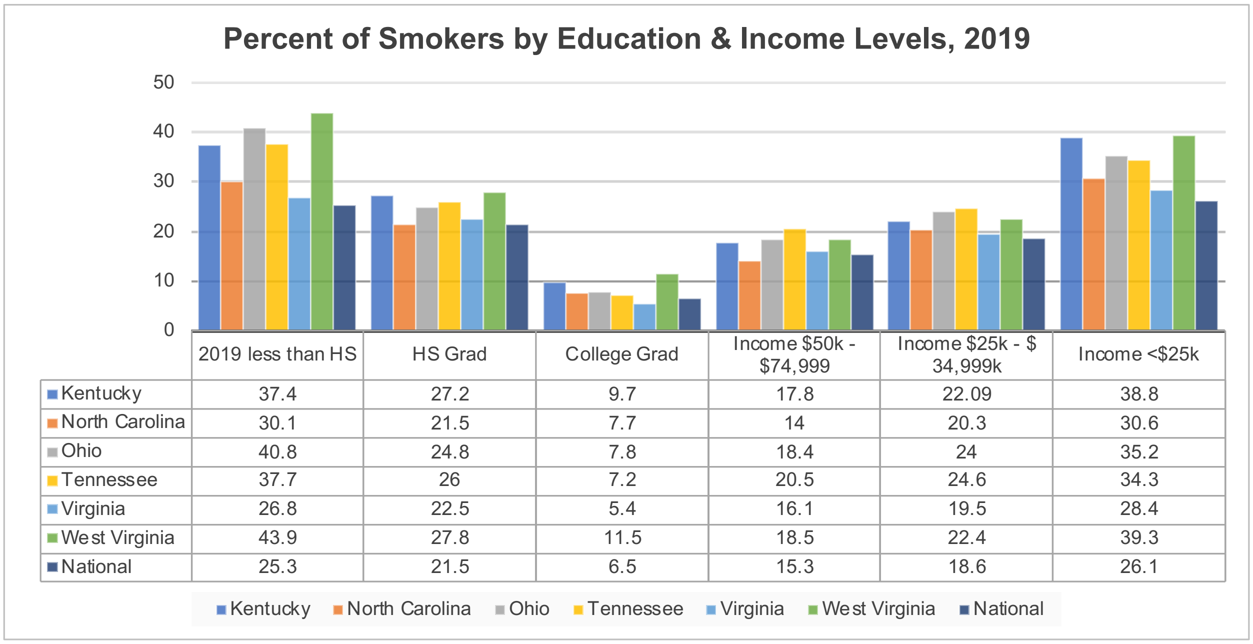
*Percentage of Smokers by State and Year*



*Note.* Percent of adults, 18+, who reported smoking at least 100 cigarettes in their lifetime and currently smoke daily or some days. Data from America's Health Rankings analysis of CDC, Behavioral Risk Factor Surveillance System, 2011, 2015, and 2019 (America's Health Rankings, 2022b).

**Figure 1.12**

*Smokers by Education and Income Level, 2019*



| | 2019 less than HS | HS Grad | College Grad | Income $50k - $74,999 | Income $25k - $ 34,999k | Income <$25k |
|---|---|---|---|---|---|---|
| Kentucky | 37.4 | 27.2 | 9.7 | 17.8 | 22.09 | 38.8 |
| North Carolina | 30.1 | 21.5 | 7.7 | 14 | 20.3 | 30.6 |
| Ohio | 40.8 | 24.8 | 7.8 | 18.4 | 24 | 35.2 |
| Tennessee | 37.7 | 26 | 7.2 | 20.5 | 24.6 | 34.3 |
| Virginia | 26.8 | 22.5 | 5.4 | 16.1 | 19.5 | 28.4 |
| West Virginia | 43.9 | 27.8 | 11.5 | 18.5 | 22.4 | 39.3 |
| National | 25.3 | 21.5 | 6.5 | 15.3 | 18.6 | 26.1 |

*Note.* Percent of adults, 25+, who reported smoking at least 100 cigarettes in their lifetime and currently smoke daily or some days, by education and income level, 2019. Data from America's Health Rankings analysis of CDC, Behavioral Risk Factor Surveillance System, 2019 (America's Health Rankings, 2022b).

HTN, and HC are both often the consequence of unhealthy lifestyle behaviors such as an unhealthy diet, obesity, smoking, and an inadequate amount of PA, while cigarette smoking on its own is a behavioral choice. Research has found that behaviors are driven by a variety of factors, subsequently philosophical models and theories for health behavior change attempt to identify what drives these factors in order to inform targeted interventions. The Health Belief

Model (HBM) was developed in the early 1950s in an effort to understand why people failed to implement disease prevention strategies, utilizing six constructs as its guide: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action, and self-efficacy (LaMorte, 2019a; Rural Health Information Hub, 2018b). Another theory, the Theory of Planned Behavior was developed in 1980 in an attempt to predict an individual's intention to perform a behavior by evaluating the following six constructs: attitudes, behavioral intention, subjective norms, social norms, perceived power, and perceived behavioral control (LaMorte, 2019b; Rural Health Information Hub, 2018c). These among other behavioral theories have common aspects at their core, behaviors are the result of a complex and dynamic interplay of an individual's internal perceptions and external influences.

A sample of studies conducted in the Appalachian region have sought to explore perceptions of health in relation to behaviors and medical conditions. While these small studies cannot be considered a representative sample of the region, they highlighted findings from previous research. These studies found that Appalachians tended to be less likely to identify the extent that health behaviors drove morbidity, as well as associate morbidity factors as poor health. Questions on survey at a fair in WV collected health information from participants, including nutrition behaviors and weight, exercise behavior, and risk factors for CVD including blood pressure, cholesterol levels, smoking status, and self-rated health (Griffith et al., 2011). They found that although being sedentary, hypertensive, overweight, or hyperlipidemic, 65% to 79% reported being healthy while living with one of these conditions; and 57% to 66% had at minimum two conditions or poor health behaviors (Griffith et al., 2011). Another study found rural West Virginians correlated good health to job productivity, resulting in forgoing preventative care and only seeking medical services when symptoms became severe (Deskins et al., 2006). Researchers also examined obesity beliefs between Appalachians and Non-Appalachians, and found Appalachians were significantly less likely to report health behaviors as a determining factor (Rice et al., 2018). Moreover, a survey among West Virginians examined perceived behavioral control over mitigating cancer odds found that 48% of adults believed there was nothing they could do to prevent cancer, and 36% said they would not want to know if they had cancer; illustrating general beliefs about the control one has over disease progression (Deskins et al., 2006).

Overall, these studies begin to provide some insight into the knowledge and beliefs of this population and begin to touch on several constructs of behavioral theories and models. It has been well established that the major risk factors for CVD can be mitigated by living a healthy lifestyle, therefore the perception of control over health outcomes is an important consideration. Additionally, it is important to note that internal perceptions are not developed in isolation, as external influences play an integral role in influencing and molding these perceptions. These perceptions, in conjunction with community facilitators and barriers to developing and sustaining healthy lifestyles all have a role to play.

### ***Community Determinants***

Communities designed to promote healthy lifestyles through the built environment, health policies, and community programs provide the necessary infrastructure to promote health at the primordial level. The AHA Guide for Improving Cardiovascular Health at the Community Level provides a framework of strategies, goals and recommendations, for communities to implement and organize around three dimensions: (1) the behaviors targeted for change; (2) the community settings in which interventions might be implemented; and (3) the interventions themselves (Pearson et al., 2003). The intention of these dimensions is to inform strategies in the framework to create an environment conducive to health. The framework itself consists of six strategies: assessment of the community, education, community organization and partnering, assuring personal health services, environmental change, and policy change (Pearson et al., 2003). These strategies are congruent with the constructs of the SEM, which seeks to assess influences on behavior through exploration of individuals and their environments. As such, the impact of built environment, community programs, and health policies on CVD prevention will be explored.

**Built Environment.** When considering strategies to impact the health of a community, the reciprocal relationship between a community's built environment and its populations health must be assessed. The built environment is the physical make up of communities, it consists of the community's infrastructure, homes, businesses, streets, sidewalks, and green spaces, among other things. Public concerns over the built environment and its impact on health has been an evolving issue spanning throughout human history. The desire to decrease the spread of disease has driven populations to develop sewer systems, improve work conditions, establish specific zoning for homes and industrial facilities, and improve air quality. Subsequently, these accomplishments have successfully improved health, decreased the spread of infectious disease and lengthened the life span. While the spread of infectious disease has decreased over the centuries, the prevalence of chronic diseases has emerged as the leading cause of morbidity and mortality, challenging communities to develop new strategies to mitigate their impact on the population.

Many chronic diseases stem from poor diet, obesity and inactivity. Studies have found physical inactivity increases the relative risk of coronary artery disease by 42%, HTN by 30%, stroke by 60% (Booth & Lees, 2007); and a 2% increase in consumption of trans fats is associated with a 23% increase in coronary events (Bhatnagar, 2017). Additionally, the Nurses' Health study found that women who lived a healthy lifestyle were 80% less likely to have coronary events (Stampfer et al.). The built environment has a significant influence on these outcomes, studies have found that factors such as the walkability of neighborhoods, the density of fast-food restaurants, proximity of grocery stores and recreational spaces, access to cigarettes, transportation services, healthcare access, and land-use mix all play a role. A study of middle aged and older adults in Portland, Oregon found neighborhoods with higher walkability had a negative association with participants weight and waist circumference, and higher density of fast-food restaurants had a positive association (Li et al., 2009). Systematic reviews of built environment and obesity determined a positive association between food prices, fast food restaurants, convivence stores, recreational facilities, minutes spent in a car and BMI, and a negative association between presence of supermarkets, and fruit and vegetable prices (Malambo et al., 2016; Papas et al., 2007).

Many of these studies examined the interplay of the built environment and health in urban areas, however 55% of the population of Appalachia live in rural areas. The geographical and social environmental influence across the levels of urbanization present different challenges for communities. One study provided some insight and examined personal and community barriers that contributed to obesity related to inactivity in rural, micropolitan, small metropolitan, and large metropolitan areas. It found that participants in rural areas were more likely to cite lack of sidewalks, poor health, fear of injury, dislike of exercise, and concerns about traffic safety (Joshu et al., 2008). Another study utilized the Rural Active Living Assessment to explore barriers to physical activity in 16 rural towns within the North Carolina Appalachian Mountains. It found many of the towns lacked safety features to promote activity for pedestrians, such as sidewalks on both sides of main streets, crosswalks, distinguishable shoulders on the side of streets, and schools that children could walk to (Hege et al., 2017).

The built food environment in rural areas is also a topic that has not been extensively studied.(Chrisman et al., 2015) Researchers from the University of Pittsburg sought to examine the role of the changing food environment and obesity in the Appalachian region from 2007 to 2011, by examining the change in the amount of grocery stores, convenience stores, supercenters, and fast-food restaurants. It found although there was an increase in the number of supercenters, there was an overall decrease in food availability as a result of a decrease in the per capita number of grocery stores, convenience stores, and fast-food restaurants. The impact of decreasing grocery stores was significantly associated with increasing age adjusted obesity rates, while the changes in other food establishment did not cause a significant impact (Booth et al., 2017). To explain this, it was suggested that the lower prices of supercenters incentivized this population to drive longer to supercenters, which in return decreased the economic feasibility of smaller grocery stores. This simultaneously changed dietary patterns away from healthier perishable food items to processed foods with longer shelf lives in order to offset the time and transportation demands of driving to supercenters (Booth et al., 2017). Another cross-sectional study in rural Southwest Georgia surveyed adults between the ages of forty and seventy, found healthy weight participants were more likely to report access to healthy foods in their neighborhoods. However, it did not find a difference among healthy weight, overweight and obese participants and the consumption of fruits, vegetables, and fat (Kegler et al., 2014).

**Community Programs.** While the built environment can provide the necessary infrastructure to support healthy lifestyles, community programs can provide a launching point to educate and increase the population’s self-efficacy. However, successfully sustaining programs to decrease CVD risk by improving health through physical activity and healthy diets, has been met with many challenges. A study in rural KY sought to examine the challenges and opportunities to implement physical activity community programs through focus groups and key informant interviews. Participants cited without a large population, community programs struggled economically from low or sporadic participation, ultimately resulting in their closure (Kruger et al., 2012). One participant from the health department cited being unable to justify the cost of maintaining an aerobics class with low attendance; while other participants discussed having to travel 45 minutes to workout facilities made them unfeasible, due to time constraints and poor road conditions (Kruger et al., 2012). Participants also identified the potential for local churches to successfully implement community programs, due to their accessibility and their ability to incorporate the whole family.

Dietary changes to improve health and reduce CVD risk has been another focus of community programs in the CCA region. A rural Appalachian study in KY sought to understand the influence of culture on dietary preferences, this information was then used to inform a culturally relevant cooking program. Their assessment found that barriers to achieving a healthy diet included cost, lack of knowledge, food availability, time constraints, and concern over the acceptance of new foods from other family members (Hardin-Fanning & Ricks, 2017). Utilizing this information, a cooking program was developed that ensured all ingredients could be easily found locally, recipes consisted of traditional foods prepared in a healthier method, recipes were simple with few ingredients, and time saving tips were taught. The program was successfully able to introduce new foods and recipes to participants, and knowledge on how to incorporate healthier food choices into their cooking routine. However, the influence of family attachment appeared to have a potentially substantial impact on participants ability to sustain these changes.

Participants whose families did not enjoy the recipes cited it would be a waste of money to continue to prepare them, while families that did enjoy the new foods were more likely to continue to incorporate them (Hardin-Fanning & Ricks, 2017).

Taking a more holistic approach, a pilot study in rural Appalachian OH sought to improve health through a program that simultaneously addressed diet and exercise. This intervention used the Complete Health Improvement Program, a program that has been found to reduce risk factors for chronic diseases through a comprehensive lifestyle modification approach (Drozek et al., 2014). Each of the 16 two-hour classes provided participants with educational material, a cooking demonstration, a group discussion, and an exercise component. The program, coupled with a daily 30-minute walk, focused on a plant-based diet that emphasized whole foods, fresh fruit and vegetables, and low sodium, fat and sugar. Prior to the start, participant chronic disease risk factors were obtained through the measurement of BP, BMI, cholesterol, and plasma glucose, for comparison upon the conclusion of the program. This study found that all participants had significant improvements in all most all of the identified risk factors (Drozek et al., 2014). The success of this program reinforces the impact lifestyle has on mitigating disease risks, and the potential community programs have on improving overall health.

Overall, these small studies at the local community level illustrate only some of the challenges and opportunities community programs encounter throughout the CCA region, and do not provide enough data to provide a comprehensive look into community programs. The small size of these and other similar studies within the region presents limitations to achieving a saturation of themes within the research. Additionally, review of the literature has resulted in the identification of many other health programs within the region targeted towards children in the school setting, versus adults that may have already developed unhealthy habits.

**Health Policies.** Local, state and governmental health policies have the power to influence behaviors and shape communities into environments conducive to supporting healthy lifestyles, ultimately reducing risk for CVD. The development of strategic policies can target specific risk factors at all levels of the SEM through a variety of legislation, regulations, and public programs. The U.S. government has a long history of safeguarding the public through policies, with one of the most significant initiatives being the passage of the Pure Foods and Drugs act in 1906. From this act, the Food and Drug Administration (FDA) was given the authority to regulate foods and medications for the safety of the population. As it has grown, new strategies to improve the population's diet have been developed, such as nutrition labels on all food packaging to keep the public informed, and the banning of artificial trans fats due to their link heart disease.

In addition to the FDA, other governmental policy initiatives to address CVD are taking place in the U.S. Department of Health and Human Services (HHS), as well as the CDC and the Centers for Medicare & Medicaid Services (CMMS). The department of HHS's Office of Disease Prevention and Health Promotion (ODPHP), Healthy People 2030 initiative provides data-driven national objectives with a goal to improve cardiovascular health and reduce deaths from heart disease and stroke. The ODPHP currently has 19 objectives under this goal, however all but two of the objectives are in the baseline only, or developmental stage. Of the remaining two, the objective aimed to reduce death due to coronary heart disease has seen improvement, while the objective to reduce stroke deaths has seen little to no detectable change (U.S. Department of Health and Human Services, 2022).

The CDC's Division for Heart Disease and Stroke Prevention, and the CMMS co-lead a national initiative called Million Hearts, the goal of Million Hearts 2027 is to prevent one million heart attacks and strokes within 5 years. To achieve this, Million Hearts partners with other private and public sector organizations to target three main priorities: building healthy communities, optimizing care, and focusing on health equality (Million Hearts, 2020). The priorities within building healthy communities are decreasing tobacco use, physical inactivity, and particle pollution exposure. While optimizing care focuses on increasing use of cardiac rehabilitation, and improving appropriate aspirin or anticoagulant use, blood pressure control, cholesterol management, and smoking cessation. Finally, focusing on health equality targets pregnant and postpartum women with hypertension, and people from minority groups, lower incomes, live in rural areas or access deserts, or have behavioral health issues and use tobacco. Million Hearts has seen success and estimates 135,000 heart attacks, strokes, and related cardiovascular events were prevented during their first five-year cycle between 2012 and 2016; moreover, this translates into approximately 5.6 billion dollars in direct medical costs saved (Million Hearts, 2020). Within the CCA region, this initiative has partnered with organizations in each of the states to raise CVD awareness and provide education to their populations.

At the state policy level, the CDC's Nutrition, Physical Activity, and Obesity Legislation provides data on legislation and regulations congruent with its name between the years of 2001 and 2017. This data was filtered to only include states within the CCA region, then within the "setting" categories early care and education, medical and/or hospital, school/after school were excluded, leaving only the community setting, next under "status" policies that were not enacted were excluded, and finally policies before 2012 were excluded to provide a snapshot of recent community level initiatives. Table 1.1 provides the few policies resulting from the filtered search that are targeted for the general population, Table 1.2 provides an abstract for each. This snapshot consists of eleven total policies, nine pertain to nutrition and promoting healthy eating, two pertain to providing recreational spaces to encourage physical activity, and none pertain to obesity (CDC National Center for Chronic Disease Prevention and Health Promotion Division of Nutrition Physical Activity and Obesity, 2018). Overall, this delineates a slow rate of policy change within the CCA states targeted at nutrition, physical activity, and obesity.

**Table 1.1**

*Nutrition, Physical Activity, and Obesity Legislations and Regulations by State, 2012-2017*

| Year | State | Health Topic | Policy Topic | Title | Citation | Policy Type |
|---|---|---|---|---|---|---|
| 2012 | KY | Physical Activity | Parks, Recreation and Trails | Promoting Enhanced Opportunities for Outdoor Activity for Kentucky's Children | HCR29 | Legislation |
| 2012 | KY | Nutrition | Food Assistance Programs | Nutrition Program for Older Persons | 20001 | Regulation |
| 2012 | NC | Nutrition | Task Forces/Councils | An Act to Extend the Sunset Date | S491 | Legislation |
| 2012 | OH | Nutrition | Food Assistance Programs | Uniform Definitions of Title XX Services | 17196 | Regulation |
| 2012 | OH | Nutrition | Nutrition Standards | Meal Service | 17020 | Regulation |
| 2012 | WV | Nutrition | Agriculture and Farming | Department of Agriculture | H4046 | Legislation |
| 2012 | WV | Nutrition | Farmers Markets | Making Appropriations of Public Money out of the Treasury | S160 | Legislation |
| 2014 | KY | Nutrition | Access to Healthy Foods | Nutrition Program For Older Persons | 20577 | Regulation |
| 2015 | KY | Nutrition | Disparities/Equity | An act amending the 2014-2016 executive branch and transportation cabinet biennial budgets, making an appropriation therefor, and declaring an emergency | HB510 | Legislation |
| 2017 | NC | Physical Activity | Parks, Recreation and Trails | State Parks—Trails | SB244 | Legislation |
| 2017 | TN | Nutrition | Access to Healthy Foods | Food and Food Products - As introduced, changes from 15 days to 14 days the time in which a department of agriculture agent must remove a tag | SB651 | Legislation |

*Note.* Data from CDC's Nutrition, Physical Activity, and Obesity Legislation (CDC National Center for Chronic Disease Prevention and Health Promotion Division of Nutrition Physical Activity and Obesity, 2018).

**Table 1.2**

*Legislation and Regulation Abstracts by Citation*

| Citation | Abstract |
|---|---|
| HCR29 | Makes a public policy goal to increase outdoor participation of the states' children and young adults. Encourages children to explore outdoor recreational venues, and bike in safe areas and routes to schools, among other things. |
| 20001 | Establishes nutrition requirements and provides for nutrition education and counseling for meals for qualified seniors in his or her place of residence and sets out requirements for home-delivered meal services. |
| S491 | Extends the sunset date on the law establishing the North Carolina Sustainable Local Food Advisory Council. |
| 17196 | Defines food assistance as the provision and distribution of supplemental food items to needy individuals and families to reduce hunger and to promote healthy nutrition and diet, among other things. |
| 17020 | Sets out nutrition requirements, based on the Dietary Guidelines for Americans, for home-delivered meals in the state, and the menus required for each meal. Requires that modified meals be given to individuals with specific needs. |
| H4046 | Develops marketing, promotional and development programs to advance the states' agriculture sector and sets regulations for the marketing of agricultural products. |
| S160 | Appropriates monies for various farmers' markets in the state and to the United States Department of Agriculture Senior Farmers' Market Nutrition Coupon Program. |
| 20577 | Sets the eligibility requirements for the nutrition program for older persons, which provides access to healthy meals for elderly individuals without access to daily nutritious meals. Provides funding for nutritious meals and sets nutrition requirements. |
| HB510 | Appropriates monies to Farms to Food Banks to benefit both Kentucky farmers and the needy by providing fresh, locally grown produce to food pantries. |
| SB244 | Creates the Coastal Crescent Trail and adds it to the Mountains-to-Sea state trail. |
| SB651 | Encourages the expansion of agricultural sales by farmers and of the accessibility to farm-produced foods by consumers through: facilitating the purchase and consumption of fresh local agricultural products; enhancing the agricultural economy; and providing Tennesseans with unimpeded access to healthy food from known sources. |

*Note.* Data from CDC's Nutrition, Physical Activity, and Obesity Legislation (CDC National Center for Chronic Disease Prevention and Health Promotion Division of Nutrition Physical Activity and Obesity, 2018).

The fundamental role of built environment on the population's health has been well established, however addressing the various barriers and needs to create these environments requires resources that may not be available. Studies within the CCA region have identified due to the ruralness of many areas, it is difficult for community programs and businesses intended to promote health, to remain economically sustainable. Compounded with a sprawling geography, that does not support ideal land-use mix, public transportation, nor implementation of safety infrastructure such as continuous well-lit sidewalks present even more challenges for communities. State level policies have leverage to implement programs to address these needs, however development of such policies has been a slow process, potentially due to the large financial burden that would need to be untaken. Subsequently, this remains an area that requires more focus on each individual community to determine what is most needed, what economically feasible changes can be made, and what partnerships are needed to facilitate an impact on the community's health.

### *Patient Centered Care*

In healthcare systems that strive to provide dynamic state of the art care for a mass variety of illnesses and injuries, it is a challenge to also address and tailor to the individualized needs of its diverse population. Individualized needs may vary based on culture, socio-economic status, access, and personal preferences. This results in the need for HCPs to individualize standard best practice treatment plans from one patient to the next, when aiming to develop the best course of actions for their patients. The PCC model seeks to address this very issue and has been used to develop guidelines for practitioners to consider and implement. Given the progressive nature of CVD, and the opportunity to mitigate disease processes through early treatment, access to healthcare and relationships between HCPs and patients it a critical component.

**Definitions of PCC.** The concept of PCC was initially introduced decades ago and has subsequently been evolving as the preferences of the population has changed and technology has advanced. The Institute of Medicine (IOM) in their 2001 report: Crossing the Quality Chasm: A New Health System for the 21st Century, defined patient-centered as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions"(Institute of Medicine, 2001). The report outlines six dimensions of PCC drawing on previous research conducted by the Picker Institute and includes: (1) respect for patient's values, preferences, and expressed needs; (2) coordination and integration of care; (3) information, communication, and education; (4) physical comfort; (5) emotional support – relieving fear and anxiety; and (6) involvement of family and friends (Institute of Medicine, 2001). The combination and coordination of these six dimensions seek to put the patient, as an individual, at the center of their healthcare experiences.

The American College of Cardiology Foundation Clinical Quality Committee has further examined PCC in cardiovascular medicine and identified eight essential elements in their 2012 report: (1) enhanced clinician-patient communication; (2) health literacy; (3) clinician-directed patient education; (4) assessment of patient-centered outcomes; (5) shared decision-making; (6) collaborative care planning; (7) collaborative goal setting; (8) patient empowerment and self-management (Walsh et al., 2012). Many of these elements overlap with the dimensions identified by the IOM, including communication, education/health literacy, and shared decision making.

The literature agrees that patient-provider communication is a core component of PCC in and outside of cardiovascular care. The term patient-centered communication identifies "the patient perspective, and the psychosocial context along with shared understanding, power, and responsibility" (Walsh et al., 2012), as fundamental ingredients in this pursuit. American College of Cardiology Foundation Clinical Quality Committee have developed seven essential tasks to achieve this desired level of communication and include: (1) build the doctor-patient relationship; (2) open the discussion; (3) gather information; (4) understand the patient's perspective; (5) share information; (6) reach agreement on problems and plans; and (7) provide closure (Walsh et al., 2012). Development and refinement of these skills by healthcare providers has the potential to make a substantial impact on the health of their patients. Effective communication has been shown to be associated with improved health status, recall, treatment adherence, and satisfaction (King & Hoppe, 2013; Rao et al., 2007). One meta-analysis looked at the effect communication had on patient's adherence to treatment, and the impact of physician communication training. This research found a significant correlation between physician communication and patient adherence, with poor communication resulting in a 19% higher risk of non-adherence (Haskard Zolnierek & DiMatteo, 2009). Additionally, physicians who have received communication training increased the odds of their patient's adhering to treatment by 1.62 times, while those untrained had nonadherence 1.27 time greater (Haskard Zolnierek & DiMatteo, 2009).

Patient health literacy and provider education are essential components to ensuring PCC is achieved. Health literacy is defined as, "the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decision" (Berkman et al., 2011). Adequate health literacy involves a combination of skills including the ability to read and write, interpret information, understand quantitative data, communicate effectively orally, and listen (Berkman et al., 2011). These skills are necessary to understand disease processes, treatment options, and proper utilization of medications. Unfortunately, many adults do not possess all these necessary skills. To assess health literacy in adults, the US Department of Education conducted a comprehensive survey in 2003. The National Assessment of Adult Literacy surveyed over 19,000 adults and found that 36% had limited health literacy (Berkman et al., 2011). These rates were the highest among the elderly, minorities, those with less than a high school education, and people living in poverty (Berkman et al., 2011). This is a major concern, as those with limited health literacy are less likely to engage in preventive care and screenings, and are more likely to be hospitalized, and suffer from chronic diseases and related complications (Berkman et al., 2011).

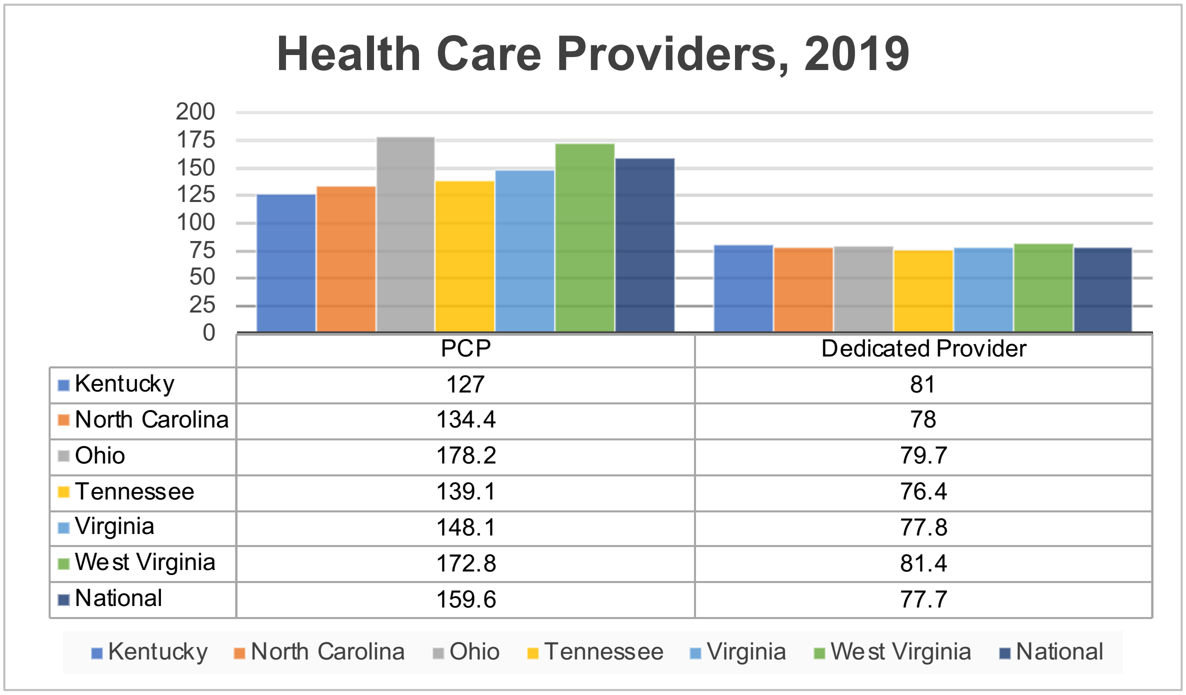
Shared decision making is another component in delivering PCC, however the amount of decision-making patients prefer varies among individuals. A systematic review of patient preferences from 1980 to 2007 determined that 63% of the studies resulted in patients preferring to participate in decision making, 21% preferring to delegate decisions to HCPs, and 16% had mixed findings (Chewning et al., 2012). Even more notable from this research was the change in preferences over the decades. From 1974 to 1989, 43% preferred to participate and 43% preferred to delegate, then from 2000 to 2007 this percentage significantly increased with 71% preferring to participate and 16% delegate (Chewning et al., 2012). This illustrates an ongoing paradigm shift from HCPs deciding what is best for their patients, to a partnership between providers and patients.

**Patient Centered Care in CCA.** While the above definitions provide constructs conducive to PCC, the unique cultural influence within the CCA, along with provider shortages and barriers to healthcare access barriers creates challenges to the delivery of this care. A 2017 report from the ARC found that the number of primary care providers (PCP) per 100,000 in Appalachia was 12% lower than the national average (Marshall et al., 2017). Looking closer at the region the ARC found further disparities, with Central Appalachia’s rate 33% lower, rural counties 20% lower than metro counties, and distressed counties 40% lower compare to non-distressed counties (Marshall et al., 2017). When reviewing data on specialty physicians the ARC found the Appalachian region at 28% lower than the national average, Central Appalachia 65% lower, rural counties 57% lower than metro counties, and distressed counties 76% lower than non-distressed counties (Marshall et al., 2017). However, this data was based off 2013 data from the HHS Area Health Resources Files, and the ARC has not updated their report since, and subsequently may not accurately represent the status of the region currently. America's Health Rankings provides some more recent state level data, however it does not distinguish between Appalachian and Non-Appalachian counties. Figure 1.13 compiles state level data from 2019, showing the number of PCP per 100,000 across the states and the national average, as well as the percentage of individuals with a dedicated provider (United Health Foundation, 2022b).

Other smaller studies have sought to address this gap and gather data on the perceptions of Appalachians in relation to healthcare. One study in Ohio surveyed 695 individuals living in Appalachian and Non-Appalachian counties within the state, about their perceptions to healthcare access. The results of this survey were then compared to selected indicators on the 2019 County Health Rankings (CHR) to determine to what level their perceptions correlated to the CHR data. The perception of access to healthcare providers was consistent to the CHR, with those in Appalachian counties having less access than non-Appalachian, and identified that only 29% of those in Appalachian counties perceived there were enough services versus 57% in non-Appalachian counties (Morrone et al., 2021). The use of screening services was another area considered, in comparison to the CHR data, at 38.7%, both Appalachian and non-Appalachian participants reported lower rates of screening with rates 24% and 26.5% respectively; additionally, 12.8% of participants in Appalachian counties received these services within their home county, versus 19.4% in non-Appalachian counties (Morrone et al., 2021). The study also surveyed participants perceptions relating to healthcare providers and convenience, cost, quality, information, and courtesy. Within each category those residing within Appalachian counties reported lower rates of satisfaction compared to their counterpart, with rates less than 50% in all areas with the exception of courtesy at 58.1% (Morrone et al., 2021). Several quotes from participants were highlighted, emphasizing feelings of judgement and intimidation from providers due to their low socio-economic status (Morrone et al., 2021).

**Figure 1.13**

*Health Care Providers by State, 2019*



| | PCP | Dedicated Provider |
|---|---|---|
| Kentucky | 127 | 81 |
| North Carolina | 134.4 | 78 |
| Ohio | 178.2 | 79.7 |
| Tennessee | 139.1 | 76.4 |
| Virginia | 148.1 | 77.8 |
| West Virginia | 172.8 | 81.4 |
| National | 159.6 | 77.7 |

*Note.* Number of active primary care physicians (including general practice, family practice, obstetrics and gynecology, pediatrics, geriatrics and internal medicine) per 100,000 population; and the percentage of adults who reported having a personal doctor or health care provider (United Health Foundation, 2022b).

Another study conducted in rural North Carolina Appalachia found greater health care access disparities existed within towns in the same county. Two towns with populations of 4,000 and 1,000 within a county of approximately 80,000, were studied to learn how the social determinants of health impacted their quality of life (Hege et al., 2018). Demographic data revealed these towns both had lower education and income rates, and higher unemployment and poverty when compared to state level data (Hege et al., 2018). Additionally, both towns had higher uninsured rates at 23.7% and 24.1%, compared to the county and state at 16.2% and 14.4% respectively (Hege et al., 2018). Focus group participants reported financial strain had a large impact on their health, limiting their ability to seek healthcare as well as nutritious foods (Hege et al., 2018). Lack of transportation to health care resources was another issue of concern, particularly among the elderly who did not have the financial resources to own vehicles and lived in communities devoid of public transportation (Hege et al., 2018). Additionally, barriers to physical activity were cited as fear of violence outside their homes, and the inability to afford gym memberships or even decent shoes (Hege et al., 2018).

Consistent with the previous two studies, participants in a small study at a Remote Area Medical (RAM) mobile clinic in TN found similar themes that created barriers to health care access. The RAM clinic is a nonprofit organization that periodically pops-up in underserved areas for a weekend to provide free medical, vision, and dental services; individuals from surrounding areas begin to get into line at midnight, the night before services are to begin just to secure their spot in line (Lazar et al., 2020). This study interviewed twelve of the RAM clinic patients to obtain their perceptions on health care. Participants reported an inability to afford healthcare, with one participant citing a need to choose between food and care, while others reported the frustration of watching family and friends suffering through illnesses due to their inability to afford care or medications (Lazar et al., 2020). Additional barriers to access included lack of HCP in their area, lack of providers that accepted their type of medical insurance, and the financial strain of taking time off work to drive long distances to care (Lazar et al., 2020). HCP turner over was another area of stress, as it disrupted their continuity of care and level of comfort around providers; and when they did receive care, they perceived the aspects of quality of care should include feeling valued and worthy of the providers time, being spoken to like a human being, being listened to respectfully, not rushed, and kindness and compassion from providers (Lazar et al., 2020).

Integrating all the defined components of PCC into a cohesive patient-centered healthcare system remains a challenge, as the healthcare system in the U.S. imposes many barriers upon individuals attempting to access and navigate it. In its current state it is highly fragmented and is afflicted with many disparities and inequities (Meyers & Clancy, 2011), while this is felt through the country, portions of the CCA population experience these in greater rates, and are additionally exacerbated by local challenges. Ongoing studies within CCA have been tuning into the exploration of the barriers to PCC, among the poorest and most underserved in the region. Participants in the highlighted studies, expressed feelings of powerlessness when they perceived HCPs lacked empathy, were judgmental, and dismissive of their concerns. In contrast, when they did encounter HCPs that treated them with respect and compassion, they felt great satisfaction with the interaction and their care. However, before PCC constructs can be consistently provided to this subgroup of the population, the larger issue of access to care requires remediation through areas such as expansion of transportation, affordable healthcare insurance, and the quantity of local providers.

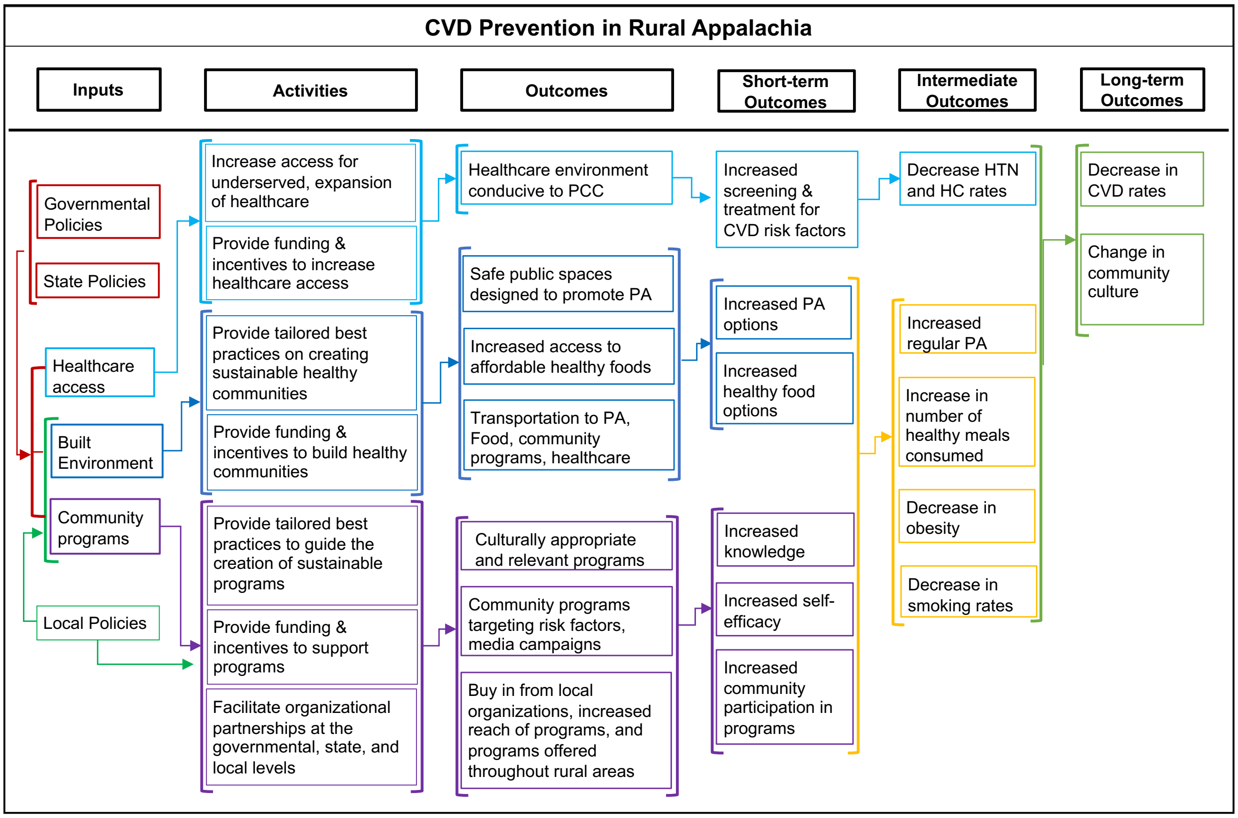
## Summary

As a result of looking across the SEM and the role each construct contributes to the burden of CVD in the CCA region, the correlative nature of the issue becomes apparent. Figure 1.14 conceptualizes findings from the literature by illustrating the interplay of the constructs of the SEM, and the dynamical influence each construct has on the next. At the policy level, government, state and local policies have the ability to begin to influence change through the expansion of healthcare access, providing support to develop the necessary infrastructure to create healthy communities through built environment, as well as community programs. Addressing healthcare access for the underserved would require addressing multiple issues, including the expansion of affordable insurance coverage, funding and incentives to bring more providers into these regions, expanding the number of providers in the region that accept the insurance coverage of the population, as well as addressing transportation needs. Policies to develop a healthy community environment, with limited resources in sprawling rural communities, would need to determine best practices to have the biggest impact working within the available resources. Funding and incentives would then be needed to build PA and healthy food environment infrastructure, as well as access through transportation. Policies to facilitate the creation of culturally relevant community programs to spread awareness and knowledge among the community to support and encourage the adaption of healthier lifestyles would also need development.

Once policies begin to form the development of activities aimed at reducing the CVD, barriers can then be broken down while facilitators to change are built up. Increased access to healthcare would provide the necessary infrastructure to launch a PCC environment for patients with continuous care throughout the lifespan. PCC would then lead to increased early screening and treatment for CVD risk factors, and a decrease in HTN and hypercholesterolemia. Changes in the built environment would increase transportation and access to PA, healthy foods, and community programs. Community programs would then be able to provide PA, nutrition and smoking cessation education, instruction, and support, increasing self-efficacy among participants. Media campaigns would increase awareness of changes in the community, available programs, healthy lifestyles, and raise CVD awareness. While partnerships with local organizations would increase the buy in from community leaders, subsequently expanding the reach of programs. Overall, the combination of the supporting components would lead to an increase in the amount of regular PA and healthy meals consumed, while decreasing obesity and smoking rates, ultimately decreasing CVD rates and changing the community culture.

**Figure 1.14**

*CVD Prevention in Rural Appalachia, Logic Model*



*Note.* Logic model representation of the interplay of the constructs of the SEM, and their correlating sequence of effects on the prevention of CVD.

It is important to note that Figure 1.14 cannot be seen as a solely linear relationship, as behaviors also have the ability to influence other constructs of the SEM through supply and demand. As demand for PCC, and the infrastructure to decrease CVD and increase healthy lifestyles through PA and healthy food access becomes a priority among the population, the community's culture begins to shift by normalizing a healthier lifestyle. This shift would then allow community programs to become sustainable and grow through the support of the community. Ultimately, this demand would result in change at the policy level, by influencing funding priorities centered on access to PCC and overall health.

However, as no two communities are completely identical, before interventions to improve healthy communities can begin it is necessary to determine the immediate priorities of each population within the CCA region. To begin to facilitate this, a more in-depth examination into the perspectives and needs of the community is warranted to begin to identify leading facilitators and barriers to improving health and decreasing the overall burden of CVD.

# Chapter 2. An Exploratory Study of Barriers to Cardiovascular Disease Prevention and Mitigation of Behavioral Risk Factors Among Cardiovascular Disease Patients and Non-Licensed Care Givers in Central Appalachia

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*Abstract.* Central Appalachia disproportionately experiences higher rates of cardiovascular diseases and associated risk factors often stemming from behavioral choices. This study explored knowledge, perceptions, and behavioral influences among patients with cardiovascular diseases and non-licensed caregivers within these communities. Seven focus groups were conducted across the six states in the region involving a total of 78 participants. Each of the discussions were audio-recorded, transcribed, and underwent thematic analysis to identify major themes. Three major themes were identified centering around healthy lifestyle behaviors: 1) healthy diets, 2) the influence of interpersonal relationships on diet and stress, and 3) physical activity. Participants identified internal and external barriers to sustaining healthy diets, the impact of interpersonal relationships on diet and stress, and influential role of cardiac rehabilitation in physical activity following a major cardiac event. These findings provide specific issues of salience among this population while providing insight into opportunities to influence behavior change.

*Key words:* Cardiovascular disease, Central Appalachia, behavioral risk factors, diet, physical activity, cardiac rehabilitation, multiple generation households, rural communities, Appalachian culture.

## Introduction

Cardiovascular diseases (CVDs) are the leading cause of mortality in the United States (U.S.), accounting for one in every three deaths, and contributing approximately $200 billion annually to healthcare costs and loss in productivity.[1] While CVDs impingement on quality of life is experienced throughout the country, greater disparities exist within the population of the Central Appalachian region, with mortality rates up to 42% higher than the national average.[2] CVDs often stem from progressive damage to the heart and blood vessels caused by controllable lifestyle choices and behaviors.[3,4] The American College of Cardiology and the American Heart Association have identified the burden of CVDs can be mitigated through optimized prevention strategies and the curtailment of associated risk factors,[1] including hypertension (HTN), hypercholesterolemia (HC), and cigarette smoking.[4] Each of these risk factors is directly associated with physical inactivity and poor diets, subsequently 80% of CVDs can be prevented through not smoking, eating a healthy diet, engaging in physical activity (PA), maintaining a healthy weight, and controlling hypertension, diabetes mellitus, and elevated lipid levels.[4]

The overall impact of physical inactivity and poor diets on health is significant,[1] in response the U.S. Department of Health and Human Services (HHS), and the U.S. Department of Agriculture (USDA) have conducted research to inform the issue, and have established guidelines for the population.[5] The HHS Physical Activity Guidelines for Americans found that lack of PA is associated with approximately 10% of premature mortality, and $117 billion in health care costs annually.[5] Additionally, it was found that only 26% of men and 19% of women meet the PA guidelines, which recommends adults engage in at least 150 to 300 minutes of moderate intensity aerobic PA each week, or 75 minutes to 150 minutes of vigorous intensity, in addition to two or more days of muscle strengthening PA.[5] The USDA Dietary Guidelines for Americans found approximately 60% of adults have one or more chronic diseases that stem from diet, including CVDs and associated risk factors.[6] Moreover, 97% of males and 82% of females overconsume sodium, which is known to increase HTN risk, and 73% of males and 70% of females overconsume saturated fat, increasing HC risk.[6]

It has been established that diet and PA is directly linked to HTN and HC risk, and if left uncontrolled ultimately increases the risk of CVD mortality.[1,4,7] Despite this knowledge, large portions of the U.S. population fail to engage in protective health activities to diminish their risks. In the Central Appalachian region, rates of inadequate PA and diet are higher than national averages, contributing to higher rates of HTN and HC, and the development of CVDs.[2] Smaller studies within the region have sought to evaluate how the beliefs and knowledge of this populations impacted behavior.[8-10] One study found that Appalachians tended to be less likely to identify the extent that health behaviors drove morbidity, as well as associate morbidity factors as poor health.[8] This survey conducted in WV found that despite being sedentary, hypertensive, overweight, and/or hyperlipidemic, 65% to 79% of participants reported a perception of good personal health while living with one of these conditions.[8] Another study found rural West Virginians correlated good health to job productivity, resulting in forgoing preventative care and only seeking medical services when symptoms became severe.[9] Researchers also examined obesity beliefs between Appalachians and Non-Appalachians, and found Appalachians were significantly less likely to report health behaviors as a determining factor.[10] While these small studies cannot be considered a representative sample of the region, they provide insights into the possible relationship between health beliefs and health outcomes among this population.

The aim of this study was to investigate the perceptions of CVD prevention behaviors, and associated barriers among CVD patients and non-licensed caregivers (NLCs) residing within Central Appalachia. This subregion within Appalachia spans six states and 228 contiguous counties, and is afflicted with even higher rates of poverty, physical inactivity, food insecurity, HTN, HC and tobacco use.[2] Exploration of this population's knowledge, beliefs, and influences related to engaging in protective health behaviors is an area of research that is still being developed and would benefit from further study. Investigating perspectives directly from those at risk for CVDs, CVD patients and NLCs will provide insight into their specific challenges, and the contributing factors driving high CVD rates within these communities. Results from this study will inform future relevant studies and interventions in these underserved communities.

## Methods

This study utilized a qualitative exploratory study design to discover themes and barriers related to the prevention of CVDs among CVD patients and NLCs in the Central Appalachian region. Use of an exploratory design allowed researchers to take an inductive approach in gathering insights and perspectives among the study population and identifying themes to inform future research agendas.[11] Focus groups discussions (FGDs) were conducted within Central Appalachian communities, in each of the six states that span the central region: Kentucky, North Carolina, Ohio, Tennessee, Virginia, and West Virginia (Figure 2.1). A total of seven FGDs were conducted, four at senior centers, two at CVD patient support meetings, and one at a predominately African American church. The specific counties in which FGDs were conducted have been withheld to ensure participant confidentiality. Additionally, due to limitations within

IRB approval, data concerning participants attributes including distinguishing between CVD patients and NLCs was not collected.

**Figure 2.1**

*Central Appalachian Region of the United States*

Data provided by Appalachian Regional Commission
Created by AMP

*Note:* This map shows the states and counties in the Central Appalachian region where focus groups discussions were conducted.

### *Participants*

Consistent with exploratory study designs, convenience sampling was utilized to recruit a total of 78 participants with CVD or at risk for developing CVDs and NLCs, through community-based organizations within Central Appalachia.[11] This was achieved by first conducting an environmental scan at the community level within Central Appalachian communities to identify existing community organizations, including public and private organizations that provided services to the community and had access to individuals with CVD. These organizations were then contacted by the researchers, during which they were given a summary of reasons for the research, research goals, research needs, and inquired if the organization had access to the target population, were interested in participating, and were willing to recruit participants. The inclusion criteria involved residents in Central Appalachian counties of Kentucky (n=10), North Carolina (n=13), Ohio (n=9), Tennessee (n=27), Virginia (n=8), and West Virginia (n=11), and the exclusion criteria involved residing outside these 228 contiguous counties. Given the nearly homogenous populations within this area, the study sample was predominately non-Hispanic white, apart from an additional FGD held in Tennessee with an at risk African American subpopulation group. The addition of the FGD among the subpopulation was arranged as the result of the church's interest in the research, discovered through contact with a member of the research team during community outreach efforts conducted by the church.

### ***Data Collection***

Focus groups were conducted between March and June of 2019 utilizing a discussion guide drafted by three qualitative researchers that were a part of the larger multi-disciplinary research team. The research team consisted of academic researchers and community members, who rigorously reviewed the discussion guide before a final draft was approved through consensus. The discussion guide consisted of semi structured broad open-ended questions to facilitate the input of participant knowledge and perceptions.[11] Additionally, the discussion guide touched on levels of the Ecological Model of Health Behavior (EMHB) to gather information at the individual, community, and organizational levels.[12] The EMHB recognizes that health outcomes are the result of dynamic influences within each of the levels,[12] therefore, to identify factors influencing CVD rates within the region, the phenomena must be explored across multiple levels.

At the start of each FGD, participants were provided with a brief introduction to the study, written informed consent, contact information for the principal investigator and project coordinator, ensured every effort would be made to protect their confidentiality, and permission to record the discussion was obtained. Focus group session lasted approximately 60 minutes, during which participants were asked to discuss issues concerning CVD prevention, screening, management, treatment at the community and individual level, in addition to identifying CVD priorities and their definition of patient-centered care. For purposes of this study, data pertaining to the individual level will be explored. As a compensation for their time, meals and snacks were provided for all the participants.

This study was approved by the East Tennessee State University Institutional Review Board.

### *Data Analysis*

FGD recordings were transcribed using BabbleType, then manually examined by two qualitative researchers utilizing qualitative thematic analysis methodology, in which researchers first gain familiarity with the data, then generate initial codes, group codes into themes and develop a codebook, apply codes to the data, and compare and discuss findings.[13] Initially, structural coding was used to code content at the individual level of the EMHB to obtain data within that construct and generate reports of the inclusion data for each of the FGDs. Next, two qualitative researchers independently examined the first FGD transcript and used inductive coding to identify themes, then compared findings, discussed discrepancies, and drafted a preliminary codebook. Researchers then independently coded the second FGD transcript, compared findings and discrepancies, and revised the codebook. All transcripts were then independently coded using the updated codebook, and researchers compared and discussed codes to ensure dependability and accuracy in coding. Once completed, one researcher compiled data from each theme and compared the coverage across each of the FGDs.

## Results

### *Characteristics of Study Population*

The study population consisted of 78 patients/NLCs within the Central Appalachian counties of Kentucky (KY), North Carolina (NC), Ohio (OH), Tennessee (TN), Virginia (VA), and West Virginia (WV). Participants were primarily female (81%) and non-Hispanic White (86%). A FGDs was held in each of the represented six states, with an additional session held in TN with a primarily African American group, subsequently 37% of the total participants were from TN (Table 2.1).

**Table 2.1**

*Focus Group Discussion Participant's Attributes*

| State | No. of Participants (%) | Sex | Racial Composition |
|---|---|---|---|
| Kentucky | 10 (12.82) | All female | Mixed |
| North Carolina | 13 (16.67) | All female | All non-Hispanic White |
| Ohio | 9 (11.53) | 6 females, 3 males | All non-Hispanic White |
| Tennessee | 15 (19.23) | 8 females, 7 males | All non-Hispanic White |
| Tennessee | 12 (15.38) | 10 females, 2 males | 11 AA, 1 non-Hispanic white |
| Virginia | 8 (10.25) | 5 females, 3 males | All non-Hispanic White |
| West Virginia | 11 (14.10) | All female | All non-Hispanic White |

*Notes:*
AA = African American

### *Themes about CVD Prevention at the Behavioral Level*

Participants were asked to identify what helps them the most to prevent and manage CVD and related conditions, as well as the biggest challenges they face. These questions invoked participants to share their own personal experiences with CVDs, from which three major themes emerged centered around healthy lifestyles: 1) the importance of implementing healthy diets and perceived barriers, 2) the impact of interpersonal relationships on diet and stress, and 3) the significance of physical activity.

**Healthy Diets.** The first theme that emerged from FGDs, and was indicated in each of the FGs, involved implementing healthy dietary practices into their daily lives to prevent and manage CVD. Participants were knowledgeable about general dietary practices conducive to healthy lifestyles including reducing sodium intake, eating more fresh fruit and vegetables, and cutting out fired food, red meat, soda, and pork. However, following and maintaining a healthy diet that incorporated their knowledge was cited as the biggest challenge. While several participants acknowledged this need in a dismissive tone rather than an urgent need, many others expressed a strong desire to improve their habits. One participant in TN stated:

> Yes, I know I need to eat right. I need to stay on that, I need to prevent stuff. I know I can prevent. I can either get back eating salads and eating plenty of time before I go to bed. Sometimes when I eat, I'm ready to go to bed. I've got to cut that out. That's my issue. I've got some bad issues. I need to get my blood pressure down. I do check it. I was checking it regularly, but sometimes I balk and don't do that. I do take my blood pressure medicine daily, and I'm doing better, but I need to do much better.

Despite recognizing behaviors that could be improved upon, committing to and sustaining healthy diet practices was a challenge for this participant, and represented frustrations expressed among participants within each of the FGDs. Additionally, participants discussed internal and external factors which affected their ability to consume heart healthy diets consistently, including struggling to resist numerous opportunities to stray outside healthy parameters. One reoccurring challenge identified was the daily temptation from the food environment in their communities. The following two quotes from participants in TN illustrate the allurement of cravings faced with innumerable opportunities to indulge in unhealthy dietary consumption.

> That food thing I think is a lot of our problems because we can do good with managing everything, but you have to be self-conscious about… You're going someplace to eat and you've got to want to eat good. You go in there and see all this good fancy food and stuff you're going to get you a little piece of it. I don't look at myself. I can't do that anymore.

> The craving for certain foods, and you know they're the ones that are bad for you. For instance, if I leave here in the evening and drive home I'm driving by Hal's, The Cookout, Wendy's, Zaxby's, Bojangles, McDonald's. It's like a big neon sign flashing. "You know you want that hamburger."

Continuously processing these visual temptations while negotiating internally to either resist or submit was expressed as an exasperating experience among many FGD participants. However, navigating the food environment outside the home only presented as a portion of their daily challenges, with the role of interpersonal relationships still requiring consideration.

**Interpersonal Relationships.** Interpersonal relationships within families were reported as having a substantial impact on dietary practices as well as on stress. Participants often associated diet with comfort, upbringing, and the culture of their community. Many of the examples provided centered around experiencing an upbringing of misinformation concerning what exactly a healthy diet consists of and associated cooking methods. Participants that shared stories presented information in a predominately nostalgic tone that attempted to reconcile the enjoyment of these meals with their evolved knowledge of a healthy diet. One participant in OH stated:

> My mom would cook a healthy meal. She'd say, "Oh, I cooked a healthy meal tonight," and you would go out, and everything was fried. Everything, but it was a little healthy. It was good too.

Despite acknowledging an upbringing of dietary habits perceived as unhealthy, there was little discussion of adaptations to diets made since that point in time. Participants went on to address current stressors they contended with in their own households and how it impacted diets. One issue in particular that was discussed in sessions in OH, VA and WV were the impact of changes within the family living structure as they grew older. Participants cited caring for and taking in grandchildren effected endeavors to engage in healthy lifestyle choices, in addition to adding stress and financial strain to their daily lives. One participant in VA stated:

> The mental strain in people our age is harder on our hearts than they were our parents. They didn't have as much mental stress as we have, especially with the kids that were in this generation. They don't have to raise their kids. They just pop them out and then granny or Aunt Lucy will grow them.

This participant went on to discuss the financial strain it put on grandparents who were already on a fixed budget and trying to balance providing food for the household and purchasing needed medication to manage their own conditions. However, the circumstances in which grandchildren came to live with grandparents was not always due to absent parents as indicated in the previous quote. The remaining two groups emphasized this evolution in families was often associated with economic need. A participant in OH expressed the strain of caring for not only grandchildren, but also their children and great-grandchildren within one household, and the impact on diet.

> Four generations living in the same house. One of the primary funding sources for that household is social security. A lot of times we use diet to make us feel better. When they say comfort food, comfort food comforts you at that particular time but it's not necessarily good for you, and we do that.

While the financial aspect of supporting healthy diets in extended families was one barrier, managing the dietary preferences within this dynamic was also noted. The desire for comfort food, in conjunction with temptation of having unhealthy dietary choices within the home compounded the burden of consciously and continuously having to make choices to improve their own health. A participant in WV addressed the difficulty of following a healthy diet while caring for grandchildren:

> I'm not supposed to eat any red meat. I'm not supposed to have any sugar much. If you got grandchildren, they're going to eat what they want. When you're trying to eat yogurt and they're eating bacon and eggs, that's hard.

Each of the previous examples illustrated reoccurring issues found within the FGDs held within OH, VA and WV, and the potential impact of interpersonal relationships on sustaining healthy behavioral practices. Despite these additional challenges, it is important to note that the role of family was emphasized as fundamental in pursuing happy lives and reducing stress within all seven of the FGDs. The importance of keeping families connected and cared for was identified as a core component of their culture and brought pride to participants. One participant in OH described the magnitude of this perceived obligation, and how individuals outside of their communities potentially misunderstand the importance of this role.

> It’s not a bad thing. They feel needed because they are still providing for their families. It’s a great thing. Sometimes social workers from outside the area will almost look at that as being some use or financial obligation, and it’s not that at all. I can remember several older ladies that great-grandmothers when they came to a meeting they’d be carrying a baby with them. It wasn’t their baby, it was their great-grandchild. They wouldn’t have it any other way. We are truly Appalachian. Close and kin really do matter.

**Physical Activity.** The third theme that surfaced from the FGDs was the importance of physical exercise to prevent and manage CVDs. Each of the seven groups identified physical exercise as an essential component of living a healthy lifestyle, however participants in four of the seven groups provided only vague information on how they personally engaged in this behavior. Common responses within these groups consisted of simply citing walking as a great activity. In contrast, the remaining three groups discussions (OH, TN, WV) pertaining to personally engaging in physical activity centered around experiences with cardiac rehabilitation after having a major CVD event. For many of the participants these events served as a catalyst to changing one of the primary behaviors associated with CVD risk.

Cardiac rehabilitation is a medically supervised program designed to improve health outcomes after a cardiac event by providing individualized education on diet, exercise, and reducing stress.[14] This program usually begins while being a hospitalized inpatient and continues after transitioning to an outpatient status. The experience of suffering a major health scare combined with an opportunity to receive practical tailored instruction provided the motivation to change and the means by which to do it. The most beneficial aspects of cardiac rehabilitation for the participants in the three groups consisted of finding exercises they enjoyed, learning how far they could push themselves, and the social support they received.

One of the participants in TN expressed learning to engage in exercises he enjoyed was beneficial, however watching the drastic impact it had on other participants was also a motivational experience. Below describes the individualized adaption of strategies in the program he attended for a woman who up to that point had not been successful in meeting physical activity goals.

> Finally, they'd got on the subject of bicycles one day, and they said, "Did you ever have a bicycle when you were young?" She said, "No, but I always wanted to ride one." They managed to get her to try a stationary bike upright. All of that was the best thing that ever happened. And she'd get on that and ride for 20 minutes and then go get her juice and crackers and go right back. What I realized, she was getting younger and younger and younger the more she did. She went from being in her 90s to her 80s, down to her 70s.

While finding exercises the participants enjoyed was a first step toward achieving greater physical health, having medical staff present was also greatly comforting. As each of these individuals had suffered a significant CVD event, beginning to engage in physical activity in the aftermath caused some anxiety. Discovering how far they could push themselves, while mitigating the risk of doing any additional damage to their bodies, allowed them to learn what their bodies were capable of and how to recognize the warning signs of over exertion. One participant from OH stated:

> I'm going to tell you it was very beneficial to me because I have a pulse ox thing at home. I have to check my pulse ox and my heart runs too fast and so I have to check it all the time. When I couldn't breathe, or my heart was (exhales) I would quit because I didn't know how far to push myself. There on a heart monitor constantly, I can push myself more because they can watch the whole time. It lets me push myself further than I would have pushed myself at home.

Additionally, the social support these participants received from other individuals in cardiac rehab, as well as the staff, had a positive impact on them emotionally as they transitioned into healthier lifestyle habits. Participants in OH, TN, and WV stated all the new information received after a CVD event in conjunction with implementing behavior changes could be overwhelming. However, connecting with others in rehabilitation was advantageous in alleviating some of that stress.

One participant in TN stated:

> But you also share information with the other patients. "Has this happened to you?" It's very comforting. That is a very good word, because of the 20 people in there, we're all in the same boat. And our heart attacks were probably all different.

Another participant in WV stated:

> Cardiac rehab is not only the physical aspect of training the heart, it's that they give you that emotional support, they give you the tools to provide that support for yourself.

Finally, these participants discussed the continuation of physical activity practices they developed during cardiac rehab after the conclusion of the program. Many found other opportunities to seek activity through local gyms, community centers, and senior centers, indicating long term behavior change as a result of their experiences.

## Discussion

The significance of health behaviors on influencing cardiovascular health outcomes was discussed by participants in all seven of the FGDs, with healthy diets and physical exercise identified as two primary controllable determinants. In addition, interpersonal relationships were identified as an external determinant that potentially impacted participants' ability to engage in healthy diets. Beyond identifying the importance of diet, participants provided limited information on effective strategies to alter dietary practices, and this limitation presented challenges that confronted them in their everyday lives. A unique finding related to the impact of having multiple generations cohabitating in a single household, uncovered another aspect within several of the communities that requires further investigation. Previous research has sought to understand how dietary behaviors are developed throughout childhood in relationship to influences within the family. However, much of this research has predominately focused on the parent-child family environment, including parental modeling, parental parenting styles, and availability of foods within the household as chosen by parents.[15,16] Research has found that food insecurity and concerns over food waste influenced purchasing decisions made by parents, predominately within low-income homes.[17,18] These homes are more likely to provide a food environment with less healthy choices by avoiding purchasing of healthier perishable items such as fruit and vegetables that may not get consumed, may be less likely to experiment with new healthier food options, and favor processed foods with longer shelf lives that children prefer.[17,18] However, as much of this research focuses on the dynamics within parent child households, it does not address further complexities that exist within multiple generation households. Little research exists on how dietary patterns are influenced within these family environments, and presents a considerable gap in research particularly effecting the Central Appalachian region which experiences higher rates of custodial grandparents.[19] Within this region 7% of children reside within the care of custodial grandparents, in contrast to 3.8% nationally; in addition these households experience higher rates of poverty at 19.3% versus 8% nationally.[19] One global systematic review investigated the influence of grandparents on child health, by specifically investigating three-generation families, and skipped-generation families in which grandparents assumed the role of their grandchildren's parents. Findings within the U.S. determined three-generation families were more common when parents were divorced, less educated, younger, and a minority; this make-up resulted in more economic stability for single mothers, however children were more likely to have higher BMIs.[20] Findings within skipped-generation families within the U.S. determined grandparents often took on the role of the primary caregiver due to parental incarceration, and drug use; this make-up resulted in greater economic instability and poorer health outcomes for children.[20]

Findings from this present study suggest there exists a greater complexity of dietary influences within multiple generation households within the Central Appalachian region that requires further investigation. Consistent with previous research that has found food insecurity and poverty contribute to dietary patterns and the development of food preferences early in life,[15-18] these factors were identified as having an influential effect among FGD participants. Compounding these challenges within some households was the additional influence of contending with multiple generations cohabitating, and the responsibilities of custodial grandparents, which was found to affect the dietary patterns of older adults. Subsequently, an additional need to explore how grandchildren and their parents influence the dietary behaviors of grandparents is implicated, as well as how it contributes to CVD rates within this vulnerable population. While this was generally discussed as a barrier to healthy lifestyles, it also highlights a potential opportunity to design culturally relevant behavior change interventions that simultaneously target multiple generations. Leveraging the unique family culture of these communities in conjunction with their stated desire to improve health may provide a needed launching point to impact the long-term health of these populations.

The impact of cardiac rehabilitation on behavior change in relation to physical exercise was an additional major finding of this study, as it was cited in three of the groups as having an influential impact on participants' adoption of healthier exercise practices following a cardiac event. A scientific statement from the AHA and the American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR) identified cardiac rehabilitation as an integral component of care for those with CVDs to reduce disability through programs that provide dietary education, PA training, risk factor management, and stress reduction counseling.[21] Rehabilitation programs in the U.S. are primarily center-based, and are conducted either in hospitals or in outpatient facilities within communities.[22] Exercise-based cardiac rehabilitation has been found to be effective in reducing mortality and the reoccurrence of cardiac events,[23,24] with hospital and community-based programs having similar benefits in improving exercise capacity and health outcomes.[20,25,26] However, these programs are underutilized, in 2017 only 28.6% of eligible Medicare beneficiaries enrolled, and among them 27.6% completed the programs by attending between 25 to 36 sessions within 36 weeks.[25] Rates within KY, NC, OH, TN, VA, and WV are consistent with these national averages, with the exception of WV enrollment at 17.9% and TN completion at 41.1%.[25] Research from Million Hearts identified several barriers to attendance including transportation, the cost of attendance, inadequate program hours,[26,27] as well as the existence of cardiac rehabilitation deserts throughout the country.[27] Additional participation disparities have been found among females, the uninsured, self-payers, the unemployed, seniors, those with educational achievement at the high school level and below,[28] low socioeconomic status groups, and residing within rural populations.[29] Program costs are the most significant barrier, and have been an ongoing topic for research and advocacy groups who support the need for adequate reimbursement for cardiac rehabilitation.[21,26,30] Moreover, even if all these barriers were removed, the current capacity of center-based facilities are not substantial enough to meet needs, if all programs were filled to capacity they would not be able to accommodate more than 45% of eligible patients.[30]

Home-based programs offer another approach to cardiac rehabilitation,[26,30] and have been an area of research primarily outside the U.S., with Canada and the United Kingdom having successfully incorporating this option for their populations.[22] However, recently home-based virtual programs delivered synchronously or asynchronously have been a growing area of study, and have been found to provide similar clinical and physical activity outcomes as center-based programs.[22,24,31,32] Within this current study, participants highlighted the aspect of having medical staff on site while re-learning how far they could push themselves physically was an important aspect of rehabilitation services, and was consistent with findings within home/virtual based study which cited patients had anxiety over the lack of HCP supervision while exercising.[22,32,33] Despite these concerns, home-based studies have not found a significant difference in exercise intensity when compared to center-based programs.[33,34] Additionally, the social support received through in-person participation was identified in this study as a source of motivation and stress reduction. The social aspect of rehabilitation has been a consideration in virtual studies and as such was integrated into programs.[31-33] While home/virtual-based studies provided online social interaction, these interactions fell short of meeting their needs with participants perceiving the lack of in-person socialization as a barrier,[33] resulted in inferior improvements in depression,[32] and did not improve social support or optimism.[31]

Considering the notable role cardiac rehabilitation had in improving PA among many of the participants within three of the FGDs, and the lack of inclusion within the other four FGDs presents additional questions. To date, there are no known studies within Central Appalachia regarding access disparities and completion barriers to center-based programs, nor access and effectiveness of home-based programs, despite disparities in CVD rates.[2] As a result, it brings into question if the other focus groups did not consider PA improvements associated with cardiac rehabilitation as a topic of discussion due to a perceived insignificant effect of programs, or if disparities to access resulted in lack of experience with these programs. Additional mixed method research within these parameters is needed to determine access and utilization rates, as well as perceptions pertaining to participation and associated barriers. Furthermore, the expansion of rehabilitation programs via home/virtual-based methods has the potential to fill access gaps and improve PA within these groups. However, further research is required to determine the feasibility and effectiveness of such programs within Central Appalachia. Results from this study also emphasize the importance of the social support component of programs, other home/virtual-based programs have fallen short of delivering this aspect of care,[31-33] presenting an additional consideration for future studies within the region.

## Conclusion

Limitations to this study include a using a priori of seven FGDs to represent the Central Appalachian region, therefore the point of saturation was not used as the determining factor. However, general knowledge pertaining to the importance of diet and exercise as two of the primary controllable behavioral determinants was identified by all groups. Other emergent themes related to multiple generations residing in single households, and the impact of cardiac rehab were unprompted and the result of the natural flow of discussions. Although they became a reoccurring theme in several of the groups, they were not questions asked by the researchers and present an opportunity for future research. Other limitations related to IRB approval included the inability to collect extensive information concerning the participants attributes, as well as distinguish between CVD patients and NLCs. Nonetheless, this qualitative exploratory study brings to light perceived barriers within these communities, and potential areas for future research to expound upon to inform interventions.

In conclusion, this qualitative investigation of the knowledge, perceptions, and barriers/facilitators to prevention at the behavioral level among residents in the Central Appalachian area yielded intriguing and novel findings. Based on this work, there is a greater need for further in-depth investigation into barriers associated with healthy lifestyles in this population. Results from this study have brought to light several gaps within the current research, including health outcomes within multigenerational families cohabiting within the Central Appalachian region, and the influence of grandchild dietary preferences on grandparents as caregivers. In addition, further research is needed into policy reform as grandparents are often not considered in research and policy initiatives despite they often pay a caregiver role.[19,20] Few government programs exist that provide financial support for custodial grandparents, unless the children first enter the foster care system,[19] sequentially exasperating the health of an already vulnerable populations, and contributing to the generational cycle of poor dietary practices.

Finally, this study is consistent with previous cardiac rehabilitation findings in relation to facilitating PA behavior change following a major cardiac event. However, this opportunity was only provided following a major cardiac event as a form of secondary prevention, suggesting a greater need for primary prevention opportunities at system level before heart health degrades into CVD. However, considering the extent of barriers to access rehabilitation programs, expanding secondary prevention into primary prevention presents a formable undertaking. Policy reform has the potential to address some of this need through greater reimbursement for cardiac rehabilitation[19,24,28] and the expansion of alternative home/virtual-based delivery methods. Additional research is needed assess the effectiveness of alternative methods within this population, as well as to inform such program designs.

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## References

1. Arnett DK, Blumenthal RS, Albert MA, et al. 2019 ACC/AHA Guideline on the primary prevention of cardiovascular disease: A report of the American College of

Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019;140(11):e596-e646. doi:10.1161/CIR.0000000000000678

2. Marshall JL, Thomas L, Lane NM, et al. Creating a culture of health in Appalachia disparities and bright spots. Washington, D.C.: Appalachian Regional Commission, 2017.
3. American Heart Association. Life’s simple 7. Available at: https://playbook.heart.org/lifes-simple-7/
4. Benjamin EJ, Muntner P, Alonso A, et al. Heart disease and stroke statistics-2019 update: A report from the American Heart Association. Circulation. Mar 5 2019;139(10):e56-e528. doi:10.1161/CIR.0000000000000659
5. U.S. Department of Health and Human Services. Physical activity guidelines for Americans, 2nd Edition. 2018. Available at: https://health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf
6. U.S. Department of Agriculture and U.S. Department of Health and Human Services. Dietary guidelines for Americans 2020-2025. Available at: https://www.dietaryguidelines.gov/sites/default/files/2021-03/Dietary_Guidelines_for_Americans-2020-2025.pdf
7. Carey RM, Muntner P, Bosworth HB, Whelton PK. Prevention and control of hypertension: JACC Health Promotion Series. Journal of American College of Cardiology. 2018;72(11):1278-1293. doi:10.1016/j.jacc.2018.07.008
8. Griffith BN, Lovett GD, Pyle DN, Miller WC. Self-rated health in rural Appalachia: health perceptions are incongruent with health status and health behaviors. BMC Public Health. Apr 13 2011;11doi:10.1186/1471-2458-11-229

9. Deskins S, Harris C, Bradlyn A, et al. Preventive Care in Appalachia- Use of the theory of planned behavior to identify barriers to participation in cholesterol screenings among West Virginians. National Rural Health Association. 2006. Available at: https://doi.org/10.1111/j.1748-0361.2006.00060.x

10. Rice EL, Patel M, Serrano KJ, Thai CL, Blake KD, Vanderpool RC. Beliefs About behavioral determinants of obesity in Appalachia, 2011-2014. Public Health Reports. Jul/Aug 2018;133(4):379-384. doi:10.1177/0033354918774064

11. Rendle KA, Abramson CM, Garrett SB, Halley MC, Dohan D. Beyond exploratory: A tailored framework for designing and assessing qualitative health research. BMJ Open. Aug 27 2019;9(8):e030123. doi:10.1136/bmjopen-2019-030123

12. Kennedy W, Fruin R, Lue A, Logan SW. Using Ecological Models of Health Behavior to promote health care access and physical activity engagement for persons with disabilities. J Patient Exp. 2021;8:23743735211034031. doi:10.1177/23743735211034031

13. Tolley EE, Ulin PR, Mack N, Robinson ET, Succop SM. Qualitative Methods in Public Health: A Field Guide for Applied Research. Second Edition ed. John Wiley & Sons, Incorporated 2016. Available at: https://ebookcentral.proquest.com/lib/etsu/detail.action?docID=7104122.

14. Cleveland Clinic. Cardiac rehab. 2021. Available at: https://my.clevelandclinic.org/health/treatments/22069-cardiac-rehab

15. Mahmood L, Flores-Barrantes P, Moreno LA, Manios Y, Gonzalez-Gil EM. The influence of parental dietary behaviors and practices on children's eating habits. Nutrients. Mar 30 2021;13(4)doi:10.3390/nu13041138

16. Carbert NS, Brussoni M, Geller J, Masse LC. Moderating effects of family environment on overweight/obese adolescents' dietary behaviours. Appetite. Mar 1 2019;134:69-77. doi:10.1016/j.appet.2018.12.034

17. Arlinghaus KR, Laska MN. Parent feeding practices in the context of food insecurity. Int J Environ Res Public Health. Jan 6 2021;18(2)doi:10.3390/ijerph18020366

18. Daniel C. Economic constraints on taste formation and the true cost of healthy eating. Soc Sci Med. Jan 2016;148:34-41. doi:10.1016/j.socscimed.2015.11.025

19. Phillips DL, Alexander-Eitzman B. Intersections of poverty, geography, and custodial grandparent caregiving in Appalachia. GrandFamilies: The Contemporary Journal of Research, Practice and Policy. 2016;3(1)

20. Sadruddin AFA, Ponguta LA, Zonderman AL, Wiley KS, Grimshaw A, Panter-Brick C. How do grandparents influence child health and development? A systematic review. Social Science & Medicine. Oct 2019;239:112476. doi:10.1016/j.socscimed.2019.112476

21. Balady GJ, Williams MA, Ades PA, et al. Core components of cardiac rehabilitation/secondary prevention programs: 2007 update: A scientific statement from the American Heart Association Exercise, Cardiac Rehabilitation, and Prevention Committee, the Council on Clinical Cardiology; the Councils on Cardiovascular Nursing, Epidemiology and Prevention, and Nutrition, Physical Activity, and Metabolism; and the American Association of Cardiovascular and Pulmonary Rehabilitation. Circulation. May 22 2007;115(20):2675-82. doi:10.1161/CIRCULATIONAHA.106.180945

22. Thomas RJ, Beatty AL, Beckie TM, et al. Home-Based Cardiac Rehabilitation: A scientific statement from the American Association of Cardiovascular and Pulmonary Rehabilitation,

the American Heart Association, and the American College of Cardiology. J Am Coll Cardiol. Jul 9 2019;74(1):133-153. doi:10.1016/j.jacc.2019.03.008

23. Lawler PR, Filion KB, Eisenberg MJ. Efficacy of exercise-based cardiac rehabilitation post-myocardial infarction: a systematic review and meta-analysis of randomized controlled trials. Am Heart J. Oct 2011;162(4):571-584 e2. doi:10.1016/j.ahj.2011.07.017

24. Tegegne TK, Rawstorn JC, Nourse RA, Kibret KT, Ahmed KY, Maddison R. Effects of exercise-based cardiac rehabilitation delivery modes on exercise capacity and health-related quality of life in heart failure: a systematic review and network meta-analysis. Open Heart. Jun 2022;9(1)doi:10.1136/openhrt-2021-001949

25. Keteyian SJ, Jackson SL, Chang A, et al. Tracking Cardiac rehabilitation utilization in Medicare beneficiaries: 2017 update. J Cardiopulm Rehabil Prev. Jul 1 2022;42(4):235-245. doi:10.1097/HCR.0000000000000675

26. Beatty AL, Brown TM, Corbett M, et al. Million Hearts Cardiac Rehabilitation Think Tank: Accelerating new care models. Circulation: Cardiovascular Quality Outcomes. Oct 2021;14(10):e008215. doi:10.1161/CIRCOUTCOMES.121.008215

27. Wall HK, Stolp H, Wright JS, et al. The million hearts initiative: catalyzing utilization of cardiac rehabilitation and accelerating implementation of new care models. J Cardiopulm Rehabil Prev. Sep 2020;40(5):290-293. doi:10.1097/HCR.0000000000000547

28. Sun EY, Jadotte YT, Halperin W. Disparities in cardiac rehabilitation participation in the United States: A systematic review and meta-analysis. J Cardiopulm Rehabil Prev. Jan 2017;37(1):2-10. doi:10.1097/HCR.0000000000000203

29. Shanmugasegaram S, Oh P, Reid RD, McCumber T, Grace SL. Cardiac rehabilitation barriers by rurality and socioeconomic status- a cross-sectional study. International Journal for Equity in Health. 2013;

30. Pack QR, Squires RW, Lopez-Jimenez F, et al. The current and potential capacity for cardiac rehabilitation utilization in the United States. J Cardiopulm Rehabil Prev. Sep-Oct 2014;34(5):318-26. doi:10.1097/HCR.0000000000000076

31. Brewer LC, Abraham H, Kaihoi B, et al. A community-informed virtual world-based cardiac rehabilitation program as an extension of center-based cardiac rehabilitation: Mixed-methods analysis of a multicenter pilot study. J Cardiopulm Rehabil Prev. Jan 1 2023;43(1):22-30. doi:10.1097/HCR.0000000000000705

32. Ganeshan S, Jackson H, Grandis DJ, et al. Clinical outcomes and qualitative perceptions of in-person, hybrid, and virtual cardiac rehabilitation. J Cardiopulm Rehabil Prev. Sep 1 2022;42(5):338-346. doi:10.1097/HCR.0000000000000688

33. Cotie LM, Ghisi GLM, Vanzella LM, Aultman C, Oh P, Colella TJF. A social-ecological perspective of the perceived barriers and facilitators to virtual education in cardiac rehabilitation: A mixed-methods approach. J Cardiopulm Rehabil Prev. May 1 2022;42(3):183-189. doi:10.1097/HCR.0000000000000663

34. Keteyian SJ, Grimshaw C, Brawner CA, et al. A comparison of exercise intensity in hybrid versus standard phase two cardiac rehabilitation. J Cardiopulm Rehabil Prev. Jan 1 2021;41(1):19-22. doi:10.1097/HCR.0000000000000569

# Chapter 3. An Exploratory Study of Community Level Cardiovascular Disease Prevention Efforts and Barriers Among Cardiovascular Disease Patients and Non-Licensed Care Givers in Central Appalachia

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*Abstract.* Communities within the Central Appalachian region experience higher rates of cardiovascular disease and associated risk factors. This study used qualitative methodology to explore the attributes of communities within this region in relation to health and disease prevention through the perspective of cardiovascular disease patients and non-licensed caregivers. Seven focus groups were conducted across the six states in the region involving a total of 78 participants. Each of the discussions were audio-recorded, transcribed, and underwent thematic analysis to identify major themes. Three major themes were identified: 1) community economic characteristics, 2) community infrastructure, and 3) community organizations. Participants depicted the influence of poverty and limited employment opportunities, a need for expanded community infrastructure to support physical activity, and the commendatory role of community organizations. These findings provide a look into the core of these communities and highlight additional needs and opportunities to improve and facilitate healthy lifestyles.

*Key words:* Cardiovascular disease, Central Appalachia, built environment, community organizations, mountainous topography, rural communities, Appalachian culture.

## Introduction

Many chronic diseases stem from unhealthy lifestyle factors including poor diet, obesity and inactivity, all of which in turn contribute to the burden of cardiovascular diseases (CVDs). Studies have found physical inactivity increases the relative risk of coronary artery disease by 42%, hypertension (HTN) by 30%, stroke by 60%;[1] and a 2% increase in consumption of trans fats is associated with a 23% increase in coronary events.[2] The Nurses' Health study found that women who lived a healthy lifestyle were 80% less likely to have coronary events.[3] While dietary practices and physical inactivity are behavioral choices, they are not formed and reinforced in isolation. The design of communities has been found to directly influence behaviors and the health of populations through a complex interplay of built environment and socioeconomics.[4] Built environment consists of infrastructure such as land use, roads, sidewalks, green spaces, residential density, and access to food;[5] and socioeconomic factors include income, education, social support, and community safety.[6] Given the reciprocal relationship between population health and the design of communities, numerous studies have sought to determine how to leverage attributes of communities to promote health. In particular, CVDs have been a focus of many of these studies, as it is the leading cause of death in the United States (U.S.).[7] Much of this research has focused on mitigating the root cause of CVDs in urban areas, by investigating the relationship between a community's structure and physical activity and diet. These studies have found that factors such as land-use mix[5,8-11] walkability of neighborhoods, access to recreational spaces[2,8,10-12] density of fast food restaurants, and proximity of grocery stores,[2,8,10,11] all play a role in lifestyle behaviors. Systematic reviews of built environment and obesity have determined a positive association between food prices, density of fast food restaurants, convivence stores, recreational facilities, minutes spent in a car and BMI, and a negative association between presence of supermarkets, and fruit and vegetable prices.[2,10,11]

Communities within the Appalachian region of the U.S. suffer from higher rates of disease morbidity, and mortality, including CVDs.[13] Within the Central Appalachian region, 33.8% of adults are physically inactive, and 34.7% are obese, contributing to higher rates of CVD primary risk factors, including HTN and hypercholesterolemia.[13] Improving the built environment of these communities to promote healthier lifestyles, and subsequently decrease CVDs rates, presents additional challenges due to rurality. With only two-fifths of the counties containing population densities at or above the national average,[14] the sprawling nature of the rural geography of underserved, at risk communities does not easily provide an environment conducive to promote PA. Furthermore, research into changes to the Appalachian food environment and the increase of obesity rates between 2007 to 2011, found that while there was an increase in the number of supercenters, there was an overall decrease in food availability as a result of a decrease in the per capita number of grocery stores.[15] It was suggested that the lower prices of supercenters incentivized this population to drive longer to supercenters, which in return decreased the economic feasibility of smaller grocery stores.[15] This simultaneously changed dietary patterns away from healthier perishable food items to processed foods with longer shelf lives in order to offset the time and transportation demands of driving to supercenters.[15]

While the built environment can provide the necessary infrastructure to support healthy lifestyles, community programs can provide a launching point to educate and increase the population's self-efficacy. However, successfully sustaining programs to decrease CVD risk by improving health through physical activity and healthy diets is a challenge due to economic and community organization constraints. The Central Appalachian region experiences disparities in poverty rates that surpass the national average of 12.8%, with drastic variations existing between some Appalachian and non-Appalachian counties within the same state; as seen in KY with rates reaching 23.5% in Appalachia counties, compared to 14.2% in non-Appalachian counties.[14] Nearly half of the counties in the region have been classified as distressed or at-risk by the Appalachian Regional Commission (ARC), and most are clustered within the Central Appalachian sub-region.[16] Additionally, the rate of social associations is lower than national averages at 8.8 versus 12.5 per 10,000 population respectively,[13] limiting opportunities to engage community resources. Inclusion for social organizations within this measure included membership organizations such as gyms and bowling alleys, and business, religious, civic, political, professional, or sport organizations.[13]

Few studies have focused on the unique relationship between the built environment, social capacity, and CVDs within the confines of the Central Appalachian region. Despite high rates of physical inactivity in rural regions as a whole, built environment research has predominately focused on urban areas.[17] The aim of this study was to investigate community level barriers and facilitators to CVD prevention from the perspective of those at risk for CVDs, CVD patients and non-licensed caregivers (NLCs). As stakeholders in their own communities, their distinct knowledge of their community's culture and infrastructure provides essential data to inform future capacity building interventions.

## Methods

This study utilized a qualitative exploratory study design to discover themes and barriers related to the prevention of CVDs among CVD patients and NLCs in the Central Appalachian region. Use of an exploratory design allowed researchers to take an inductive approach in gathering insights and perspectives among the study population and identifying themes to inform future research agendas.[18] Focus groups discussions (FGDs) were conducted within Central Appalachian communities, in each of the six states that span the central region: Kentucky, North Carolina, Ohio, Tennessee, Virginia, and West Virginia (Figure 3.1). A total of seven FGDs were conducted, four at senior centers, two at CVD patient support meetings, and one predominately African American church. The specific counties in which FGDs were conducted have been withheld to ensure participant confidentiality. Additionally, due to limitations within IRB approval, data concerning participants attributes including distinguishing between CVD patients and NLCs was not collected.

**Figure 3.1**

*Central Appalachian Region of the United States*

*Note:* This geographical information system (GIS) map shows the states in the Central Appalachian region where focus groups discussions were conducted.

### *Participants*

Consistent with exploratory study designs, convenience sampling was utilized to recruit a total of 78 participants with CVD or at risk for developing CVDs and NLCs, through community-based organizations within Central Appalachia.[18] This was achieved by first conducting an environmental scan at the community level within Central Appalachian communities to identify existing community organizations, including public and private organizations that provided services to the community and had access to individuals with CVD. These organizations were then contacted by the researchers, during which they were given a summary of reasons for the research, research goals, research needs, and inquired if the organization had access to the target population, were interested in participating, and were willing to recruit participants. The inclusion criteria involved residents in Central Appalachian counties of Kentucky (n=10), North Carolina (n=13), Ohio (n=9), Tennessee (n=27), Virginia (n=8), and West Virginia (n=11), and the exclusion criteria involved residing outside these 228 contiguous counties. Given the nearly homogenous populations within this area, sampling resulted in a predominately non-Hispanic white, apart from an additional FGD held in Tennessee with an at risk African American subpopulation group. The addition of the FGD among the subpopulation was arranged as the result of the church's interest in the research, discovered through contact with a member of the research team during community outreach efforts conducted by the church.

### *Data Collection*

Focus groups were conducted between March and June of 2019 utilizing a discussion guide drafted by three qualitative researchers that were a part of the larger multi-disciplinary research team. The research team consisted of academic researchers and community members, who rigorously reviewed the discussion guide before a final draft was approved through consensus. The discussion guide consisted of semi structured broad open-ended questions to facilitate the input of participant knowledge and perceptions.[18] Additionally, the discussion guide touched on levels of the Ecological Model of Health Behavior (EMHB) to gather information at the individual, community, and organizational levels.[19] The EMHB recognizes that health outcomes are the result of dynamic influences within each of the levels,[19] therefore, to identify factors influencing CVD rates within the region, the phenomena must be explored across multiple levels.

At the start of each FGD, participants were provided with a brief introduction to the study, written informed consent, contact information for the principal investigator and project coordinator, ensured every effort would be made to protect their confidentiality, and permission to record the discussion was obtained. Focus group session lasted approximately 60 minutes, during which participants were asked to discuss issues concerning CVD prevention, screening, management, treatment at the community and individual level, in addition to identifying CVD priorities and their definition of patient-centered care. For purposes of this study, data pertaining to the community level will be explored. As a compensation for their time, meals and snacks were provided for all the participants.

This study was approved by the East Tennessee State University Institutional Review Board.

### ***Data Analysis***

FGD recordings were transcribed using BabbleType, then manually examined by two qualitative researchers utilizing qualitative thematic analysis methodology, in which researchers first gain familiarity with the data, then generate initial codes, group codes into themes and develop a codebook, apply codes to the data, and compare and discuss findings.[20] Initially, structural coding was used to code content at the community level of the EMHB to obtain data within that construct and generate reports of the inclusion data for each of the FGDs. Next, two qualitative researchers independently examined the first FGD transcript and used inductive coding to identify themes, then compared findings, discussed discrepancies, and drafted a preliminary codebook. Researchers then independently coded the second FGD transcript, compared findings and discrepancies, and revised the codebook. All transcripts were then independently coded using the updated codebook, and researchers compared and discussed codes to ensure dependability and accuracy in coding. Once completed, one researcher compiled data from each theme and compared the coverage across each of the FGDs.

## Results

### *Characteristics of Study Population*

The study population consisted of 78 patients/NLCs within the Central Appalachian counties of Kentucky (KY), North Carolina (NC), Ohio (OH), Tennessee (TN), Virginia (VA), and West Virginia (WV). Participants were primarily female (81%) and non-Hispanic White (86%). A FGD was held in each of the represented six states, with an additional session held in TN with a primarily African American group, subsequently 37% of the total participants were from TN (Table 3.1).

### *Themes about CVD Prevention at the Community Level*

Participants were asked to identify current efforts in their communities, as well as what is needed in relation to preventing and managing CVDs and associated conditions. Three major themes emerged from these FGDs: 1) community economic characteristics, 2) community infrastructure in relation to exercise and diet, and 3) community organizations that provided resources.

**Table 3.1**

*Focus Group Discussion Participant's Attributes*

| State | No. of Participants (%) | Sex | Racial Composition |
|---|---|---|---|
| Kentucky | 10 (12.82) | All female | Mixed |
| North Carolina | 13 (16.67) | All female | All non-Hispanic White |
| Ohio | 9 (11.53) | 6 females, 3 males | All non-Hispanic White |
| Tennessee | 15 (19.23) | 8 females, 7 males | All non-Hispanic White |
| Tennessee | 12 (15.38) | 10 females, 2 males | 11 AA, 1 non-Hispanic white |
| Virginia | 8 (10.25) | 5 females, 3 males | All non-Hispanic White |
| West Virginia | 11 (14.10) | All female | All non-Hispanic White |

*Notes:*
AA = African American

**Community Economic Characteristics.** The first theme that emerged from FGDs concerned the impact of poverty and employment on health. Within the FGDs, limited employment opportunities and high rates of poverty were reoccurring terms used to describe the communities they lived in, and the communities in their regions. Lack of employment opportunities were primary associated with the rural geographic makeup of the region, as well the closing of coal mines. Participants noted traveling to larger communities for a more diverse range of employment options was a common necessity of rural life, and subsequently added the additional burdens of travel time and maintaining reliable transportation. In NC participants went on to expound on an additional dynamic at play within their local employment market in relation to one of the few higher paying companies:

> It is, it is, but it's hard to get jobs there too because it's usually your cousin or your brother or somebody that's already in there get you a job. You have to know somebody. It's one of those situations. Other than that, what do we have around here? For decent pay. The prison and mining. That's pretty much it.

The role of coal mining in rural communities was a noteworthy topic for several of the FGDs in the context of historically deteriorating individual's health due to environmental exposures, while currently playing a key role in exacerbating the deterioration of the community's economy. Some participants reminisced of a time when the coal mines were active and provided well-paying jobs for the families that resided in these rural areas. However, the conjunction of coal mine closures and a lack of new industries moving in has resulted in the incline of poverty rates. A participant in OH explicated perceptions within her own community:

> Also, like he said that about being a poor community, it was a miner community. The mine played out years ago. A lot of them haven't figured it out yet. They still live like the mine is there or coming back. If you go up there tomorrow, they'll tell you, "We're going to get those miner jobs back," and they're not coming back. They're never coming back. They live in that…..
> They can't afford to leave.

Some participants linked the role of poverty to diet adequacy and quality, contributing the high cost of healthy foods as a deterrent. Processed foods such as potato chips and other connivence foods were identified as being more cost effective than fresh fruits and vegetables.

However, participants also associated unhealthy diets with the culture of the communities, citing certain practices such as “frying everything” as part of their up bringing. One participant in OH articulated her observation of the multi-generational cycle of poor dietary habits:

> Because of poverty, people eat poorly. When you can get a pack of hot dogs for $1, or a thing of pasta, and feed a family, people around here eat poorly. We do not eat healthy because it’s what they can afford. Lots of times they could afford better. It’s poor education, poor upbringing. It’s what they ate their whole life, so they’ll eat a hot dog.

**Community Infrastructure.** Another theme that surfaced from FGDs revolved around community infrastructure in relation to providing opportunities for physical exercise and access to healthy food. Some participants in all seven of the FGDs noted that their communities had at least one of the following features: walking trails, bike paths, state parks, and sidewalks in some portions. The reported utilization of these resources varied between groups, and between participants within groups. Common features of utilized resources included safety, accessibility, and walkability. One participant in WV discussed some improvements to infrastructure within portions of her own community and indicated the need for expansion.

> My husband was principal at [School Name], which was up on the hill, and he went to the... What is it? The councilman and stuff and got sidewalks, because he said,” These kids have to walk here.” He got what he could toward the school, but there’s lots of places that you see people walking and they’re having to walk in the road. They might walk more if they had more sidewalks

> and stuff. But Charleston has fixed the bike path and walking path along the boulevard, which is beautiful.

While acknowledging some infrastructure was available, several of participants still perceived barriers to accessing and utilizing them. The two most common barriers discussed included having to travel to these resources as in many instances they were not available right out their own front door. In many cases not having sidewalks in their own neighborhoods required individuals to walk in roads and contend with passing vehicles. An additional barrier was the strenuous nature of physical activity due to the mountainous geography of the area, which resulted in steep paths and trails, creating difficulties for those with health conditions and those just beginning to implement a physical activity routine.

Perceptions concerning access to healthy food options within communities varied among the groups, with high costs cited as the most common barrier. However, one notable discussion addressed resistance to changes in the food environment within schools, adding a different perspective to that perception. A participant in OH brought to light:

> Even in the last presidential term when Michelle Obama tried to introduce healthy food in schools, oh my goodness. If you had read these things that people wrote, "They're making my kids eat garbage," and all this. They just wanted their kid to have pizza every day, or hot dogs every day. They said, "They won't eat this stuff. They eat macaroni and cheese. They eat hot dogs. They eat pizza. Why would you try to give them asparagus?" I'm like, "This is it." They said, "Nobody was going to eat that stuff that she tried to feed our kids."

**Community Organizations.** The final theme that emerged from FGDs was the role community organizations had in providing resources related to diet, exercise, education, and social interaction. FGD participants identified the organizations within their communities that they were aware of and provided information on which kind of services were offered. Organizations predominately cited included senior centers, lifestyle medicine programs, and social support groups.

Across all seven of the groups, senior centers were identified as accessible organizations within their communities that were utilized. Senior centers were cited to provide various opportunities to engage in exercise, consume nutritious meals, and receive education on healthy lifestyles. One participant in OH mentioned that the local senior center emphasized their mission to ensure exercise opportunities were available for their members to compensate for a deficit in affordable resources and took on an additional financial burden to make that happen.

> [Senior Center Name], when we moved into this building and knew that there was going to be an elevated track part of our mission because we do look on ourselves as a senior wellness community, we pay an extra amount of rent to allow people… We only get certain hours, two hours in the morning and one hour in the afternoon for people to walk at no cost to them. We pay extra rent so that's available, so they don't have to pay for a gym membership because we do live in an impoverished community and walking should be free.

Silver Sneakers was the next commonly discussed program to engage in physical exercise, with participants in three out of the seven groups introducing it into the discussions. This program is designed specifically for individuals over the age of 65, however the high cost of this program was identified as a barrier to participating in it. One participant in OH summed up her understanding of the program in the quote below.

> Silver Sneakers is an exercise program that is paid for through insurance. The insurance company offers this Silver Sneakers package that allows the person to exercise, use this gym membership, and they pay for it because they see the value in a person exercising for their health. They push it. Unfortunately, it's not with all insurance. It would be wonderful if Medicare put it on, but Medicare likes to trim instead of add.

Additionally, participants in the remaining two FGDs with awareness of the program concurred that many health insurance plans did not cover the cost of it, and it was too expensive for those with a fixed income. Subsequently, although it was available, it was underutilized among financially disadvantaged individuals.

Moreover, participants in the FGDs in OH, TN, and WV identified additional lifestyle medicine programs that were available in their communities and were covered by some health insurance plans. These three programs included the Complete Health Improvement Plan (CHIP), the Ornish program, and the Pritikin program. All three programs were described as endeavoring to improve health through behavior change-based interventions centered around reducing stress, increasing physical activity, and following a heart healthy plant-based diet. However, despite the participants' discussions related to the success of each of these programs in improving health, they were thought to not be financially feasible for individuals without adequate health insurance coverage to pay for them.

Finally, community social support groups were a focal point. Two of the FGDs were conducted at non-profit community CVD support/advocacy groups, both of which emphasized the significance of the social support and education they and other members had received within these groups. Both groups partnered with local hospitals to conduct outreach to CVD disease patients while they were still hospitalized, conducted follow-up after patients were discharged, held regular support group meetings, provided education, and advocated for CVD prevention and awareness across the communities they served. These participants shared many of their personal stories of experiencing a major cardiac event and the support they received from these groups, not only for themselves, but for their families as well. One participant in TN stated:

> When I had my heart surgery, Bill and his wife sat with my wife during the time. It was truly appreciated because she was scared. She was saying, “I could be a widow.” Well, it didn’t turn out that way. Eleven years down the road, my heart is still ticking, but that was what she was thinking.

This support was continued beyond immediate cardiac events as participants navigated healthcare systems, interacted with healthcare providers, and encountered new questions about their conditions. Many of the participants credited the encompassing resources at their disposal responsible for increasing their self-efficacy related to managing their conditions and preventing the development of additional CVDs. One participant in WV noted:

> I was telling my sister, next week will be my one-year anniversary of my stent and angioplasties. Knowing this group and being a part of it has empowered me so much. I have learned so much that I would not have known, even being able to go to an appointment and now knowing the right questions to ask and having this group as a support. Because when I leave that appointment, I haven’t asked everything I need to ask, but knowing that there’s somebody out

> there if I need to make a phone call or shoot a message on Facebook, it's right there. There's somebody there who, like she said, "If you don't know the answer, you're going to share it." It's been a great lifeline for me because afterwards I felt like my whole life was over.

As alluded to in the previous quote, education was also stressed as a core function of these groups, for their members, friends and family, and the community. Community education was conducted via conferences open to the public, setting up educational displays at health fairs, hosting speakers such as cardiologists, and conducting educational sessions at various organizations including churches and workplaces. Moreover, incorporating family and friends into the educational process was a preferred approach, and opportunities were provided through community education as well as during outreach with hospitalized patients. This technique allowed the organizations to raise awareness as well as present education on prevention, and resources available within the community.

A participant in WV stated:

> Of course, we're family oriented. I not only speak to the patients themselves, but I also get to talk to the family members, whether it's a son, daughter, husband, or whatever. Usually, the room is... Most patients, the room is pretty full of visitors, so we not only touch the patients, but we also get to educate the people in the family also, to let them know about the gene pool, this and that and everything else. Then usually, that starts up a discussion about what's available in their area and stuff like that.

**Discussion**

Poverty and financial strain were core elements FGD participants identified, which touched every aspect of communities and limited their ability to facilitate environments conducive to healthy lifestyles. It was cited that lack of well-paying employment opportunities contributed to poverty, which in turn caused food insecurity. In particular, the disappearance of coal mining in rural communities was found to negatively impact local economies, in addition to a lack of new industries moving into these communities. This was consistent with the ARC findings that the total number of private sector employment in mining communities has not changed since 2012, while coal mining occupations decreased by approximately 54% between 2005 and 2020.[21] Poverty is a hardship felt outside of Central Appalachian mining communities as well, with poverty rates within the region at 22.4%.[14] Contributing to this burden are high rates of individuals receiving disability benefits, 13.9% of the population receive benefits from the Social Security Administration due to health issues, compared to 5.1% nationally.[13]

Barriers to physical activity within their communities was another focal point among FGD participants and included lack of sidewalks in proximity of their homes, safety concerns with walking in roads, health conditions, travel time to PA resources, and the strenuous nature of sidewalks, paths and trails due to the mountainous topography of the region. These findings are congruent with other rural studies that have found barriers to PA included lack of safe places to walk due to no sidewalks, sidewalks in poor condition, lack of crosswalks, no distinguishable shoulders on the side of streets,[22-25] poor health,[23,25] and lack of time.[13,14] Previous rural studies have also identified additional barriers to include fear of injury, dislike of exercise,[23,25] cost of exercise facilities,[24-26] weather, lack of time, and lack of knowledge on how to exercise.[24,25] These additional barriers were not specific factors addressed in the present study, however one unique aspect was identified concerning the mountainous topography of the region. The steep nature of available PA options and infrastructure were noted as a barrier to utilization among those who were out of shape, and individuals with chronic health conditions such as CVD. Under these conditions, simply going for a walk became a feat of physical endurance that was beyond their current capabilities. This is a considerable factor, whereas adults in Central Appalachia have reported feeling physically unhealthy or in poor physical health 5.1 days per person, per month, a rate 42% higher than the national average at 3.6.[13] Moreover, the percentage of adults reporting to have a disability is considerably higher than national averages at 22.5%, versus 10.3% among 18-64 year-olds, and 47.4% versus 34% among 65 year-olds and older, respectively.[14] Disability inclusion criteria included difficulties with seeing, hearing, cognition, walking, or independent living functions.[14]

In contrast, many of the barriers identified in previous studies on the built food environment's impact on diet were not topics of discussion in this study. Aside from the cost of healthy food being an impediment, there was little to no focus on the density of fast-food restaurants, nor lack of accessible grocery stores. In fact, the Central Appalachian region has 14% more grocery stores when compared to the national average.[13] Dietary patterns cited were more related to up bringing, dietary preferences, convivence, and poverty. Participants indicated dietary preferences were a result of culture and up bringing, consistent with another study in rural Appalachian KY.[26] The financial restraints of poverty was a significant factor in dietary patterns, with the cost associated with healthy foods impeding on the feasibility of sustaining healthier choices. Research has established long-lasting effects of food insecurity[27,28] and dietary patterns developed during childhood, as these learned behaviors continue to influence dietary choices into adulthood, which in turn are taught to the next generation.[27-31] Moreover, one FGD emphasized how deep dietary preferences were rooted within the community; governmental policy changes effecting school food offerings to meet dietary standards was a source of discontent among parents, who balked at the feasibility of increasing vegetable consumption over processed foods.

Finally, while examining participant discussions about community resources, it is important to take into consideration where each of the discussions occurred. Four of the FGDs were held in senior centers, that provided opportunities to engage in PA, healthy meals, health education, and social interactions, resulting in discussion based more on activities within those centers, and barriers within their communities. Two of the FGDs were held in CVD support/advocacy groups, both of which provided peer-to-peer support networks for individuals with CVD and their families, lead and promoted CVD education and awareness within communities, and engaged in advocacy efforts to improve access to medication and treatments through policy reform and expansion. The remaining FGD was held at a predominately African American church, intriguingly their discussion focus consisted of a cross between the senior centers and support groups. While they also identified senior centers as a significant resource and adduced barriers and opportunities within their community, they furthermore emphasized the degree of social support they received within their church. Making healthy lifestyle choices was a meaningful topic, members confided in each other about health, educated each other, and provided dietary tips and suggestions. Through these bonds they were able to hold each other accountable for not following through with changes in diet, while also receiving support to continue their efforts.

Discussions pertaining to organizations outside of the FGD hosted sites found the combination of limited finances, lack of health insurance coverage, and high cost of lifestyle medicine programs and other exercise programs inhibited participants ability to utilize those resources. Although lack of health insurance was identified as a barrier, the percentage of the population without health insurance follows the national average at 10.3% and 10.6% respectively.[32] Statistically, lack of providers in the region was more profound, a 2017 report from the ARC found that the number of primary care providers per 100,000 in Central Appalachia was 33% lower than the national average, and the quantity of specialty physicians was 65% lower.[13] In this case, lack of insurance coverage refers to out-of-pocket costs, and the extent to which programs are considered eligible for reimbursement. Given the high rates of poverty, even minor costs may be viewed as insurmountable.

## Conclusion

Limitations to this study include a using a priori of seven FGDs to represent the Central Appalachian region, which did not allow for complete saturation. Additionally, although all groups comprised of CVD patients and caregivers, and researchers utilized the same guide with preset questions, the variation in the FGDs sites had an influential impact on responses inspired by the same prompts. Other limitations related to IRB approval included the inability to collect extensive information concerning the participants attributes, as well as distinguish between CVD patients and NLCs for comparison. Notwithstanding these limitations, this qualitative exploratory study highlights challenges to developing healthier communities due to community infrastructure, economic strain, and availability of community organizations.

In conclusion, this study explored CVDs prevention at the community level in Central Appalachia by leveraging the knowledge and perceptions of their residents. As a result, this study exposed a significant gap within the current research in relation to the built environment and PA, as barriers associated with the mountainous topography in rural areas has not been a considerable focal point in studies. While improving community infrastructure in urban areas to facilitate PA through the expansion of sidewalks, safety features, walking paths, and land use mix has been a well-researched area, these finding do not adequately translate over to rural communities within Central Appalachia. These features provide little use among portions of the population without the necessary health status, and/or physical endurance to utilize these resources due steep inclines that require more physical exertion. This coupled with limited financial resources within economically strained communities proposes additional questions, what is the most impactful strategy to improve the built environment and promote health within these constrains. Further research is needed to provide quantitative data as to which PA resources are utilized the most within these communities, specific features that increase usage, and the most effective usage of limited economic resources. Additionally, qualitative investigation is necessary to determine if new infrastructure will be utilized, gain insight into specific physical concerns, and determine if design features will be adequate to promote PA among vulnerable populations.

Finally, the impact of poverty was an overarching issue effecting communities in a multitude of ways. The lack of new industry specifically in mining communities, and long travel times to employment opportunities were specific areas brought to light. While these are not new findings, they do have significant policy implications as these communities will remain stagnant without intervention. One possible solution to address employment opportunities is through the rise of computer based, work from home opportunities. Nationally, the number of people who work from home has tripled from 5.7% in 2019, to 17.9% in 2021,[33] opening up new possibilities despite physical location. Access to internet in the region has been on the incline with 82.7% of households have at least one computer device, such as a smartphone, desktop or laptop computer, tablet, and 73.6% have a broadband (high speed) internet subscription.[14] Additionally, although historically these communities suffered from low education attainment, the percent of adults with at least a high school diploma has greatly increased from 52.1% in 1990, to 75% in 2013,[13] and has continued this trajectory with rates at 83.7% between 2016-2020.[14] This rate is nearly comparable to the national average of 89.5%,[14] moreover, associate degree rates are at 9.1%, comparable with 9.3% nationally, while rates of bachelor degree or higher attainment still fall short at 15.8% versus 34.3% nationally.[14] The combination of these factors presents an opportunity to increase economic stability, if home based work opportunities can be leverage. Additional research is needed to provide insight into policies that may facilitate this shift, possibly through specific training opportunities to meet work from home employment needs, and expansion of affordable and reliable broadband services.

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## References

1. Booth FW, Lees SJ. Fundamental questions about genes, inactivity, and chronic diseases. Physiol Genomics. Jan 17 2007; 28(2):146-57. doi:10.1152/physiolgenomics.00174.2006
2. Bhatnagar A. Environmental determinants of cardiovascular disease. Circulation Research. Jul 7 2017;121(2):162-180. doi:10.1161/CIRCRESAHA.117.306458

3. Stampfer M, Hu F, Manson J, Rimm E, Willett W. Primary prevention of coronary heart disease in women through diet and lifestyle. The New England Journal of Medicine, 2020. 343:16-22. Doi: 10.1056/NEJM200007063430103

4. Stankov I, Howard NJ, Daniel M, Cargo M. Policy, research and residents' perspectives on built environments implicated in heart disease: A concept mapping approach. Int J Environ Res Public Health. Feb 9 2017;14(2)doi:10.3390/ijerph14020170

5. Koohsari MJ, McCormack GR, Nakaya T, Oka K. Neighbourhood built environment and cardiovascular disease: Knowledge and future directions. Nat Rev Cardiol. May 2020;17(5):261-263. doi:10.1038/s41569-020-0343-6

6. County Health Rankings & Roadmaps. Social & economic factors. University of Wisconsin Population Health Institute. Available at: https://www.countyhealthrankings.org/explore-health-rankings/county-health-rankings-model/health-factors/social-economic-factors

7. Arnett DK, Blumenthal RS, Albert MA, et al. 2019 ACC/AHA guideline on the primary prevention of cardiovascular disease: A report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 2019;140(11):e596-e646. doi:10.1161/CIR.0000000000000678

8. Mobley LR, Root ED, Finkelstein EA, Khavjou O, Farris RP, Will JC. Environment, obesity, and cardiovascular disease risk in low-income women. Am J Prev Med. Apr 2006;30(4):327-332. doi:10.1016/j.amepre.2005.12.001

9. Kerr J, Rosenberg D, Frank L. The role of the built environment in healthy aging. Journal of Planning Literature. 2012;27(1):43-60. doi:10.1177/0885412211415283

10. Papas MA, Alberg AJ, Ewing R, Helzlsouer KJ, Gary TL, Klassen AC. The built environment and obesity. Epidemiol Rev. 2007;29:129-43. doi:10.1093/epirev/mxm009

11. Malambo P, Kengne AP, De Villiers A, Lambert EV, Puoane T. Built environment, selected risk factors and major cardiovascular disease outcomes: A systematic review. PLoS One. 2016;11(11):e0166846. doi:10.1371/journal.pone.0166846

12. Sallis JF, Floyd MF, Rodriguez DA, Saelens BE. Role of built environments in physical activity, obesity, and cardiovascular disease. Circulation. Feb 7 2012;125(5):729-37. doi:10.1161/CIRCULATIONAHA.110.969022

13. Marshall JL, Thomas L, Lane NM, et al. Creating a culture of health in Appalachia: Disparities and bright spots. Washington, D.C.: Appalachian Regional Commission, 2017.

14. Pollard K, Jacobsen LA. The Appalachian region- A data overview from the 2016-2020 American community survey chartbook. Population Reference Bureau. 2022.

15. Booth J, Wei K, Little A. Examining the impact of food environment changes on county-level obesity prevalence in the Appalachian region. Journal of Health Disparities Research and Practice. 2017;10(4). Available at: https://digitalscholarship.unlv.edu/jhdrp/vol10/iss4/2

16. Appalachian Regional Commission. County economic status in Appalachia, 2022. Available at: https://www.arc.gov/classifying-economic-distress-in-appalachian-counties/

17. Chrisman M, Nothwehr F, Yang G, Oleson J. Environmental influences on physical activity in rural Midwestern adults: a qualitative approach. Health Promot Pract. Jan 2015;16(1):142-8. doi:10.1177/1524839914524958

18. Rendle KA, Abramson CM, Garrett SB, Halley MC, Dohan D. Beyond exploratory: A tailored framework for designing and assessing qualitative health research. BMJ Open. Aug 27 2019;9(8):e030123. doi:10.1136/bmjopen-2019-030123

19. Kennedy W, Fruin R, Lue A, Logan SW. Using ccological models of health behavior to promote health care access and physical activity engagement for persons with disabilities. J Patient Exp. 2021;8:23743735211034031. doi:10.1177/23743735211034031

20. Tolley EE, Ulin PR, Mack N, Robinson ET, Succop SM. Qualitative methods in public health: A field guide for applied research. Second Edition. John Wiley & Sons, Incorporated 2016. Available at: https://ebookcentral.proquest.com/lib/etsu/detail.action?docID=7104122.

21. Bowen, E., Christiadi, Deskins, J., & Lego, B., An overview of the coal economy in Appalachia. Appalachian Regional Commission. 2020. Available at: https://www.arc.gov/report/an-overview-of-coal-and-the-economy-in-appalachia/

22. Hege A, Christiana RW, Battista R, Parkhurst H. Active living in rural Appalachia: Using the rural active living assessment (RALA) tools to explore environmental barriers. Prev Med Rep. Dec 2017;8:261-266. doi:10.1016/j.pmedr.2017.11.007

23. Joshu CE, Boehmer TK, Brownson RC, Ewing R. Personal, neighbourhood and urban factors associated with obesity in the United States. Journal of Epidemiology and Community Health. Mar 2008;62(3):202-8. doi:10.1136/jech.2006.058321

24. Gilbert AS, Duncan DD, Beck AM, Eyler AA, Brownson RC. A qualitative study identifying barriers and facilitators of physical activity in rural communities. J Environ Public Health. 2019;2019:7298692. doi:10.1155/2019/7298692

25. Jones N, Dlugonski D, Gillespie R, et al. Physical activity barriers and assets in rural Appalachian Kentucky: A mixed-methods study. Int J Environ Res Public Health. Jul 19 2021;18(14)doi:10.3390/ijerph18147646

26. Mudd-Martin G, Biddle MJ, Chung ML, et al. Rural Appalachian perspectives on heart health: social ecological contexts. Am J Health Behav. Jan 2014;38(1):134-43. doi:10.5993/AJHB.38.1.14

27. Arlinghaus KR, Laska MN. Parent feeding practices in the context of food insecurity. Int J Environ Res Public Health. Jan 6 2021;18(2)doi:10.3390/ijerph18020366

28. Daniel C. Economic constraints on taste formation and the true cost of healthy eating. Soc Sci Med. Jan 2016;148:34-41. doi:10.1016/j.socscimed.2015.11.025

29. Mahmood L, Flores-Barrantes P, Moreno LA, Manios Y, Gonzalez-Gil EM. The influence of parental dietary behaviors and practices on children's eating habits. Nutrients. Mar 30 2021;13(4)doi:10.3390/nu13041138

30. Ramos, M., & Stein, L. M. (2000). Development children’s eating behavior. Journal of Pediatrics. 76 Suppl 3, S229–S237. https://doi.org/10.2223/jped.160

31. Carbert NS, Brussoni M, Geller J, Masse LC. Moderating effects of family environment on overweight/obese adolescents' dietary behaviours. Appetite. Mar 1 2019;134:69-77. doi:10.1016/j.appet.2018.12.034

32. Pollard K, Jacobsen LA. The Appalachian Region: A Data Overview from the 2014-2018 American Community Survey Chartbook. Population Reference Bureau, 2020.

33. U.S. Census Bureau. U.S. Census Bureau releases new 2021 Community Survey 1-year estimates for all geographic areas with populations of 65,000 or more. 2022. Available at: https://www.census.gov/newsroom/press-releases/2022/people-working-from-home.html

# Chapter 4. An Exploratory Study of the Delivery of Patient-Centered Care in Relation to Cardiovascular Diseases from the Viewpoint of Professional Stakeholders within the Central Appalachian Region

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*Abstract.* Cardiovascular disease rates continue to rise and disproportionally impact the health and lives of those who reside within Central Appalachia. Given the progressive nature of these diseases, early care has the potential to mitigate rates through effective patient-centered care. This study explored the perceptions of constructs essential to the delivery of patient-centered care (PCC) among providers within the region. Twenty professional stakeholders were interviewed across five states, participant inclusion criteria consisted of being employed within the Central Appalachian region and working in a healthcare field. Each of the interviews were audio-recorded and underwent thematic analysis to identify major themes. Three themes were identified from this process: 1) PCC in the current healthcare system, 2) constructs of patient-provider interactions, and 3) the role of community outreach. Stakeholders depicted a need for healthcare systems to increase their emphasis on prevention, identified important practices to influence change among patients, and identified how community outreach has the potential to fill in gaps within healthcare.

*Key words:* Patient-centered care, cardiovascular disease, Central Appalachia, lifestyle medicine, community outreach, community health workers.

## Introduction

In healthcare systems that strive to provide dynamic state of the art care for a mass variety of illnesses and injuries, it is a challenge to also address and tailor to the individualized needs of its diverse population. Individualized needs may vary based on culture, socio-economic status, healthcare access, and personal preferences. The patient-centered care (PCC) model seeks to address this very issue through the development of guidelines for practitioners to implement. While many definitions of PCC have been established, the American College of Cardiology Clinical Quality Committee has refined the definition to specifically address cardiovascular diseases (CVD).[1] This definition consists of the following identified eight essential elements: (1) enhanced clinician-patient communication; (2) health literacy; (3) clinician-directed patient education; (4) assessment of patient-centered outcomes; (5) shared decision-making; (6) collaborative care planning; (7) collaborative goal setting; (8) patient empowerment and self-management.[1]

Effective communication between providers and patients has been shown to be associated with improved health status, recall, treatment adherence, and satisfaction;[2,3] while poor communication has shown to result in a 19% higher risk of non-adherence.[4] However, inadequate health literacy can make effective communication difficult by hampering the patient's ability to process and understand health information. Adequate health literacy involves a combination of skills including the ability to read and write, interpret information, understand quantitative data, communicate effectively orally, and listen.[5] These skills are necessary to understand disease processes, treatment options, and proper utilization of medications.

Unfortunately, many adults do not possess all these necessary skills, a survey conducted by the U.S. Department of Education found that 36% of adults had limited health literacy.[5] This is a major concern, as those with limited health literacy are less likely to engage in preventive care and screenings, and are more likely to be hospitalized, and suffer from chronic diseases and related complications.[5] This emphasizes a great need for clinician-directed education to properly inform patients and increase their empowerment and ability to collaborate with the planning of their care.

While the PCC model of care can improve health outcomes, the unique cultural influence within Central Appalachia, along with provider shortages and barriers to healthcare access creates challenges to the delivery of this care. A report from the Appalachian Regional Commission found the rate of primary care physicians in Central Appalachia was 33% lower than the national average, and the rate of specialty physicians was 65% lower.[6] Smaller studies throughout the region have found lower rates of healthcare satisfaction, feeling judged and intimidation by providers due to their low socio-economic status,[7,8] inability to afford health care, and lack of transportation options to distant healthcare providers.[7-9]

The aim of this study was to investigate the definition of PCC and important constructs within these interactions among Central Appalachian healthcare professionals. Given the difficulty to integrate all the defined components of PCC into a cohesive patient-centered healthcare system within a region that experiences barriers to access, effective interactions between providers and patients are crucial. This study will begin to identify where major gaps in PCC exist from the perspective of healthcare professions.

## Methods

This study utilized a qualitative exploratory design to discover important themes related to PCC among professional stakeholders in the Central Appalachian region. Use of an exploratory design allowed researchers to take an inductive approach in gathering insights and perspectives among stakeholders and identifying themes to inform future research agendas.[10] Data was gathered through telephone interviews with professional stakeholders within Central Appalachian communities, in each of the five states: North Carolina, Ohio, Tennessee, Virginia, and West Virginia (Figure 4.1). Professional stakeholders were defined as being employed within the Central Appalachian region and working in a healthcare field.

**Figure 4.1**

*Central Appalachian Region of the United States*

Data provided by Appalachian Regional Commission
Created by AMP

*Note:* This geographical information system (GIS) map shows the states in the Central Appalachian region where interviews were conducted.

### *Participants*

Consistent with exploratory study designs, convenience sampling was utilized to recruit a total of twenty professional stakeholders.[10] This was achieved by first conducting an environmental scan at the community level within Central Appalachian communities to identify existing health organizations including non-profits, CVD support groups, health departments, and CVD related medical practices. These organizations were then contacted by the researchers, during which they were given a summary of reasons for the research, research goals, research needs, and inquired if there was an appropriate stakeholder that was interested in being interviewed. Interviews were arranged among twenty participants and included healthcare providers, nonprofit directors, health department representatives, and hospital volunteer directors. The total quantity of participants was determined by the ability to schedule interviews during the established research timeline. The inclusion criteria involved being employed within Central Appalachian counties of Kentucky (n=0) North Carolina (n=1), Ohio (n=2), Tennessee (n=4), Virginia (n=2), and West Virginia (n=11), exclusion criteria involved being employed outside these 228 contiguous counties.

### *Data Collection*

Interviews were conducted between March and August of 2019 utilizing a discussion guide drafted by three qualitative researchers that were a part of the larger multi-disciplinary research team. The research team consisted of academic researchers and community members, who rigorously reviewed the discussion guide before a final draft was approved through consensus. The discussion guide consisted of semi structured broad open-ended questions to facilitate the input of participant knowledge and perceptions.[10] Additionally, the discussion guide touched on levels of the Ecological Model of Health Behavior (EMHB) to gather information at the individual, community, and organizational levels.[11] The EMHB recognizes that health outcomes are the result of dynamic influences within each of the levels,[11] therefore, to identify factors influencing CVD rates within the region, the phenomena must be explored across multiple levels.

At the start of each interview, participants were provided with a brief introduction to the study, informed consent, contact information for the principal investigator and project coordinator, ensured every effort would be made to protect their confidentiality, and permission to record the discussion was obtained. Interviews lasted approximately 30 to 45 minutes, during which participants were asked to discuss issues concerning CVD prevention, screening, management, treatment at the community and individual level, in addition to identifying CVD priorities and their definition of patient-centered care. For purposes of this study, data pertaining to PCC will be explored. Specifically, participants were asked "what is your definition of PCC," and "what do you feel are the important practices within your field and job that ensure that you are providing PCC."

This study was approved by the East Tennessee State University Institutional Review Board.

### ***Data Analysis***

Interview recordings were reviewed by qualitative researchers, and data were manually coded into tables in accordance with the associated discussion question. Two qualitative researchers then examined the content utilizing qualitative thematic analysis methodology, in which researchers first gain familiarity with the data, then generate initial codes, group codes into themes and develop a codebook, apply codes to the data, and compare and discuss findings.[12] Two qualitative researchers independently examined the first interview table and used inductive coding to identify themes, then compared findings, discussed discrepancies, and drafted a preliminary codebook. Researchers then independently coded the second interview table, compared findings and discrepancies, and revised the codebook. All interviews were then independently coded using the updated codebook, and researchers compared and discussed codes to ensure dependability and accuracy in coding. Once completed, one researcher compiled data from each theme and compared the coverage across each of the interviews.

## Results

### *Characteristics of the Study Stakeholders*

Stakeholders consisted of 20 professionals working within the healthcare field in the Central Appalachian counties of North Carolina (NC), Ohio (OH), Tennessee (TN), Virginia (VA), and West Virginia (WV). Five of the stakeholders were medical doctors (MDs), three were nurse practitioners (NPs) with two of them working within community organizations, two additional stakeholders worked within community organizations, one worked in a health department, and the remaining nine worked within hospitals as directors and managers (Table 4.1).

### *Themes about Perceptions of Patient-Centered Care*

Stakeholders were asked to discuss how they defined PCC and expound on their view of important practices within their field that assured PCC was being delivered. Three major themes emerged from these interviews, 1) PCC in the current healthcare system, 2) constructs of patient-provider interactions, and 3) the role of community outreach.

**Table 4.1**

*Professional Stakeholder Titles*

| State | No. of Participants (%) | Occupation |
|---|---|---|
| North Carolina | 1 | Nurse Practitioner |
| Ohio | 2 | Medical Doctor |
| | | Non-profit Director |
| Tennessee | 4 | Cardiologist |
| | | Health Department |
| | | Non-profit Director |
| | | Non-profit, NP |
| Virginia | 2 | Non-profit, NP |
| | | Cardiologist |
| West Virginia | 11 | Cardiologist |
| | | Vascular surgeon |
| | | Hospital Directors (9) |

**PCC in the Current Healthcare System.** The first theme that emerged from interviews revolved around the respondents' perceptions of the current healthcare system delivery paradigm, which was stated to focus on disease treatment and management versus prevention. The five MDs and one of the NPs discussed deficiencies within the current system which prevented care from being patient focused, these included the structure of healthcare funding, lack of prevention, and the dependency on pharmaceuticals.

Stakeholders remarked healthcare funding prioritized treating diseases and determined reimbursement based on CVDs treated versus prevented. Under this structure, HCPs are not incentivized or provided with compensation to take the additional time required to get to the cause of diseases. This was presented as a frustration among the HCPs, one MD stated:

> The current models are not changing the numbers; our system is not paying for the cause of disease, but the treatment. We need new ways of thinking.

It was perceived that this current structure did not have the capacity to remediate the growing rates of CVDs throughout the population and limited healthcare providers ability to provide impactful PCC interventions. The focal point of necessary system changes centered around practices related to prevention and disease reversal and emphasized a need for more education and modification of behaviors. Stakeholders identified components of a comprehensive approach would include providing more education to patients on how to live lifestyles that reduced disease risk, incentivizing them to make those choices, and providing the necessary resources. To achieve this, appointment times would first need to increase to allow HCPs to learn about their patients as a whole person, then provide appropriate education. Physical activity and diet were repeatedly stressed as vital to prevention education, patients needed specific information on what constitutes a healthy diet, how to read and interpret nutritional information, how to prepare food, types of physical activity, how much physical activity is needed, options to achieve physical activity goals, and the relationship between diet and exercise. Some participants noted that coupling knowledge with incentives to engage in healthy choices would then provide motivation and reinforcement for sustainable behavior change. Additionally, extending healthcare to include the coverage of exercise programs, heart healthy cooking classes, and other lifestyle programs would provide the means for the underserved to access integral resources.

Finally, some stakeholders indicated the current treatment-based model was additionally influenced by pharmaceutical companies reinforcing the acceptance of medication-based care among the population. It was acknowledged that pharmaceutical companies are a primary source of research and profited from the sales of their medications, therefore, some respondents noted the perception that there are no incentives for them to cure diseases. Greater profits exist in a system that markets pills instead of prevention, treats symptoms with medications as patients present them, while neglecting to intervene with behavioral interventions and allowing disease processes to progress. One stakeholder signified the marketing of pharmaceuticals was only legal in the United States and New Zealand, which reinforced the acceptance of medication-based healthcare. Additionally, it was also noted that medications do not address cause, and as diseases progress patients need more and more medication to treat their symptoms, contributing to a cycle of management through medications.

**Patient-Provider Interactions.** The next major PCC theme that surfaced were stakeholder perceptions of constructs pivotal to productive interactions between patients and HCPs. Five common constructs emerged: 1) individualizing care, 2) understanding at which stage of change the patient is at, 3) providing education, 4) engaging in collaborative decision making, and 5) empowering patients.

Within the first construct, individualizing care emphasized taking a holistic approach through consideration of internal and external factors that impacted the patient’s daily life. Internal factors included the need to consider the patient’s level of knowledge, education, and physical and emotional health; external factors explored the patient in terms of family and social structures, home environment, community, culture, and the tools and resources available to them. One stakeholder described the process as:

> Looking at the multidimensional attributes of patient’s stories and clinical presentations and findings to offer a specific solution to the patient. This requires new ways of analyzing patient data sets to develop specific types of therapies to offer patients.

The next construct that participants shared included understanding at which stage of change the patient was currently at and seeking to ascertain what factors motivated their behaviors. This construct was identified in the context of interactions with patients with established CVDs and was necessary to determine before engaging in healthy lifestyle education. One stakeholder detailed the questions he would commonly ask: “Do you want to do this? Do you want to feel better? Do you want to reverse your disease?” By discerning if the patient was ready to make lifestyle changes, and which changes they were most prepared to make, providers could target education efforts in a more effective manner.

The third construct emphasized proving patients with education on disease processes such as why they are experiencing their current symptoms, what triggered them, how symptoms would further progress into diseases, and ultimate outcomes. This could then be followed by education on their treatment and prevention options. Stakeholders predominately stressed increasing patient’s knowledge of options related to lifestyle changes including diet and physical activity, in addition to presenting the information in a manner that encouraged small changes that could later be built upon.

Engaging in collaborative decision making, and empowering patients were the final two constructs cited among stakeholders. Collaborative decision making was consistently described as gathering patient input, involving patients in the planning and carrying out of care, and the importance of informed/shared decision making. In practice, this involved customizing an outcome orientated plan that began with changes the patient identified as amendable and progressed temporally at a rate conducive to the patient’s intentions and resources. Moreover, empowering patients was identified as a construct of PCC, and what empowerment entailed varied from patient to patient based on needs. However, it was generally described as providing patients with the motivation and knowledge to take responsibility for their illnesses, and subsequentially make better health choices.

**Community Outreach.** The final theme that was a point of discussion across all the interviews was the need to extend PCC access to communities through the expansion of several outreach practices. It was identified that rural Central Appalachian communities faced shortages of HCPs and specialists, which required them to either seek care outside of their communities or wait months to get an appointment locally. Community outreach was seen as a method to mitigate some of this burden through community-based screening, mobile units, clinics, telemedicine, and mobile health.

The most cited outreach efforts in place were related to providing free and low-cost screenings conducted in various settings such as community centers, health fairs, free clinics, and mobile units. Several stakeholders emphasized a need to improve outreach utilization by increasing the population’s awareness of health services and opportunities available, in addition to education on CVD risk factors and types of screenings and assessments that can inform their level of risk. Stakeholders also stated a need for training of HCPs and health advocates, on appropriate techniques to conduct culturally appropriate outreach, and develop trust and buy-in from rural Appalachian communities. Developing trust was perceived by one stakeholder as an essential first step among portions of the elderly population who resided in substandard homes, as they were less likely to utilize services due to fear of being removed from their homes. It was strategized mobile units could provide trained professionals with the ability to bring programs directly to the most underserved portions of the population, those who resided in areas where no designated neighborhoods were established, and families resided in groups of houses within the hollows (a rural and isolated small valley).

Moreover, stakeholders perceived the growing usage of telemedicine and mobile health provided further opportunities to expand access to care and compensate for HCP shortages. Telemedicine provided a means to enable patients to receive immediate care for services not offered at their location, through partnerships with, and between, hospitals, specialists, and medical groups. Additionally, mobile health provided a platform for patients to access their own medical records, review their conditions and medications, and send messages directly to their HCPs.

## Discussion

While the aim of this study was to investigate the definition of PCC, it became apparent that exclusively focusing on constructs of patient provider interactions was seen as only one component of this care. Underlying barriers within the healthcare system itself presented challenges to creating an environment conducive to PCC, primarily around healthcare reimbursement practices. Other research has also identified reimbursement practices as a significant hinderance to providing PCC in the context of the inability to provide lifestyle education without taking on a financial loss.[13-16] Providing meaningful education requires appointments that extend beyond 15 to 20 minutes, however under current reimbursement plans additional time is not covered.[13,14,16] Additionally, a survey among lifestyle medical practitioners highlighted “perverse quality measure incentives” that discourage preventative care by providing more reimbursement for procedures, health management through medication, and financial penalties for taking patients off medications in favor of conditions being controlled through lifestyle modifications.[13]

An interesting finding from the study was the perceived influence pharmaceutical companies had over health care and was described as having a negative impact on PCC.

Implications associated with direct-to-consumer (DTC) marketing of pharmaceuticals has been an ongoing topic of research for decades within the U.S. and New Zealand, the only two countries in which it is legal.[17,18] Advocates for DTC advertising cite they educate and empower patients, promote communication between patients and providers, improve relationships with providers, encourage compliance, reduce untreated conditions, reduces disease stigma, and lowers pharmaceutical costs.[19] In contrast, opponents cite ads misinform patients, overemphasize drug benefits, promote new drugs before safety is fully assessed, manufacture diseases by medicalizing trivial aliments and natural conditions, encourages overutilization of drugs, strains relationships with providers, and increases costs.[19] Despite this ongoing debate, within the U.S. DTC prescription drug advertising expenditures have increased from $1.3 billion in 1997, to $6 billion in 2016, and drug spending increased from $116.5 billion to $328.6 billion during the same time period.[18] Additionally, the length of television ads increased by 30% between 2004 and 2016.[20] In 2015 the American Medical Association called for a ban on this advertising due to concerns that ads were increasing demand for expensive procedures in lieu of less expensive alternatives, and increased demand for expensive drugs at the expense of patients that could not afford them.[21] Regardless of concerns among opponents, DTC marketing remains a thriving industry within the U.S.

Findings from this study also identified a need for insurance coverage of exercise and dietary programs outside of healthcare facilities, to provide the necessary skills to implement lifestyle changes. Behavior change research has identified that lifestyle knowledge alone is not sufficient enough to impact change among significant portions of the population,[13,22-25] additional resources are needed to provide practical skills on how to prepare healthier meals,[22] and engage in physical activity,[23,25] while providing continuous support through lifestyle coaching.[25,26]

However, with already established deficiencies in reimbursement practices,[13-16] coverage of this type of preventive care is not easily obtained. Correlating with this need, this study emphasized a call for increased community outreach to raise risk factor awareness and to provide free screening opportunities directly to the population in their own neighborhoods. However, it was identified that the rural Central Appalachian region faces shortages of HCPs, subsequently presenting a barrier to addressing this need. This is consistent with findings from a survey in Appalachia, which found 24% of participants reported engaging in health screenings, and 87.2% left their home county to receive these services.[7] Additionally, a previous CVD study within Appalachian KY identified that even when free screening opportunities were offered, people could not always afford follow-up care.[27]

Research has found community health workers (CHW) have the potential to supplement this gap. CHWs are lay health care workers that provide culturally competent support to patients within the same communities they live by facilitating education, adherence to treatment plans, assisting with navigating the health care system, and self-care.[28,29] A systematic review of community-based interventions utilizing CHW to improve management and care of chronic diseases among vulnerable populations found some of these interventions were successful in decreasing blood pressure, blood glucose, weight, and increasing screening for some types of cancer.[30] Of the 67 publications identified, 30 involved cancer prevention, 26 focused on CVDs and associated risk factors, three on mental disorders, and one on asthma.[30] Intervention sites included participants homes, community health clinics, community-based organizations, and faith-based organizations at 51%, 25%, 18%, and 7% respectively.[30] Within these cancer screening was improved by 70%, and 62% found a significant effect on CVD risk reduction including improvements lipid profiles, blood pressure, and hemoglobin A1C.[30] Moreover, this review noted that only eight articles included a cost analysis, cited CHWs were primarily compensated through grants, community organizations, or were strictly volunteers, and integration of workers into the health care system was rarely discussed.[30] In contrast, another systematic review of reviews examining CHWs across low, middle, and high income countries found that integration into healthcare systems was a key enabler to intervention success, and increasing the credibility of findings.[31] It also cited that although most interventions did improve health outcomes, many of the reviews noted that studies were often low of quality, and only 14 out of 122 articles included data on cost-effectiveness.[31]

Currently within rural Appalachia, a promising researched based CHW intervention has been ongoing among diabetes patients with high health care costs, with results being used to develop a new CHW-based chronic care model (CCM).[29] Within this model CHWs are part of a CCM team that includes a mid-level provider and a nurse, and provide support in patients homes. Findings from their 2017-2019 cohort has shown that between baseline and six to twelve months after enrollment, 63% lowered their blood glucose; moreover, as a result of 96 patients that lowered their $HbA_{1c}$ below 10%, they have estimated a savings of $384,000 in healthcare costs.[29] These finding were presented to health insurance companies through ongoing meetings in an effort to establish new payment models that will provide reimbursement for CHWs, subsequently two companies began monitoring claims and health outcomes to determine the extent of cost savings.[29]

A final theme that emerged from this study was the importance of productive patient-provider interactions. The constructs identified within these interactions were common themes across all the interviews, while stakeholders did not recite each of the constructs as a list, their definitions commonly touched on all points. In comparison to the American College of Cardiology Clinical

Quality Committee's definition of PCC,[1] it becomes apparent that perceptions of what constitutes PCC within the constraints of patient-provider interactions is consistent with established definitions. The importance of communication, education, and collaboration between HCPs and patients, in addition to empowering patients are core components in each of the definitions. However, the bigger issue identified were the multitude of barriers to providing this care due to the current structure of healthcare and HCP shortages.

## Conclusion

Limitations to this study included the quantity of stakeholders interviewed was determined by the ability of the research team to secure time with busy professionals, versus reaching a point of saturation. Additionally, the sample of stakeholders utilized was a small selection of professionals within the region and may not serve as a strong representation of those within their fields. Notwithstanding these limitations, this qualitative exploratory study spotlights perceptions of PCC within the region and identified fundamental challenges to providing care due to lack of resources, and short comings within the health care structure.

In conclusion, findings from this study exposed underlying barriers to providing PCC within the Central Appalachian region due to cost and access barriers. Healthcare spending and costs were overarching themes throughout these findings, impacting the health of the population through prioritization of funding. Study findings emphasized HCP limitations in implementing all constructs of PCC due to reimbursement practices, including time spent with patients, and the exclusion/inadequate coverage of lifestyle intervention resources. Achieving complete PCC would require insurance reform to expand primary prevention efforts, and ultimately shift the paradigm of health care away from care focused primarily on disease maintenance.

Finally, expanding community outreach to compensate for inadequate health care access is an issue that requires further investigation. Studies have found that utilization of CHW has the potential to improve health behaviors, outcomes, and mitigate healthcare costs,[29-31] however common limitations within these studies included a lack of cost savings analysis and flaws in research designs.[30,31] Stronger mix-method studies that provide replicable quantitative clinical-based improvements in health outcomes, program sustainability, health care savings, and qualitative improvements in quality of life are required to influence meaningful policy reform in funding.

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## References

1. Walsh MN, Bove AA, Cross RR, et al. ACCF 2012 health policy statement on patient-centered care in cardiovascular medicine: A report of the American College of Cardiology Foundation Clinical Quality Committee. Journal of the American College of Cardiology. 06-05-2012 2012;59(23):2125-43. doi:10.1016/j.jacc.2012.03.016
2. Rao JK, Anderson LA, Inui TS, Frankel RM. Communication interventions make a difference in conversations between physicians and patients: A systematic review of the evidence. Medical Care. 2007;45:340-349. https://doi.org/10.1097/01.mlr.0000254516.04961.d5

3. King A, Hoppe RB. "Best practice" for patient-centered communication: A narrative review. Journal of Graduate Medical Education. September 2013 2013;5(3):385-93. doi:10.4300/JGME-D-13-00072.1

4. Haskard Zolnierek KB, DiMatteo MR. Physician communication and patient adherence to treatment: A meta-analysis. Medical Care. 2009:826-834. Doi: 10.1097/MLR.0b013e31819a5acc

5. Berkman N, Sheridan S, Donahue K, et al. Health literacy interventions and outcomes: An updated systematic review. 2011. Evidence Report/Technology Assesment No 199. Publication No. 11-E006.

6. Marshall JL, Thomas L, Lane NM, et al. Creating a culture of health in Appalachia: Disparities and bright spots. Washington, D.C.: Appalachian Regional Commission, 2017.

7. Morrone M, Cronin CE, Schuller K, Nicks SE. Access to health care in Appalachia: Perception and reality. J Appalach Health. 2021;3(4):123-136. doi:10.13023/jah.0304.10

8. Lazar M, Thomas S, Davenport L. Seeking care at free episodic health care clinics in Appalachia. J Appalach Health. 2020;2(2):67-79. doi:10.13023/jah.0202.07

9. Hege A, Ball L, Christiana RW, et al. Social determinants of health and the effects on quality of life and well-being in 2 rural Appalachia communities: The community members' perspective and Iimplications for health disparities. Fam Community Health. Oct/Dec 2018;41(4):244-254. doi:10.1097/FCH.0000000000000201

10. Rendle KA, Abramson CM, Garrett SB, Halley MC, Dohan D. Beyond exploratory: a tailored framework for designing and assessing qualitative health research. BMJ Open. Aug 27 2019;9(8):e030123. doi:10.1136/bmjopen-2019-030123

11. Kennedy W, Fruin R, Lue A, Logan SW. Using ecological models of health behavior to promote health care access and physical activity engagement for persons with disabilities. J Patient Exp. 2021;8:23743735211034031. doi:10.1177/23743735211034031

12. Tolley EE, Ulin PR, Mack N, Robinson ET, Succop SM. Qualitative methods in public health: A field guide for applied research. Second Edition. John Wiley & Sons, Incorporated 2016. Available at: https://ebookcentral.proquest.com/lib/etsu/detail.action?docID=7104122.

13. Freeman KJ, Grega ML, Friedman SM, et al. Lifestyle medicine reimbursement: A proposal for policy priorities informed by a cross-sectional survey of lifestyle medicine practitioners. Int J Environ Res Public Health. Nov 5 2021;18(21). doi:10.3390/ijerph182111632

14. Hivert MF, Arena R, Forman DE, et al. Medical training to achieve competency in lifestyle counseling: An essential foundation for prevention and treatment of cardiovascular diseases and other chronic medical conditions: A scientific statement from the american heart association. Circulation. Oct 11 2016;134(15):e308-e327. doi:10.1161/CIR.0000000000000442

15. DeVote JE. The incompatibility of patient-centered care with fee-for-service payment. JAMA Internal Medicine. 2020;180(12):1571-1572. doi:10.1001/jamainternmed.2020.4331

16. Jensen LL, Drozek DS, Grega ML, Gobble J. Lifestyle medicine: Successful reimbursement methods and practice models. Am J Lifestyle Med. May-Jun 2019;13(3):246-252. doi:10.1177/1559827618817294

17. Zadeh NK, Robertson K, Green JA. Lifestyle determinants of behavioural outcomes triggered by direct-to-consumer advertising of prescription medicines: A cross-sectional study. Aust N Z J Public Health. Apr 2019;43(2):190-196. doi:10.1111/1753-6405.12883

18. Schwartz LM, Woloshin S. Medical marketing in the United States, 1997-2016. JAMA. Jan 1 2019;321(1):80-96. doi:10.1001/jama.2018.19320

19. Ventola CL. Direct-to-consumer pharmaceutical advertising: Therapeutic or toxic? P.T. 2011;36(10):669-684. PMID: 22346300.

20. Applequist J, Ball JG. An Updated analysis of direct-to-consumer television advertisements for prescription drugs. Ann Fam Med. May 2018;16(3):211-216. doi:10.1370/afm.2220

21. American Medical Association. AMA calls for ban on DTC ads of prescription drugs and medical devices. 2015. Available at: https://www.ama-assn.org/press-center/press-releases/ama-calls-ban-dtc-ads-prescription-drugs-and-medical-devices

22. Arlinghaus KR, Johnston CA. Advocating for behavior change with education. Am J Lifestyle Med. Mar-Apr 2018;12(2):113-116. doi:10.1177/1559827617745479

23. Williamson TM, Moran C, McLennan A, et al. Promoting adherence to physical activity among individuals with cardiovascular disease using behavioral counseling: A theory and research-based primer for health care professionals. Prog Cardiovasc Dis. Jan-Feb 2021;64:41-54. doi:10.1016/j.pcad.2020.12.007

24. Ghisi GL, Abdallah F, Grace SL, Thomas S, Oh P. A systematic review of patient education in cardiac patients: do they increase knowledge and promote health behavior change? Patient Educ Couns. May 2014;95(2):160-74. doi:10.1016/j.pec.2014.01.012

25. Whitsel LP, Bantham A, Jarrin R, Sanders L, Stoutenberg M. Physical activity assessment, prescription and referral in US healthcare: How do we make this a standard of clinical practice? Prog Cardiovasc Dis. Jan-Feb 2021;64:88-95. doi:10.1016/j.pcad.2020.12.006

26. Franco AA, Bouma H, Bronswijk JEMHV. Health care paradigms in transition. Gerontechnology. 2014;13(1)doi:10.4017/gt.2014.13.1.001.00

27. Mudd-Martin G, Biddle MJ, Chung ML, et al. Rural Appalachian perspectives on heart health: social ecological contexts. Am J Health Behav. Jan 2014;38(1):134-43. doi:10.5993/AJHB.38.1.14

28. Brownstein JN, Bone LR, Dennison CR, Hill MN, Kim MT, Levine DM. Community health workers as interventionists in the prevention and control of heart disease and stroke. Am J Prev Med. Dec 2005;29(5 Suppl 1):128-33. doi:10.1016/j.amepre.2005.07.024

29. Crespo R, Christiansen M, Tieman K, Wittberg R. An emerging model for community health worker-based chronic care management for patients with high health care costs in rural Appalachia. Prev Chronic Dis. Feb 13 2020;17:E13. doi:10.5888/pcd17.190316

30. Kim K, Choi JS, Choi E, et al. Effects of community-based health worker interventions to improve chronic disease management and care among vulnerable populations: A systematic review. Am J Public Health. Apr 2016;106(4):e3-e28. doi:10.2105/AJPH.2015.302987

31. Scott K, Beckham SW, Gross M, et al. What do we know about community-based health worker programs? A systematic review of existing reviews on community health workers. Hum Resour Health. Aug 16 2018;16(1):39. doi:10.1186/s12960-018-0304-x

# Chapter 5. Discussion

## Research Methodology

Research methodology for the collection of primary data for this dissertation utilized a qualitative exploratory study design to discover themes and barriers related to the prevention of CVDs among CVD patients, non-licensed caregivers (NLCs), and professional stakeholders in the Central Appalachian region. Use of an exploratory design allowed researchers to take an inductive approach in gathering insights and perspectives among the study population and identifying themes to inform future research agendas (Rendle et al., 2019). Focus groups discussions (FGDs) and interviews were conducted within Central Appalachian communities, in each of the six states that span the central region: Kentucky, North Carolina, Ohio, Tennessee, Virginia, and West Virginia.

Focus groups were conducted between March and June of 2019 utilizing a discussion guide (Appendix A) drafted by three qualitative researchers that were a part of the larger multi-disciplinary research team, and participants were provided written informed consent (Appendix B). Interviews were conducted between March and August of 2019 utilizing a slightly altered version of the FGD guide (Appendix C) and were also provided informed consent (Appendix D). Both of the discussion guides touched on levels of the Ecological Model of Health Behavior (EMHB) to gather information at the individual, community, and organizational levels (Kennedy et al., 2021). The EMHB recognizes that health outcomes are the result of dynamic influences within each of the levels (Kennedy et al., 2021), therefore, to identify factors influencing CVD rates within the region, the phenomena must be explored across multiple levels. FGD and interviews data were examined by two qualitative researchers utilizing qualitative thematic analysis methodology, in which researchers first gain familiarity with the data, then generate initial codes, group codes into themes and develop a codebook, apply codes to the data, and compare and discuss findings (Tolley et al., 2016). Once completed, one researcher compiled data from each theme and compared the coverage across each of the FGDs and wrote up the findings.

### SEM Findings

The utilization of the SEM to explore the multitude of factors that influence CVDs in the CCA region, in conjunction with previous research and the results from this study, has provided an additional understanding of the contributors to high CVD rates within the region. It was found that prevention of CVDs was met with various challenges throughout the individual, PCC, built environment, community programs, and health policy constructs of the SEM. However, findings did not exist in isolation within constructs, common themes within them all included dietary patterns, engagement in physical activity, interpersonal influences, financial hardships, poverty, and health care access disparities.

Poverty and financial strain were core elements FGD participants identified, which touched every aspect of communities and limited their ability to facilitate environments conducive to healthy lifestyles. It was cited that lack of well-paying employment opportunities contributed to poverty, which in turn caused food insecurity. Poverty is a hardship felt outside of Central Appalachian mining communities as well, with poverty rates within the region at 22.4% (Pollard & Jacobsen, 2022). Contributing to this burden are high rates of individuals receiving disability benefits, 13.9% of the population receive benefits from the Social Security Administration due to health issues, compared to 5.1% nationally (Marshall et al., 2017).

Barriers to following a healthy diet was the next significant topic of discussion. Challenges at the individual level included the temptation to indulge in unhealthy choices, already established dietary preferences, the mental and financial strain of providing for additional family members within multiple generational households, and the influence grandchild dietary preference among caregiver and custodial grandparents. At the community level, cultural influences, poverty, and the cost of healthy food was cited. At the PCC level, deficiencies within reimbursement practices were a determinant. The combination of these factors presented a story that provides insight into interdependent relationships of each level, and their contribution to continuing the cycle of unhealthy diets across generations.

Participants indicated dietary preferences were a result of culture and upbringing, consistent with another study in rural Appalachian KY (Mudd-Martin et al., 2014). It was indicated that unhealthy cooking methods such as frying all foods was commonly practiced, and as an adult, cravings for these traditional “comfort foods” were hard to resist when faced with stress. This is consistent with research which has established dietary patterns developed during childhood shape taste preferences, which continue to influence dietary choices into adulthood (Arlinghaus & Laska, 2021; Carbert et al., 2019; Daniel, 2016; Mahmood et al., 2021; Ramos & Stein, 2000). Additionally, financial strain and poverty were found to be significant factors in dietary choices, with the cost associated with healthy foods impeding on the feasibility of sustaining healthier choices. Poverty was noted to be prevalent concern within custodial grandparent homes, and multiple generational homes were found to be particularly vulnerable to food insecurity. A review of the literature indicates food insecurity and concerns over food waste have been found to influence purchasing decisions made by parents, predominately within low-income homes (Arlinghaus & Laska, 2021; Daniel, 2016). These homes are more likely to provide a food environment with less healthy choices by avoiding purchasing of healthier perishable items such as fruit and vegetables that may not get consumed, may be less likely to experiment with new healthier food options, and favor processed foods with longer shelf lives that children prefer (Arlinghaus & Laska, 2021; Daniel, 2016). Moreover, long-lasting effects of food insecurity experienced as a child continues to influence choices into adulthood, which in turn are taught to the next generation (Arlinghaus & Laska, 2021; Daniel, 2016).

Although this research does not specifically address households outside of the traditional mom, dad, and child parameters, it does provide insight into the development of unhealthy diets, and the continuation of the cycle. Furthermore, within the PCC construct, professional stakeholders identified in order to disrupt these established dietary patterns and improve health, dietary and physical activity programs needed to be covered under insurance plans to provide patients with specific information on what constitutes a healthy diet, how to read and interpret nutritional information, types of physical activity, how much physical activity is needed, along with access to exercise programs, and practical cooking classes to provide the necessary skills to implement lifestyle changes. Behavior change research has identified that lifestyle knowledge alone is not sufficient enough to impact change among significant portions of the population (Arlinghaus & Johnston, 2018; Freeman et al., 2021; Ghisi et al., 2014; Whitsel et al., 2021; Williamson et al., 2021), additional resources are needed to provide practical skills on how to prepare healthier meals (Arlinghaus & Johnston, 2018), and engage in physical activity (Whitsel et al., 2021; Williamson et al., 2021), while providing continuous support through lifestyle coaching (Franco et al., 2014; Whitsel et al., 2021). However, with existing deficiencies in reimbursement practices that limit the allotted time HCPs are able to spend educating patients, and lack of reimbursement for lifestyle medicine (DeVote, 2020; Freeman et al., 2021; Hivert et al., 2016; Jensen et al., 2019), coverage of this type of preventive care is not easily obtained.

Barriers to physical activity within communities was another focal point among FGD participants and included lack of sidewalks in proximity of their homes, safety concerns with walking in roads, health conditions, travel time to PA resources, and the strenuous nature of sidewalks, paths and trails due to the mountainous topography of the region. These findings are congruent with other rural studies that have found barriers to PA included lack of safe places to walk due to no sidewalks, sidewalks in poor condition, lack of crosswalks, no distinguishable shoulders on the side of streets (Gilbert et al., 2019; Hege et al., 2017; Jones et al., 2021; Joshu et al., 2008), poor health (Jones et al., 2021; Joshu et al., 2008), and lack of time (Marshall et al., 2017; Pollard, 2022). However, one unique aspect was identified concerning the strenuous nature of sidewalks, paths, and trails due to mountainous topography of the region. Utilization of these resources among those who were out of shape, and individuals with chronic health conditions such as CVD was not perceived as being feasible. Under these conditions, simply going for a walk became a feat of physical endurance that was beyond their current capabilities. This is a considerable factor, whereas the percentage of adults in Central Appalachia reporting to have a disability is considerably higher than national averages at 22.5%, versus 10.3% among 18-64 year-olds, and 47.4% versus 34% among 65 year-olds and older, respectively (Pollard & Jacobsen, 2022). Disability inclusion criteria included difficulties with seeing, hearing, cognition, walking, or independent living functions (Pollard & Jacobsen, 2022).

Among portions of this population with health conditions, engaging in significant physical activity was only brought about following a significant cardiac event, which made them eligible for cardiac rehabilitation programs. Cardiac rehabilitation is a medically supervised program designed to improve health outcomes after a cardiac event by providing individualized education on diet, exercise, and reducing stress (Cleveland Clinic, 2021). Exercise-based cardiac rehabilitation has been found to be effective in reducing mortality and the reoccurrence of cardiac events (Lawler et al., 2011; Tegegne et al., 2022). Professional stakeholders identified the need for PCC to include exercise education, and insurance coverage of exercise programs. However, coverage does not begin until after health has deteriorated into significant health issues. Lack of affordable programs among financially insecure individuals, combined with PA barriers within the natural environment, and unhealthy dietary practices presents significant barriers to improving health. However, recently home-based virtual cardiac rehabilitation programs delivered synchronously or asynchronously have been a growing area of study, and have been found to provide similar clinical and physical activity outcomes as center-based programs (Brewer et al., 2023; Ganeshan et al., 2022; Tegegne et al., 2022; Thomas et al., 2019). As these programs continued to be developed, opportunities to expand program eligibility to cover at risk patients before a major cardiac event may be leverage, reducing morbidity and health care costs.

Additional findings within the PCC construct identified underlying barriers within the healthcare system itself presented challenges to creating an environment conducive to PCC, primarily around healthcare reimbursement practices. Providing meaningful education requires appointments that extend beyond 15 to 20 minutes, however under current reimbursement plans additional time is not covered (Freeman et al., 2021; Hivert et al., 2016; Jensen et al., 2019). Additionally, a survey among lifestyle medical practitioners highlighted “perverse quality measure incentives” that discourage preventative care by providing more reimbursement for procedures, health management through medication, and financial penalties for taking patients off medications in favor of conditions being controlled through lifestyle modifications (Freeman et al., 2021).

Correlating with this need, this study emphasized a call for increased community outreach to raise risk factor awareness and to provide free screening opportunities directly to the population in their own neighborhoods. However, it was identified that the rural Central Appalachian region faces shortages of HCPs, subsequently preventing a barrier to addressing this need. This is consistent with findings from a survey in Appalachia, which found 24% of participants reported engaging in health screenings, and 87.2% left their home county to receive these services (Morrone et al., 2021). Additionally, a previous CVD study within Appalachian KY identified that even when free screening opportunities were offered, people could not always afford follow-up care (Mudd-Martin et al., 2014).

Research has found community health workers (CHW) have the potential to supplement this gap. CHWs are lay health care workers that provide culturally competent support to patients within the same communities they live by facilitating education, adherence to treatment plans, assisting with navigating the health care system, and self-care (Brownstein et al., 2005; Crespo et al., 2020). Currently within rural Appalachia, a promising researched based CHW intervention has been ongoing among diabetes patients with high health care costs, with results being used to develop a new CHW-based chronic care model (CCM) (Crespo et al., 2020). Within this model CHWs are part of a CCM team that includes a mid-level provider and a nurse, and provide support in patients homes. Findings from their 2017-2019 cohort has shown that between baseline and six to twelve months after enrollment, 63% lowered their blood glucose; moreover, as a result of 96 patients that lowered their $HbA_{1c}$ below 10%, they have estimated a savings of $384,000 in healthcare costs (Crespo et al., 2020). These finding were presented to health insurance companies through ongoing meetings in an effort to establish new payment models that will provide reimbursement for CHWs, subsequently two companies began monitoring claims and health outcomes to determine the extent of cost savings (Crespo et al., 2020).

Finally, health policy was a construct that was touched on throughout findings within each level of the SEM. One community in the study discussed advocating for sidewalks outside of a school influenced city planning, and noted expansion of sidewalks into other areas of the community was still needed. Expansion of this infrastructure to promote PA within the built environment was only achieved through support from the local government to secure resources. Changes to dietary requirements within schools as the result of governmental policy was another topic, although the intention of the policy was to improve diets, it was met with resistance within the local community. Moreover, healthcare policy reform in relation to expanding insurance coverage to reimburse for lifestyle medicine and additional community programs was cited as a need. However, stakeholders perceived an underlying barrier to reform was linked to profit margins within a healthcare system that markets pills instead of prevention, and treats symptoms with medications as patients present them, while neglecting to intervene with behavioral interventions and allowing disease processes to progress. Although a debatable topic, between 1997 and 2016, prescription drug spending did increase from $116.5 billion to $328.6 billion (Schwartz & Woloshin, 2019); and in 2015, the American Medical Association called for a ban on this advertising due to concerns that ads were increasing demand for expensive procedures in lieu of less expensive alternatives, and increased demand for expensive drugs at the expense of patients that could not afford them (American Medical Association, 2015).

# Chapter 6. Conclusion

The interplay between each SEM construct demonstrates that achieving a substantial change in CVD rates through prevention is a comprehensive undertaking. These constructs do not exist in isolation, with each contributing to the others ability to influence change. As previously illustrated in Figure 1.14, utilizing a structured and coordinated approach to prevention through consideration of all levels of influence would create environments that provided the necessary resources to influence health on a population level. Ultimately, it would be perceivable the long-term impact of this design would create environments in which healthy choices became the default behaviors of the communities, and in turn shifted the culture to one of long-term health.

Given the finite resources of communities, significantly impacting population level behavior is an undertaking that may take generations to achieve. However, potential leverage points exist in the context of extending PCC constructs beyond health care facilities into communities and homes. Deployment of CHWs can fill in gaps in care by providing health education and empowering patients, assessing adherence to treatment plans, and assisting with navigating the health care system. Expansion of cardiac rehabilitation programs to provide prevention to at risk patients through home-based virtual programs, by increasing PA knowledge, self-efficacy, and facilitating behavior change. Finally, leveraging the strong ties within Appalachian families and multiple generation households through lifestyle interventions that simultaneously target all generations, and break the cycle of poor dietary patterns.

# References

Ahmed, S., Shah, P., & Ahmed, O. (2021). *Biochemistry, lipids*. StatPearls Publishing. https://www.ncbi.nlm.nih.gov/books/NBK525952/

America's Health Rankings. (2022a). *Public health impact: High cholesterol*. United Health Foundation. https://www.americashealthrankings.org/explore/annual/measure/High_Chol/state/ALL

America's Health Rankings. (2022b). *Public health impact: Smoking*. United Health Foundation. https://www.americashealthrankings.org/explore/disparity/measure/smoking/state/ALL

American Heart Association. (2023). *Life's essential eight.* https://www.heart.org/en/healthy-living/healthy-lifestyle/lifes-essential-8

American Heart Association [AHA]. (2021). *High blood pressure*. American Heart Association. https://www.heart.org/-/media/files/health-topics/answers-by-heart/what-is-high-blood-pressure.pdf

American Medical Association. (2015, November 17). *AMA calls for ban on DTC ads of prescription drugs and medical devices.* https://www.ama-assn.org/press-center/press-releases/ama-calls-ban-dtc-ads-prescription-drugs-and-medical-devices

Appalachian Regional Commission [ARC]. (2019). *About the Appalachian region*. Appalachian Regional Commission. https://www.arc.gov/about-the-appalachian-region/

Appalachian Regional Commission [ARC]. (2022). *County economic status in Appalachia*. https://www.arc.gov/classifying-economic-distress-in-appalachian-counties/

Applequist, J., & Ball, J. G. (2018, May). An updated analysis of direct-to-consumer television advertisements for prescription drugs. *Annals of Family Medicine*, *16*(3), 211-216. https://doi.org/10.1370/afm.2220

Arlinghaus, K. R., & Johnston, C. A. (2018). Advocating for behavior change with education. *American Journal of Lifestyle Medicine*, *12*(2), 113-116. https://doi.org/10.1177/1559827617745479

Arlinghaus, K. R., & Laska, M. N. (2021). Parent feeding practices in the context of food insecurity. *International Journal of Environmental Research and Public Health*, *18*(2). https://doi.org/10.3390/ijerph18020366

Arnett, D. K., Blumenthal, R. S., Albert, M. A., Buroker, A. B., Goldberger, Z. D., Hahn, E. J., Himmelfarb, C. D., Khera, A., Lloyd-Jones, D., McEvoy, J. W., Michos, E. D., Miedema, M. D., Munoz, D., Smith, S. C., Jr., Virani, S. S., Williams, K. A., Sr., Yeboah, J., & Ziaeian, B. (2019). *2019 ACC/AHA guideline on the primary prevention of cardiovascular disease: A report of the American College of Cardiology/American Heart Association Task Force on clinical practice guidelines*. American Heart Association. https://doi.org/10.1161/CIR.0000000000000678

Balady, G. J., Williams, M. A., Ades, P. A., Bittner, V., Comoss, P., Foody, J. M., Franklin, B., Sanderson, B., Southard, D. (2007). Core components of cardiac rehabilitation/secondary prevention programs: 2007 update: A scientific statement from the American Heart Association Exercise, Cardiac Rehabilitation, and Prevention Committee, the Council on Clinical Cardiology; the Councils on Cardiovascular Nursing, Epidemiology and Prevention, and Nutrition, Physical Activity, and Metabolism; and the American Association of Cardiovascular and Pulmonary Rehabilitation. *Circulation*, *115*(20), 2675-2682. https://doi.org/10.1161/CIRCULATIONAHA.106.180945

Balcazar, H., Wise, S., Rosenthal, E. L., Ochoa, C., Rodriguez, J., Hastings, D., Flores, L., Hernandez, L., & Duarte-Gardea, M. (2012). An ecological model using promotores de salud to prevent cardiovascular disease on the US-Mexico border: The HEART project. *Preventing Chronic Disease*, 9:110100. https://doi.org/10.5888/pcd9.110100

Beatty, A. L., Brown, T. M., Corbett, M., Diersing, D., Keteyian, S. J., Mola, A., Stolp, H., Wall, H. K., & L. S. Sperling. (2021). Million Hearts cardiac rehabilitation think tank: accelerating new care models. *Circulation: Cardiovascular Quality Outcomes*, *14*(10), e008215. https://doi.org/10.1161/CIRCOUTCOMES.121.008215

Benjamin, E. J., Muntner, P., Alonso, A., Bittencourt, M. S., Callaway, C. W., Carson, A. P., Chamberlain, A. M., Chang, A. R., Cheng, S., Das, S. R., Delling, F. N., Djousse, L., Elkind, M. S. V., Ferguson, J. F., Fornage, M., Jordan, L. C., Khan, S. S., Kissela, B. M., Knutson, K. L., . . . Virani, S. S. (2019). Heart disease and stroke statistics-2019 update: A report from the American Heart Association. *Circulation*, *139*(10), e56-e528. https://doi.org/10.1161/CIR.0000000000000659

Berkman, N., Sheridan, S., Donahue, K., Halpern, D., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohr, K., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). Health literacy interventions and outcomes: An updated systematic review. Evidence report/technology assesment No. 199. *Agency for Healthcare Research and Quality,* Publication No. 11-E006.

Bhatnagar, A. (2017). Environmental determinants of cardiovascular disease. *Circulation*, *121*(2), 162-180. https://doi.org/10.1161/CIRCRESAHA.117.306458

Booth, F. W., & Lees, S. J. (2007). Fundamental questions about genes, inactivity, and chronic diseases. *Physiological Genomics*, *28*(2), 146-157. https://doi.org/10.1152/physiolgenomics.00174.2006

Booth, J., Wei, K., & Little, A. (2017). Examining the impact of food environment changes on county-level obesity prevalence in the Appalachian Region. *Journal of Health Disparities Research and Practice*, *10*(4). https://digitalscholarship.unlv.edu/jhdrp/vol10/iss4/2

Bowen, E., Christiadi, Deskins, J., & Lego, B. (2020). An overview of the coal economy in Appalachia. *Appalachian Regional Commission*. https://www.arc.gov/report/an-overview-of-coal-and-the-economy-in-appalachia/

Brewer, L. C., Abraham, H., Kaihoi, B., Leth, S., Egginton, J., Slusser, J., Scott, C., Penheiter, S., Albertie, M., Squires, R., Thomas, R., Scales, R., Trejo-Gutierrez, J., & Kopecky, S. (2023). A community-informed virtual world-based cardiac rehabilitation program as an extension of center-based cardiac rehabilitation: Mixed-methods analysis of a multicenter pilot study. *Journal of Cardiopulmonary Rehabilitation and Prevention*, *43*(1), 22-30. https://doi.org/10.1097/HCR.0000000000000705

Brownstein, J. N., Bone, L. R., Dennison, C. R., Hill, M. N., Kim, M. T., & Levine, D. M. (2005). Community health workers as interventionists in the prevention and control of heart disease and stroke. *American Journal of Preventitive Medicine*, *29* (5 Suppl 1), 128-133. https://doi.org/10.1016/j.amepre.2005.07.024

Carbert, N. S., Brussoni, M., Geller, J., & Masse, L. C. (2019). Moderating effects of family environment on overweight/obese adolescents' dietary behaviours. *Appetite*, *134*, 69-77. https://doi.org/10.1016/j.appet.2018.12.034

CDC Division for Heart Disease and Stroke Prevention. (2020). *Interactive atlas of heart disease and stroke*. https://www.cdc.gov/dhdsp/maps/atlas/index.htm

CDC National Center for Chronic Disease Prevention and Health Promotion Division of Nutrition Physical Activity and Obesity. (2018). *CDC nutrition, physical activity, and* *obesity legislation [Data set]*. Centers for Disease Control and Prevention. https://chronicdata.cdc.gov/Nutrition-Physical-Activity-and-Obesity/CDC-Nutrition-Physical-Activity-and-Obesity-Legisl/nxst-x9p4

Centers for Disease Control and Prevention Agency for Toxic Substances and Disease Registry [CDC ATSDR]. (2011). *Principles of community engagement second edition* (Second ed., Vol. No. 11-7782). U.S. Department of Health & Human Services. https://www.atsdr.cdc.gov/communityengagement/pce_models.html

Centers for Disease Control and Prevention Office on Smoking and Health. (2022). *Smoking and cardiovascular diseases*. https://www.cdc.gov/tobacco/data_statistics/sgr/50th-anniversary/pdfs/fs_smoking_CVD_508.pdf

Chewning, B., Bylund, C. L., Shah, B., Arora, N. K., Gueguen, J. A., & Makoul, G. (2012). Patient preferences for shared decisions: A systematic review. *Patient Education and Counseling*, 86(1), 9-18. https://doi.org/10.1016/j.pec.2011.02.004

Chrisman, M., Nothwehr, F., Yang, G., & Oleson, J. (2015). Environmental influences on physical activity in rural midwestern adults: a qualitative approach. *Health Promotion Practice*, 16(1), 142-148. https://doi.org/10.1177/1524839914524958

Cleveland Clinic. (2021). *Cardiac rehab*. https://my.clevelandclinic.org/health/treatments/22069-cardiac-rehab

Cotie, L. M., Ghisi, G. L. M., Vanzella, L. M., Aultman, C., Oh, P., & Colella, T. J. F. (2022). A social-ecological perspective of the perceived barriers and facilitators to virtual education in cardiac rehabilitation: A mixed-methods approach. *Journal of Cardiopulmonary Rehabilitation and Prevention*, 42(3), 183-189. https://doi.org/10.1097/HCR.0000000000000663

County Health Rankings & Roadmaps. (2022). *Social & economic factors*. University of Wisconsin Population Health Institute. https://www.countyhealthrankings.org/explore-health-rankings/county-health-rankings-model/health-factors/social-economic-factors

Crespo, R., Christiansen, M., Tieman, K., & Wittberg, R. (2020). An emerging model for community health worker-based chronic care management for patients with high health care costs in Rural Appalachia. *Preventing Chronic Disease*, 17, E13. https://doi.org/10.5888/pcd17.190316

Daniel, C. (2016). Economic constraints on taste formation and the true cost of healthy eating. *Social Science & Medicine*, 148, 34-41. https://doi.org/10.1016/j.socscimed.2015.11.025

Deskins, S., Harris, C., Bradlyn, A., Cottrell, L., Coffman, J., Olexa, J., & Neal, W. (2006). Preventive care in Appalachia: Use of the theory of planned behavior to identify barriers to participation in cholesterol screenings among West Virginians. *The Journal of rural health : Official journal of the American Rural Health Association and the National Rural Health Care Association,* 22(4), 367–374. *https://doi.org/10.1111/j.1748-0361.2006.00060.x*

DeVote, J. E. (2020). The incompatibility of patient-centered care with fee-for-service payment. *JAMA Internal Medicine*, *180*(12), 1571-1572. https://doi.org/10.1001/jamainternmed.2020.4331

Drozek, D., Diehl, H., Nakazawa, M., Kostohryz, T., Morton, D., & Shubrook, J. H. (2014). Short-term effectiveness of a lifestyle intervention program for reducing selected chronic disease risk factors in individuals living in rural Appalachia: A pilot cohort study. *Advances in Preventative Medicine*, *2014*, 798184. https://doi.org/10.1155/2014/798184

Franco, A. A., Bouma, H., & Bronswijk, J. E. M. H. V. (2014). Health care paradigms in transition. *Gerontechnology*, *13*(1). https://doi.org/10.4017/gt.2014.13.1.001.00

Freeman, K. J., Grega, M. L., Friedman, S. M., Patel, P. M., Stout, R. W., Campbell, T. M., Tollefson, M. L., Lianov, L. S., Pauly, K. R., Pollard, K. J., & Karlsen, M. C. (2021). Lifestyle medicine reimbursement: A proposal for policy priorities informed by a cross-sectional survey of lifestyle medicine practitioners. *International Journal Environtal Research and Public Health*, *18*(21). https://doi.org/10.3390/ijerph182111632

Ganeshan, S., Jackson, H., Grandis, D. J., Janke, D., Murray, M. L., Valle, V., & Beatty, A. L. (2022). Clinical outcomes and qualitative perceptions of in-person, hybrid, and virtual cardiac rehabilitation. *Journal of Cardiopulmonary Rehabilitation and Prevention*, *42*(5), 338-346. https://doi.org/10.1097/HCR.0000000000000688

George, L., Yagley, J., Davidson, S., DeJager, T., Pinder, J., Singleton, T., Stover, M., & Strauss, L. R. (2002). Taking stock rural people, poverty, and housing at the turn of the 21st century. *Housing Assistance Council*. https://ruralhome.org/wp-content/uploads/storage/documents/appalov.pdf

Ghisi, G. L., Abdallah, F., Grace, S. L., Thomas, S., & Oh, P. (2014). A systematic review of patient education in cardiac patients: Do they increase knowledge and promote health behavior change? *Patient Education and Counseling*, *95*(2), 160-174. https://doi.org/10.1016/j.pec.2014.01.012

Gilbert, A. S., Duncan, D. D., Beck, A. M., Eyler, A. A., & Brownson, R. C. (2019). A qualitative study identifying barriers and facilitators of physical activity in rural communities. *Journal of Environmental and Public Health*, *2019*, 7298692. https://doi.org/10.1155/2019/7298692

Griffith, B. N., Lovett, G. D., Pyle, D. N., & Miller, W. C. (2011). Self-rated health in rural Appalachia: Health perceptions are incongruent with health status and health behaviors. *BMC Public Health*, *11*. https://doi.org/10.1186/1471-2458-11-229

Hardin-Fanning, F., & Ricks, J. M. (2017). Attitudes, social norms and perceived behavioral control factors influencing participation in a cooking skills program in rural Central Appalachia. *Global Health Promotion*, *24*(4), 43-52. https://doi.org/10.1177/1757975916636792

Haskard Zolnierek, K. B., & DiMatteo, M. R. (2009). Physician communication and patient adherence to treatment: A meta-analysis. *Medical Care*, 47(8):826-34. Doi: 10.1097/MLR.0b013e31819a5acc

Hege, A., Ball, L., Christiana, R. W., Wallace, C., Hubbard, C., Truesdale, D., Hege, J., & Fleming, H. (2018). Social determinants of health and the effects on quality of life and well-being in 2 rural Appalachia communities: The community members' perspective and implications for health disparities. *Family and Community Health*, *41*(4), 244-254. https://doi.org/10.1097/FCH.0000000000000201

Hege, A., Christiana, R. W., Battista, R., & Parkhurst, H. (2017). Active living in rural Appalachia: Using the rural active living assessment (RALA) tools to explore environmental barriers. *Preventive Medicine Reports*, 8, 261-266. https://doi.org/10.1016/j.pmedr.2017.11.007

Hivert, M. F., Arena, R., Forman, D. E., Kris-Etherton, P. M., McBride, P. E., Pate, R. R., Spring, B., Trilk, J., Van Horn, L. V., Kraus, W. E., (2016). Medical training to achieve competency in lifestyle counseling: An essential foundation for prevention and treatment of cardiovascular diseases and other chronic medical conditions: A scientific statement from the American Heart Association. *Circulation*, 134(15), e308-e327. https://doi.org/10.1161/CIR.0000000000000442

Ibrahim, M. A., Asuka, E., & Jialal, I. (2022). *Hypercholesterolemia*. Stats Pearl Publishing. https://www.ncbi.nlm.nih.gov/books/NBK459188/

Institute of Medicine. (2001). Crossing the quality chasm: A new health system for the 21st century. *National Academies Press*. https://doi.org/https://doi.org/10.17226/10027

Jensen, L. L., Drozek, D. S., Grega, M. L., & Gobble, J. (2019). Lifestyle medicine: Successful reimbursement methods and practice models. *American Journal of Lifestyle Medicine*, *13*(3), 246-252. https://doi.org/10.1177/1559827618817294

Jones, N., Dlugonski, D., Gillespie, R., DeWitt, E., Lianekhammy, J., Slone, S., & Cardarelli, K. M. (2021). Physical activity barriers and assets in rural Appalachian Kentucky: A mixed-methods study. *International Journal of Environmental Research and Public Health*, *18*(14). https://doi.org/10.3390/ijerph18147646

Joseph, P., Leong, D., McKee, M., Anand, S. S., Schwalm, J. D., Teo, K., Mente, A., & Yusuf, S. (2017). Reducing the global burden of cardiovascular disease, part 1: The epidemiology and risk factors. *Circulation Research*, *121*(6), 677-694. https://doi.org/10.1161/CIRCRESAHA.117.308903

Joshu, C. E., Boehmer, T. K., Brownson, R. C., & Ewing, R. (2008). Personal, neighborhood and urban factors associated with obesity in the United States. *Journal of Epidemiology and Community Health*, *62*(3), 202-208. https://doi.org/10.1136/jech.2006.058321

Kegler, M. C., Swan, D. W., Alcantara, I., Feldman, L., & Glanz, K. (2014). The influence of rural home and neighborhood environments on healthy eating, physical activity, and weight. *Prevention Science: The Official Journal of the Society for Prevention Research*, *15*(1). https://doi.org/10.1007/s11121-012-0349-3

Kennedy, W., Fruin, R., Lue, A., & Logan, S. W. (2021). Using ecological models of health behavior to promote health care access and physical activity engagement for persons with disabilities. *Journal of Patient Experience*, *8*, 23743735211034031. https://doi.org/10.1177/23743735211034031

Kerr, J., Rosenberg, D., & Frank, L. (2012). The role of the built environment in healthy aging. *Journal of Planning Literature*, *27*(1), 43-60. https://doi.org/10.1177/0885412211415283

Keteyian, S. J., Grimshaw, C., Brawner, C. A., Kerrigan, D. J., Reasons, L., Berry, R., Peterson, E. L., & Ehrman, J. K. (2021). A comparison of exercise intensity in hybrid versus standard phase two cardiac rehabilitation. *Journal of Cardiopulmonary Rehabilitation and Prevention*, *41*(1), 19-22. https://doi.org/10.1097/HCR.0000000000000569

Keteyian, S. J., Jackson, S. L., Chang, A., Brawner, C. A., Wall, H. K., Forman, D. E., Sukul, D., Ritchey, M. D., & Sperling, L. S. (2022). Tracking cardiac rehabilitation utilization in medicare beneficiaries: 2017 update. *Journal of Cardiopulmonary Rehabilitation and Prevention*, *42*(4), 235-245. https://doi.org/10.1097/HCR.0000000000000675

Kim, K., Choi, J. S., Choi, E., Nieman, C. L., Joo, J. H., Lin, F. R., Gitlin, L. N., & Han, H. R. (2016). Effects of community-based health worker interventions to improve chronic disease management and care among vulnerable populations: A systematic review. *American Journal of Public Health*, *106*(4), e3-e28. https://doi.org/10.2105/AJPH.2015.302987

King, A., & Hoppe, R. B. (2013). "Best practice" for patient-centered communication: A narrative review. *Journal of Graduate Medical Education*, *5*(3), 385-393. https://doi.org/10.4300/JGME-D-13-00072.1

Koohsari, M. J., McCormack, G. R., Nakaya, T., & Oka, K. (2020). Neighborhood built environment and cardiovascular disease: Knowledge and future directions. *Nature Reviews Cardiology*, *17*(5), 261-263. https://doi.org/10.1038/s41569-020-0343-6

Kruger, T. M., Swanson, M., Davis, R. E., Wright, S., Dollarhide, K., & Schoenberg, N. E. (2012). Formative research conducted in rural Appalachia to inform a community physical activity intervention. *American Jornal of Health Promotion*, *26*(3), 143-151. https://doi.org/10.4278/ajhp.091223-QUAL-399

LaMorte, W. W. (2019a). *Behavior change models, the health belief model*. Boston University School of Public Health. https://sphweb.bumc.bu.edu/otlt/mph-modules/sb/behavioralchangetheories/behavioralchangetheories2.html

LaMorte, W. W. (2019b). *Behavior change models, the theory of planned behavior*. Boston University School of Public Health. https://sphweb.bumc.bu.edu/otlt/mph-modules/sb/behavioralchangetheories/BehavioralChangeTheories3.html

Lawler, P. R., Filion, K. B., & Eisenberg, M. J. (2011). Efficacy of exercise-based cardiac rehabilitation post-myocardial infarction: a systematic review and meta-analysis of randomized controlled trials. *American Heart Journal*, *162*(4), 571-584 e572. https://doi.org/10.1016/j.ahj.2011.07.017

Lazar, M., Thomas, S., & Davenport, L. (2020). Seeking care at free episodic health care clinics in Appalachia. *Journal of Appalachian Health*, *2*(2), 67-79. https://doi.org/10.13023/jah.0202.07

Li, F., Harmer, P., Cardinal, B. J., Bosworth, M., Johnson-Shelton, D., Moore, J. M., Acock, A., & Vongjaturapat, N. (2009). Built environment and 1-year change in weight and waist circumference in middle-aged and older adults: Portland neighborhood environment and health study. *American Journal of Epidemiology*, *169*(4), 401-408. https://doi.org/10.1093/aje/kwn398

Mahmood, L., Flores-Barrantes, P., Moreno, L. A., Manios, Y., & Gonzalez-Gil, E. M. (2021). The influence of parental dietary behaviors and practices on children's eating habits. *Nutrients*, *13*(4). https://doi.org/10.3390/nu13041138

Malambo, P., Kengne, A. P., De Villiers, A., Lambert, E. V., & Puoane, T. (2016). Built environment, selected risk factors and major cardiovascular disease outcomes: A systematic review. *PLOS One*, *11*(11), e0166846. https://doi.org/10.1371/journal.pone.0166846

Marshall, J. L., Thomas, L., Lane, N. M., Holmes, G. M., Arcury, T. A., Randolph, R., Silberman, P., Holding, W., Villamil, L., Thomas, S., Lane, M., Latus, J., Rodgers, J., & Ivey, K. (2017). *Creating a culture of health in Appalachia disparities and bright spots*. Appalachian Regional Commission.

MedlinePlus. (2020a). *Cholesterol*. National Library of Medicine. https://medlineplus.gov/cholesterol.html

MedlinePlus. (2020b). *LDL: The "bad" cholesterol*. National Library of Medicine. https://medlineplus.gov/ldlthebadcholesterol.html

Meyers, D., & Clancy, C. M. (2011). The patient-centered medical home: putting the patient at the center of care. *Journal of Primary Care & Community Health*, *2*(1), 2-5. https://doi.org/10.1177/2150131910386178

Million Hearts. (2020, 2022-02-28T05:11:53Z). *Million hearts continues to make significant national impact*. Centers for Disease Control and Prevention. https://millionhearts.hhs.gov/data-reports/reports.html

Mobley, L. R., Root, E. D., Finkelstein, E. A., Khavjou, O., Farris, R. P., & Will, J. C. (2006). Environment, obesity, and cardiovascular disease risk in low-income women. *American Journal of Preventive Medicine*, *30*(4), 327-332. https://doi.org/10.1016/j.amepre.2005.12.001

Morrone, M., Cronin, C. E., Schuller, K., & Nicks, S. E. (2021). Access to health care in Appalachia: Perception and reality. *Journal of Appalachian Health*, *3*(4), 123-136. https://doi.org/10.13023/jah.0304.10

Mudd-Martin, G., Biddle, M. J., Chung, M. L., Lennie, T. A., Bailey, A. L., Casey, B. R., Novak, M. J., & Moser, D. K. (2014). Rural Appalachian perspectives on heart health: social ecological contexts. *American Journal of Health Behavior*, *38*(1), 134-143. https://doi.org/10.5993/AJHB.38.1.14

National Center for Chronic Disease Prevention and Health Promotion Office on Smoking and Health. (2020, 2020). *Smoking & tobacco use, heart disease and stroke*. Centers for Disease Control and Prevention. https://www.cdc.gov/tobacco/basic_information/health_effects/index.htm

National Center for Chronic Disease Prevention and Health Promotion Office on Smoking and Health. (2021, 2022). *Smoking & tobacco use fast facts*. Centers for Disease Control and Prevention. https://www.cdc.gov/tobacco/data_statistics/fact_sheets/fast_facts/index.htm

Nelson, R. H. (2013). Hyperlipidemia as a risk factor for cardiovascular disease. *Primary Care.* Mar;40(1):195-211. Doi: 10.1016/j.pop.2012.11.003.

Pack, Q. R., Squires, R. W., Lopez-Jimenez, F., Lichtman, S. W., Rodriguez-Escudero, J. P., Zysek, V. N., & Thomas, R. J. (2014). The current and potential capacity for cardiac rehabilitation utilization in the United States. *Journal of Cardiopulmonary Rehabilitation and Prevention*, *34*(5), 318-326. https://doi.org/10.1097/HCR.0000000000000076

Papas, M. A., Alberg, A. J., Ewing, R., Helzlsouer, K. J., Gary, T. L., & Klassen, A. C. (2007). The built environment and obesity. *Epidemiologic Reviews*, *29*, 129-143. https://doi.org/10.1093/epirev/mxm009

Pearson, T. A., Bazzarre, T. L., Daniels, S. R., Fair, J. M., Fortmann, S. P., Franklin, B. A., Goldstein, L. B., Hong, Y., Mensah, G. A., Sallis, J. F., Jr., Smith, S., Jr., Stone, N. J., Taubert, K. A., American Heart Association Expert Panel on, P., & Prevention, S. (2003). American Heart Association guide for improving cardiovascular health at the community level: a statement for public health practitioners, healthcare providers, and health policy makers from the American Heart Association expert panel on population and prevention science. *Circulation*, *107*(4), 645-651. https://doi.org/10.1161/01.cir.0000054482.38437.13

Phillips, D. L., & Alexander-Eitzman, B. (2016). Intersections of poverty, geography, and custodial grandparent caregiving in Appalachia. *GrandFamilies: The Contemporary Journal of Research, Practice and Policy*, *3*(1).

Pollard, K., & Jacobsen, L. A. (2020). The Appalachian region: A data overview from the 2014-2018 American community survey chartbook. *Population Reference Bureau*.

Pollard, K., & Jacobsen, L. A. (2022). The Appalachian region- a data overview from the 2016-2020 American community survey chartbook. *Population Reference Bureau*.

Poux, S. (2017). *Social-ecological model offers new approach to public health*. The Borgen Project. https://borgenproject.org/social-ecological-model/

Ramos, M., & Stein, L. M. (2000). Development children's eating behavior. *Journal of Pediatrics*. 76 Suppl 3, S229–S237. https://doi.org/10.2223/jped.160

Rao, J. K., Anderson, L. A., Inui, T. S., & Frankel, R. M. (2007). Communication interventions make a difference in conversations between physicians and patients: A systematic review of the evidence. *Medical Care*, 45(4), 340–349. https://doi.org/10.1097/01.mlr.0000254516.04961.d5

Rendle, K. A., Abramson, C. M., Garrett, S. B., Halley, M. C., & Dohan, D. (2019). Beyond exploratory: A tailored framework for designing and assessing qualitative health research. *BMJ Open*, *9*(8), e030123. https://doi.org/10.1136/bmjopen-2019-030123

Rice, E. L., Patel, M., Serrano, K. J., Thai, C. L., Blake, K. D., & Vanderpool, R. C. (2018). Beliefs about behavioral determinants of obesity in Appalachia, 2011-2014. *Public Health Reports*, *133*(4), 379-384. https://doi.org/10.1177/0033354918774064

Rimer, B., & Glanz, K. (2005). *Theory at a glance a guide for health promotion and practice* (Second ed.). National Cancer Institute. http://www.sbccimplementationkits.org/demandrmnch/wp-content/uploads/2014/02/Theory-at-a-Glance-A-Guide-For-Health-Promotion-Practice.pdf

Rural Health Information Hub. (2018a). *Ecological models*. Rural Health Information. https://www.ruralhealthinfo.org/toolkits/health-promotion/2/theories-and-models/ecological

Rural Health Information Hub. (2018b). *The health belief model*. Rural Health Information https://www.ruralhealthinfo.org/toolkits/health-promotion/2/theories-and-models/health-belief

Rural Health Information Hub. (2018c). *Theory of reasoned action/planned behavior*. Rural Health Information. https://www.ruralhealthinfo.org/toolkits/health-promotion/2/theories-and-models/reasoned-action

Sadruddin, A. F. A., Ponguta, L. A., Zonderman, A. L., Wiley, K. S., Grimshaw, A., & Panter-Brick, C. (2019). How do grandparents influence child health and development? A systematic review. *Social Science & Medicine*, *239*, 112476. https://doi.org/10.1016/j.socscimed.2019.112476

Sallis, J. F., Floyd, M. F., Rodriguez, D. A., & Saelens, B. E. (2012). Role of built environments in physical activity, obesity, and cardiovascular disease. *Circulation*, *125*(5), 729-737. https://doi.org/10.1161/CIRCULATIONAHA.110.969022

Samanic, C. M., Barbour, K. E., Liu, Y., Wang, Y., Fang, J., Lu, H., Schieb, L., & Greenlund, K. J. (2020). Prevalence of self-reported hypertension and antihypertensive medication use by county and rural-urban classification - United States, 2017. *Centers for Disease Control and Prevention Morbidity and Mortality Weekly Report 2020*, *69*. Prevalence of Self-Reported Hypertension and Antihypertensive Medication Use by County and Rural-Urban Classification — United States, 2017 | MMWR (cdc.gov)

Schwartz, L. M., & Woloshin, S. (2019). Medical marketing in the United States, 1997-2016. *JAMA*, *321*(1), 80-96. https://doi.org/10.1001/jama.2018.19320

Scott, K., Beckham, S. W., Gross, M., Pariyo, G., Rao, K. D., Cometto, G., & Perry, H. B. (2018). What do we know about community-based health worker programs? A systematic review of existing reviews on community health workers. *Human Resources for Health*, *16*(1), 39. https://doi.org/10.1186/s12960-018-0304-x

Sidney, S., Quesenberry, C. P., Jr., Jaffe, M. G., Sorel, M., Nguyen-Huynh, M. N., Kushi, L. H., Go, A. S., & Rana, J. S. (2016). Recent trends in cardiovascular mortality in the United States and public health goals. *JAMA Cardiology*, *1*(5), 594-599. https://doi.org/10.1001/jamacardio.2016.1326

Shanmugasegaram, S., Oh, P., Reid, R. D., McCumber, T., & Grace, S. L. (2013). Cardiac rehabilitation barriers by rurality and socioeconomic status- a cross-sectional study. International Journal for Equity in Health. Carey, R. M., Muntner, P., Bosworth, H. B., & Whelton, P. K. (2018). Prevention and control of hypertension: JACC health promotion series. *International journal for equity in health,* 12, 72. https://doi.org/10.1186/1475-9276-12-72

Stampfer, M., Hu, F., Manson, J., Rimm, E., & Willett, W. Primary prevention of coronary heart disease in women through diet and lifestyle. (2020) *The New England Journal of Medicine*. 343:16-22. Doi: 10.1056/NEJM200007063430103

Stankov, I., Howard, N. J., Daniel, M., & Cargo, M. (2017). Policy, research and residents' perspectives on built environments implicated in heart disease: A concept mapping approach. *Int J Environ Res Public Health*, *14*(2). https://doi.org/10.3390/ijerph14020170

Sun, E. Y., Jadotte, Y. T., & Halperin, W. (2017). Disparities in cardiac rehabilitation participation in the United States: A systematic review and meta-analysis. *Journal of Cardiopulmonary Rehabilitation and Prevention*, *37*(1), 2-10. https://doi.org/10.1097/HCR.0000000000000203

Tegegne, T. K., Rawstorn, J. C., Nourse, R. A., Kibret, K. T., Ahmed, K. Y., & Maddison, R. (2022). Effects of exercise-based cardiac rehabilitation delivery modes on exercise capacity and health-related quality of life in heart failure: a systematic review and network meta-analysis. *Open Heart*, *9*(1). https://doi.org/10.1136/openhrt-2021-001949

Thomas, R. J., Beatty, A. L., Beckie, T. M., Brewer, L. C., Brown, T. M., Forman, D. E., Franklin, B. A., Keteyian, S. J., Kitzman, D. W., Regensteiner, J. G., Sanderson, B. K., & Whooley, M. A. (2019). Home-based cardiac rehabilitation: A scientific statement from the American Association of Cardiovascular and Pulmonary Rehabilitation, the American Heart Association, and the American College of Cardiology. *Journal of the American College of Cardiology*, *74*(1), 133-153. https://doi.org/10.1016/j.jacc.2019.03.008

Tolley, E. E., Ulin, P. R., Mack, N., Robinson, E. T., & Succop, S. M. (2016). *Qualitative methods in public health: A field guide for applied research* (Second Edition ed.). John Wiley & Sons, Incorporated. https://ebookcentral.proquest.com/lib/etsu/detail.action?docID=7104122.

U.S. Census Bureau. (2022, September 15). U.S. Census Bureau releases new 2021 community survey 1-year estimates for all geographic areas with populations of 65,000 or more. https://www.census.gov/newsroom/press-releases/2022/people-working-from-home.html

U.S. Department of Agriculture and U.S. Department of Health and Human Services. (2020). *Dietary guidelines for Americans 2020-2025.* https://www.dietaryguidelines.gov/sites/default/files/2021-03/Dietary_Guidelines_for_Americans-2020-2025.pdf

U.S. Department of Health and Human Services. (2005). *High blood cholesterol what you need to know*. National Institutes of Health. https://www.nccih.nih.gov/health/tips/tips-what-you-should-know-about-high-blood-cholesterol

U.S. Department of Health and Human Services. (2018). *Physical activity guidelines for Americans, 2nd Edition.* https://health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf

U.S. Department of Health and Human Services. (2022). *Healthy people 2030: Heart disease and stroke*. https://health.gov/healthypeople/objectives-and-data/browse-objectives/heart-disease-and-stroke

United Health Foundation. (2022a). *America's health rankings analysis of CDC, behavioral risk factor surveillance system, high blood pressure.* https://www.americashealthrankings.org/explore/annual/measure/Hypertension/state/ALL

United Health Foundation. (2022b). *America's health rankings analysis of U.S. HHS, Centers for Medicare & Medicaid Services, national plan and provider enumeration system.* https://www.americashealthrankings.org/

University of Minnesota School of Public Health [UMN SPH]. (2015). About the socio-ecological model. *Center for Leadership Education in Maternal & Child Public Health.* https://mch.umn.edu/sem/

Ventola, C. L. (2011). Direct-to-consumer pharmaceutical advertising: Therapeutic or toxic? P & T: A Peer-reviewed Journal for Formulary Management, 36(10), 669-684. PMID: 22346300.

Virani, S. S., Alonso, A., Benjamin, E. J., Bittencourt, M. S., Callaway, C. W., Carson, A. P., Chamberlain, A. M., Chang, A. R., Cheng, S., Delling, F. N., Djousse, L., Elkind, M. S.

V., Ferguson, J. F., Fornage, M., Khan, S. S., Kissela, B. M., Knutson, K. L., Kwan, T. W., Lackland, D. T., . . . Taso, C.W. (2020). Heart disease and stroke statistics-2020 update: A report from the American Heart Association. *Circulation*, *141*(9), e139-e596. https://doi.org/10.1161/CIR.0000000000000757

Wall, H. K., Ritchey, M. D., Gillespie, C., O'mura, J. D., Jamal, A., & George, M. G. (2018). Vital signs: Prevalence of key cardiovascular disease risk factors for Million Hearts 2022 - United States, 2011-2016. *Morbidity and Mortality Weekly Report*, *67:*983–991. DOI: http://dx.doi.org/10.15585/mmwr.mm6735a4

Wall, H. K., Stolp, H., Wright, J. S., Ritchey, M. D., Thomas, R. J., Ades, P. A., & Sperling, L. S. (2020). The million hearts initiative: Catalyzing utilization of cardiac rehabilitation and accelerating implementation of new care models. *Journal of Cardiopulmonary Rehabilitation and Prevention*, *40*(5), 290-293. https://doi.org/10.1097/HCR.0000000000000547

Walsh, M. N., Bove, A. A., Cross, R. R., Ferdinand, K. C., Forman, D. E., Freeman, A. M., Hughes, S., Klodas, E., Koplan, M., Lewis, W. R., MacDonnell, B., May, D. C., Messer, J. V., Pressler, S. J., Sanz, M. L., Spertus, J. A., Spinler, S. A., Teichholz, L. E., Wong, J. B., & Byrd, K. D. (2012). ACCF 2012 health policy statement on patient-centered care in cardiovascular medicine: A report of the American College of Cardiology Foundation Clinical Quality Committee. *Journal of the American College of Cardiology*, *59*(23), 2125-2143. https://doi.org/10.1016/j.jacc.2012.03.016

Whitsel, L. P., Bantham, A., Jarrin, R., Sanders, L., & Stoutenberg, M. (2021). Physical activity assessment, prescription, and referral in US healthcare: How do we make this a standard of clinical practice? *Progress in Cardiovascular Diseases*, *64*, 88-95. https://doi.org/10.1016/j.pcad.2020.12.006

Williamson, T. M., Moran, C., McLennan, A., Seidel, S., Ma, P. P., Koerner, M. L., & Campbell, T. S. (2021). Promoting adherence to physical activity among individuals with cardiovascular disease using behavioral counseling: A theory and research-based primer for health care professionals. *Progress in Cardiovascular Diseases*, *64*, 41-54. https://doi.org/10.1016/j.pcad.2020.12.007

Zadeh, N. K., Robertson, K., & Green, J. A. (2019). Lifestyle determinants of behavioral outcomes triggered by direct-to-consumer advertising of prescription medicines: A cross-sectional study. *Australian and New Zealand Journal of Public Health*, *43*(2), 190-196. https://doi.org/10.1111/1753-6405.12883

APPENDICES

## Appendix A: Focus Group Discussion Guide

### PCORI Focus Groups: Discussion Guide (*Below 6th grade reading level*)

Welcome

Hello and welcome to our group discussion. We are _______ and ____________ from the East Tennessee State University College of Public Health. We appreciate you being able to join us today in sharing your views.

Overview of Topic

You were selected to participate in this focus group because we want to gather your thoughts on priority issues related to heart disease. This is not a test, but rather we want an open discussion and want to hear your views. We are particularly interested in your personal experiences as a heart disease patient or caregiver.

Rules Discussion

We will start by asking general questions to get the discussion going. Remember we want your opinions and views. There are no right or wrong answers. It is important to us that you share your point of view even if it differs from what others are saying. In fact, if your opinion differs from others it is particularly important for us to know your views. We will be encouraging everyone to participate and share through thoughts. As we go along we hope you will share your personal experiences as well as opinions.

We want this to be a lively discussion, so it will be difficult to take notes on everything that is said and discussed. Therefore, we will be recording the session so that we won't miss anything. We will remove your name and any identifying information from notes we take from the audio recording. After taking notes, the recording will be destroyed. That means that everything you say in this focus group will remain anonymous.

You can decline to answer any question or leave the group at any time without any penalties

We understand how important it is to keep this information private and confidential. We ask everyone in the group to not repeat anything said here to anyone outside of the group.

You can use a nickname that you would like us to call you during this session. You can write that on your nametag and we will use that name when addressing you.

Are there any questions before we get started?

## Questions

Introductions

1. *First, we would like everyone to go around and introduce themselves. Maybe include your name, where you live or anything else that seems important for us to get to know you. Also, you might add why this topic is important to you?*

*Thanks for doing that – Great to hear from everyone.*

2. I'd like to hear about some of the community efforts in your area of Central Appalachia? Can anyone tell me what is going on in your community or area related to heart disease prevention?
   - **a.** What about related to screening for heart disease? What are some programs, or services that you have heard about?
   - **b.** What about management? What are some programs, or services that you have heard about?
   - **c.** What about heart disease treatment? Do you have treatment facility or programs nearby?
3. *Thinking about the community you live in as a whole – what is needed to prevent heart disease?*
      - **i.** *This can include obesity, diabetes, and risk behaviors, like smoking, increase physical activity and improve nutrition –*
   - **b.** *Thinking about the community you live in as a whole, what is needed to better screen for heart disease and related conditions like obesity, or diabetes?*
   - **c.** *Thinking about the community you live in as a whole, what is needed to better manage heart disease and related conditions like obesity, or diabetes.*

   - **d.** *Thinking about your community as a whole, what is needed to better treat heart disease?*

4. *What helps you the most to 1) manage, or treat heart disease as a patient or caregiver?*
   - **a.** *Probe: What things about [1) managing, 2) preventing, or 3) screening, 4) treating – ask one at a time] heart disease are the most important?*
   - **b.** *What are the biggest challenges you face in [1) managing, 2) preventing, or 3) screening, 4) treating – ask one at a time] heart disease as a patient and caregiver?*
5. *Where do most of you receive care? What things do you like best about the care you receive? What do you feel is needed to improve it?*
6. *This project is focused on patient-centered care for developing a heart disease agenda for Central Appalachia – what is your definition of patient-centered care?*
      - **i.** *What do you feel are the important practices (things your provider does) that make sure they are providing patient-centered care (care focused on your well-being)? What are provider practices that don't seem patient-centered in your experience?*
      - **ii.** *How do you feel we can make sure that the research agenda we develop is patient-centered or patient-driven (as is the main mission of our funder)?*
7. *As you might know, we are part of a project that is planning a heart disease or cardio-vascular disease conference. As part of the planning we want to make sure*

*we are covering the main priorities that are important to you as patients and caregivers.*

**a.** *So, I would like each of you to write your top 5 priorities on the index card you have. We will take about 5 minutes for everyone to do that. Priorities can at this point, be anything that comes to mind.*

**b.** *Ok, thanks, let's go around and hear everyone's top priority (assistant will write these on a flip chart).*

**c.** *Ok, let's discuss these topics. So, can you explain these priorities – why is this a priority? [group discusses each priority topic – at least up to their 3rd priority written down, if enough time will go through top 5 for each person – also look for agreement]*

**d.** *Probes include: Do others feel like this is an important priority? Do you feel this is specific to your state or area – please explain? Since we are focused on including this into our conference – how might we do this? What kind of information or research is needed to fully address this topic? How can this be addressed this within the scope of patient-centered care – how can researchers study this?*

8. *Out of the priorities we have discussed today – which ones now seem most important?*

**a.** *Please write your top two priorities on the back of you index card.*

**b.** *Does anyone want to add anything new to why this priority was chosen? [can count to see how many agreed on topics]*

9. *This is really helpful for us as we start to plan the conference – Is there anything you would like to add before we end the session?*
10. *Thanks for participating today – and we want to invite everyone to the conference and also asked you all to get the word out about it.*

## Appendix B: Interview Discussion Guide

### PCORI In-depth Interview Key-Informant: Discussion Guide

Welcome

Hello and thank you for agreeing to answer some question that will help us identify cardiovascular disease priorities for Central Appalachia. I am from the East Tennessee State University College of Public Health. We appreciate you being able to join us today in sharing your views.

Overview of Topic

You were selected to participate in this in-depth interview because as a health care provider, administrator, or public health professional, we want to gather your thoughts on priority issues related to preventing, managing and treating cardiovascular disease. The information gathered will be used to plan a cardiovascular disease (CVD) conference that is focused on prevention and control of CVD in Central Appalachia.

I will be recording the session so that important information is not excluded. We will remove your name and any identifying information from notes we take from the audio recording. After taking notes, the recording will be destroyed. That means that everything you say in this interview will remain anonymous.

Is it ok to record the interview?

You can decline to answer any question or stop the interview at any time without any penalties

Are there any questions before we get started?

### Questions

Introductions

1. *First, I'd like to introduce myself and tell you a bit about me {interviewer introduces themselves}. Do you mind telling me a bit about yourself? How long have you been practicing medicine, working as an administrator, or public health professional in the field of cardiovascular health in this region? What kind of practice do you have? Where is your practice? What is the name of it? What is your job description? Etc.*

2. *Thinking about the community you live in as a whole – **<u>what is going on</u>** (what efforts) in your area of Appalachia are being taken to prevent heart disease?*
3. *In your role, what efforts are being made to manage heart disease?*
   - **a.** *In your role, what efforts are being made to prevent heart disease?*
   - **b.** *In your role, what efforts are being made to screen for heart disease?*
   - **c.** *In your role, what efforts are being made to treat heart disease?*
4. *Thinking about the community you live in as a whole, **what is needed to prevent** for heart disease and related conditions like obesity?*
   - **a.** *Thinking about the community you live in as a whole, **what is needed to improve screening** for heart disease and related conditions?*
   - **b.** *Thinking about the community you live in as a whole, **what is needed to better treat heart disease** and related conditions like obesity, or diabetes?*
   - **c.** *Thinking about your community as a whole, what **is needed to better treat heart disease**?*
5. *In your opinion, **what things are the most important for helping patients** manage heart disease?*
   - **a.** *In your opinion, **what things are the most important for helping patients** prevent heart disease?*
   - **b.** *In your opinion, **what things are the most important for helping patients** to get screened for heart disease?*
   - **c.** *In your opinion, **what things are the most important for helping patients** treat heart disease?*
6. ***What is needed to better help caregivers in their role?***

   a. *What are the* ***biggest challenges you face as a provider/administrator/public health professional in helping patients and caregivers*** *get the care they need?*

7. *Thinking about the field of cardiovascular disease health and treatment* ***what are the state-of-the-art practices for screening and treating patients that are used or you use****?* ***Are these things always used? What would help with universal compliance with these practices or treatments?***

8. *This project is focused on patient-centered care for developing a heart disease research agenda for Central Appalachia –* ***what is your definition of patient-centered care****?*

      i. *What do you feel are* ***the important practices within your field and job that ensure that you are providing patient-centered care****?*

      ii. ***How do you feel we can make sure that the research agenda we develop is patient-centered or patient-driven*** *(as is the main mission of our funder)?*

9. *As you might know, we are part of a project that is planning a cardio-vascular disease conference. As part of the planning we want to make sure we are covering the main priorities that are important to health care and public health professionals.*

   a. *So, I would like you to think about and if needed* ***write down your top priorities****. I'll give you a few minutes to think about your list. Priorities can at this point, be anything that comes to mind.*

   b. *Ok, thanks,* ***what would be your #1 priority****?*

   c. ***Why is this a priority****? [go through top 5]*

    i. *How can this priority be addressed?*
    ii. *Additional probes: Do you feel this is specific to your state or area – please explain? Since we are focused on including this into our conference – how might we do this? What kind of information or research is needed to fully address this topic? Would you consider this a patient-centered concern – in other words do you feel patients consider this a priority? What is the best way to include this in our research agenda from a patient-centered approach?*

10. *Out of the priorities we have discussed today – which one seems most important?*
    a. *Do you want to add anything new to why this priority was chosen?*
11. *This is really helpful for us as we start to plan the conference – Is there anything you would like to add before we end the session?*
12. *Thanks for participating today – and we want to invite you to the conference and also ask you all to get the word out about it. We have post-cards, and posters – can we send you some to get the word out to your community?*
13. *Do you have any suggestions for other professionals in your area that we should interview for the project? Or perhaps patient and caregiver groups that might be good to do a focus group with.*

# VITA

## KRISTY GAGNON

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