Informing Cardiovascular Disease Prevention among Rural Appalachian Women: A Community-Engaged Mixed Method Study

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Abstract

Cardiovascular disease (CVD) accounts for the largest difference in life expectancy between Appalachian women and women outside the region. With high proportions of uncontrolled risk factors and low screening rates, identifying strategies to increase CVD prevention among Appalachian women is a public health priority. Using a community-engaged mixed method approach, including the novel pairing of spatial analysis and concept mapping, this dissertation aims to: 1) identify and summarize existing women's health research in Appalachia, 2) assess the association of county-level resource distribution and CVD mortality rates among women in the Appalachian counties of Pennsylvania (PA), and 3) uncover the range of perceived barriers and facilitators to CVD prevention along with potential community-specific interventions among Appalachian PA women. The results from Aim 1 provide newly identified gaps in the literature for future study, including the need for more research across health topics, Appalachian subregions, and throughout the life course. The complex factors across social-ecological levels found throughout the existing literature support strategies to improve CVD prevention that consider social and environmental contexts, such as those uncovered in Aims 2 and 3. Aim 2 findings show previously undescribed associations between county-level income and recreation facility density with spatial patterns of CVD mortality among women in the Appalachian PA counties. These results suggest increasing access to recreation facilities and developing ways to overcome income-related barriers may improve CVD prevention among Appalachian women.

Grounded in community insights across three counties (N=71), Aim 3 uncovers 96 items, grouped into six thematic clusters across the social-ecological model, that Appalachian PA women perceive as related to the cardiovascular health of women in their community. Participants also describe potential intervention opportunities, which build on social and community assets, promote holistic care, and utilize validating messaging. These novel mixed method findings move forward the understanding of CVD prevention among Appalachian women by identifying vital social and environmental factors. Through building a conceptual framework including the complex, multilevel influences identified by women in this region, this dissertation provides valuable guidance to better understand cardiovascular health decision-making and the corresponding action-oriented, community-specific strategies to improve CVD prevention among rural Appalachian women.

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Preface

Five years ago, I could not have guessed the path my predoctoral journey would take. I feel extremely lucky to have found such a supportive environment and to have been able to obtain financial support to turn my ideas into reality. The COVID-19 pandemic caught us all by surprise, and I feel grateful that, with the support of funders and numerous wonderful individuals, I was able to complete the majority of my dissertation vision as intended.

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and projects as I strive to become an independent researcher. I hope we will find many more ways to collaborate and work together in the future.

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1.0 Introduction

1.1 Scope of the Problem: CVD Mortality among Appalachian Women

Residents of Appalachian counties die younger from preventable causes. The Appalachian Regional Commission (ARC) reports premature mortality rates are 25 percent higher in Appalachia than for all U.S. counties.[1,2] According to the ARC, the Appalachian region consists of 420 counties in 13 states (see **Figure 1**); forty-two percent of Appalachia is rural, compared to 20% of the rest of the U.S. population.[3] Appalachian residents have a per capita income that is 74.3% of the national average. Over 17% of the residents are in poverty with counties with rates as high as 44.3%, compared to the national average of 14.8%.[4-6]

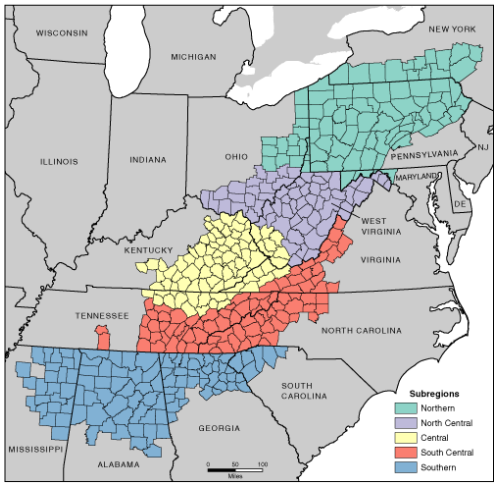

Figure 1. Map of the Appalachian Region

These counties also have lower levels of educational attainment and higher levels of unemployment than national averages.[7,8] While progress has been made in the region on some economic indicators, the existing socioeconomic disparities reflect, and contribute to, significant

health inequities, where improvements in health outcomes nationally from 2008 to 2014 outpace those in the Appalachian region, resulting in widening gaps from the rest of the country in areas like infant mortality rates and chronic diseases, such as cardiovascular disease (CVD).[2] For example, Appalachian populations have significant excesses in heart disease mortality (17% higher than national averages),[9] which is mirrored by higher stroke mortality rates (14%) and higher CVD risk factors such as diabetes prevalence (11.9%), physical inactivity (5.3%), and smoking (3.7%) than the rest of the U.S.[2] Disparities also exist for the rural residents of the region, resulting in 40% higher premature mortality rates than their urban counterparts.[2]

Appalachian women are at high risk for CVD. Heart disease is the leading cause of death for women in the United States, and 65% of cases are asymptomatic.[10] In addition, women have increased morbidity and mortality from CVD related events and are less likely to receive aggressive or invasive treatment than men.[11] These sex-specific risks emphasize the need for CVD screening among women, particularly in Appalachia. In a seminal report published in 2000, Appalachian counties were identified as one area in the country with the highest heart disease-related death rates for women,[12] and CVD continues to account for the largest portion (27.5%) of the gap in life expectancy at birth between Appalachian women and those outside the region.[13] These increased premature mortality rates hold true across race/ethnicity. For example, heart disease causes a 28% higher premature death rate among white women and a 12.2% higher rate among African American women in the region, as compared to the nation as a whole.[9,11] Notably for this largely rural population, the report included social isolation as a construct to be considered a risk factor for women developing CVD.[12] Women in this region also experience the access-related challenges found in rural communities, such as high levels of health professional shortage

areas (e.g., 39% of Appalachian counties lack the minimum number of primary care providers and 20% of counties do not have a hospital) and low rates of health insurance coverage. Overall, researchers have just begun to explore why women in this region have low rates of preventive screenings for known CVD risk factors.[14]

The need for strategies to increase CVD screening rates among rural Appalachian women remains a high priority. Screening identifies intervention opportunities to reduce future mortality and morbidity and lowers costs for healthcare systems.[15] Recommended screening for CVD covers intermediate physiologic outcomes and checks on self-reported behaviors,[16] including: labs/blood tests (e.g., cholesterol, blood glucose); body measurement screens (e.g., blood pressure, body mass index [BMI], waist circumference); and lifestyle behaviors (e.g., smoking, diet, physical activity).[17] Studies continue to describe the high proportions of women in this region with uncontrolled risk factors for CVD, such as hypertension, hypercholesterolemia, and diabetes.[10,11,18] Overall, women of this region have decreased life expectancy, increased chronic illness, and increased obesity than the nation as a whole.[19] For example, one study found only 40% of women in rural West Virginia have correctly treated and controlled hypertension.[18] Particularly alarming, four out of five women of reproductive age (age 18 to 44) in this region already have at least one risk factor for CVD.[20] Another study followed at-risk participants who were given referrals for relevant CVD risk factors, and in a subsequent publication, the authors describe minimal referral completion (18.2% for hypertension, 5.4% for smoking cessation, and 11.7% scheduled a nutrition referral but only one completed the referred session).[21]

These data have caught the attention of policy makers, who strive to improve accessibility for screenings through efforts like the CDC's WISEWOMAN (Well-Integrated Screening and

Evaluation for WOMen Across the Nation) program. While credited with a large increase in the receipt of screenings for women in states that have funded these programs,[22] studies continue to explore the challenges of reaching those most in need.[10,23,24] A perspective with growing popularity is to include a multifaceted approach that takes into consideration the social and environmental contexts that affect a woman's decision to receive preventive screening.[25] Ultimately, the improvement of CVD prevention by rural Appalachian women will require strategies that consider social and environmental contexts to shed light on what contributes to these low rates.[25]

1.2 History of Women and Health in Rural Appalachia

Understanding the history of health in the region provides an important perspective of current regional priorities and needs. Historically, women hold an important role in the health of the rural Appalachian region. Tracing roots back to the lay-midwives, commonly referred to as 'granny women' or 'granny witches,' women have played a pivotal role in health and healthcare throughout the region's mountains and hills.[26-28] Based on a combination of Scotch-Irish traditional medicine mixed with native Cherokee herbal practices, older women who survived childbirth and kept their children alive provided the main source of healthcare in the region from the 1800s to the early 1900s. These women served as birthing coaches and used herbs and healing practices as remedies for a variety of health issues. Similar to the African American granny midwives of the southern U.S., granny women held highly respected positions in communities and provided vital, otherwise unavailable, care.[27,29]

The tradition of matriarchal provision of care continues in many Appalachian communities today. Perhaps the most well-known female healthcare provider in Appalachia, Mary Breckinridge, who trained in midwifery in England, used the Scottish Highlands and Islands Services as a model for serving rural areas.[30] In 1925, she founded the Frontier Nursing Service in Hyden, Kentucky, which became a primary source of healthcare throughout Central Appalachia by training nurse-midwives who travelled around the region on horseback. Now Frontier Nursing University, which recently relocated outside Lexington, Kentucky, Breckinridge's work continues to impact the region today. Others, like Eula Hall and Sister Bernadette "Bernie" Kenny, followed in the footsteps of Mary Breckinridge to provide healthcare in various Appalachian communities. Eula Hall founded the Mud Creek Clinic in Floyd County, Kentucky in 1973, initially as a response to low water quality, women's health issues, and overall lack of care in the surrounding areas; this clinic is presently seeing over 200,000 patients per year.[31] In 1980, Sister Bernie started the Health Wagon, a mobile health service, in the back of a Volkswagen in Dickinson County, Virginia. Her goal was to address high infant mortality rates and pervasive health issues from local industries. Like Mud Creek, the Health Wagon continues to operate with five donated vans, serving more than 11,000 uninsured or underinsured patients throughout Appalachia.[32]

These notable women took the health of the region into their own hands by increasing women's access to care by creative means (e.g., horseback, mobile clinics, a clinic in the hollow), and attempting to build more sustainable healthcare structures that utilize community-driven, culturally-sensitive approaches that are both economically and socially aware. The major health issues tackled by Breckinridge, Hall, and Kenny include overcoming access challenges, prenatal care, violence and alcoholism, basic health needs (e.g., clean water), chronic health issues (e.g.,

black lung and diabetes), and mental health issues. Within the stories of these pivotal healthcare figures, health issues like CVD took a back seat to more immediate health concerns. The trends and health focus areas, and perhaps the inspiration of these courageous women, likely carry into more recent literature by researchers.

Based on funding priorities, research topics addressed in the region have shifted over time. When viewing these topics from a temporal lens, prenatal care and general health behaviors initially dominated research for women in this region, reflective of the priorities and stories of Mary Breckinridge and other early healthcare providers. However, with the establishment of the Appalachian Leadership Initiative on Cancer (1992-2000), which led to the Appalachian Cancer Network (now the Appalachian Community Cancer Network [ACCN]) being formed in 2000, funding for cancer-related disparities has greatly increased.[33-35] This increase can be particularly seen for cervical, colorectal, and lung cancers, cancers which Appalachian populations experience the greatest disparity from non-Appalachian populations.[2,9] Notably, research on drug use,[36,37] intimate partner violence (IPV),[38,39] and mental health[40,41] have increased in the last few years, which could reflect recent national priorities. Aside from research focusing on mutual risk factors with cancer, such as smoking, research focused on CVD among women has not yet followed suit, despite relevant disparities. In total, while disparities in mortality rates are increasing compared to non-Appalachian populations,[2] researchers publish relatively few articles each year (fewer than eight per year since 2010) focusing on the health of women in this population, and recent helpful books published reviewing health for Appalachian populations spend relatively little time discussing health issues particular to women in the region.[42,43]

Research on cancer disparities and its associated factors provides a valuable guide for understanding CVD screening behaviors by rural Appalachian women. The creation of the ACCN, which is one of 25 National Cancer Institute (NCI) Community Network Programs, marked an increase in community-engaged studies to address cancer health disparities.[33] With a focus on Community-Based Participatory Research (CBPR) projects, several context-driven studies have arisen from this successful network in states across Appalachia. Many of the resulting studies appropriately take place in Central Appalachia, where disparities are even higher than other parts of the region, in states like Kentucky[44,45] and Ohio.[46,47] The few Pennsylvania (PA) based studies have covered areas such as increasing colorectal cancer screening[48] and physical activity among rural breast cancer survivors.[49] These studies provide helpful information on social and contextual factors that drive screening decision-making and serve as a valuable source of comparison for understanding CVD-related preventive behaviors. While breast cancer incidence rates are not higher among Appalachian women compared with the national average, mortality rates are higher, which suggests inadequate screening and increased late stage diagnoses.[50] In Appalachian PA, which contains greater resources than many other areas in the Appalachian region, higher mortality rates have been directly connected to reduced receipt of preventive screenings.[51] These results should be considered when studying CVD prevention, as they may provide valuable insight into Northern Appalachian-specific behaviors or challenges among women.

Recent studies also have uncovered a multiplicative risk, where cancer survivors are at increased risk of CVD beyond an additive calculation; likewise, those with CVD are at an increased risk for cancer.[52] This connection further emphasizes the need to consider risk factors in a holistic manner rather than segmenting each of these topics in contextually-based studies.

Additionally, as contextual factors overlap for chronic disease among women in this region, researchers should consider the individual, interpersonal, community/policy, and sociocultural factors found in research for other chronic diseases as relevant for discussion of CVD disparities.

1.3 Documented Factors Affecting CVD Risk among Women

A variety of identified factors affect CVD risk among women and fall across levels of the social-ecological model, including individual, interpersonal, and community/environment factors. Social-ecological models allow researchers to conceptualize relationships between individuals, their behavior, and their environment[53] by providing a framework to view health beyond an intrapersonal perspective.[54] **Table 1** contains a summary of example documented risk factors.

Table 1. Example Documented Factors Affecting CVD Risk among Women by Social-ecological Level

Individual Factors	***Interpersonal Factors***	***Community/Environment Factors***
Biological/Genetic Risk	Social Roles	Natural Environment
Hormone-Related Risk (e.g., Menarche/Menopause)	Social Networks/Supports	Night & Day Cycles
Pregnancy Complications	Social Isolation	Seasons
Age		Altitude
Health Behaviors:		Latitude
Physical Activity		Greenspaces
Diet		Pollution
Smoking		Social Environment
Socioeconomic Status		Built Environment:
Psychosocial:		Medical Resources
Stressful Events		Food Environment
Chronic Stress		Exercise Environment
Adverse Childhood Events		
Depression		
Anxiety		
Negative Emotions (e.g., Hostility/Anger)		

Individual Level

Biological Pathways & Genetic Risk. In order to gain a full picture of CVD risk for women, one must consider the individual biological risk factors and processes. Major CVD risk factors include: elevated blood pressure, high triglyceride levels, smoking, diabetes, obesity, physical inactivity, unhealthy diet, older age, and family history.[17,55] As heart disease is the leading cause of death for women in the U.S. and 65% of cases are asymptomatic, screening plays an important role in understanding CVD risk.[10] Not only are women less likely to experience a cardiac event without prior symptoms than men,[56] they are more likely to present ischemia (i.e., inadequate blood supply to an organ such as the heart) or microvascular disease (i.e., the narrowing of small vessels that send blood to the heart) without evidence of obstructive coronary artery disease.[57,58] In particular, screening among women is important as symptoms of cardiac events differ from men, such as experiencing fatigue, shortness of breath, shoulder/back pain, or nausea during a heart attack rather than the classic male symptoms of radiating chest or arm pain.[57,59] Prevention and screening are also important for women as they experience worse medical prognoses after cardiac events and surgical therapies, such as revascularization.[60]

The biological pathways that lead to increases in these risk factors can help explain why women experience subsequent increased CVD risk. Atherosclerosis, a disease in which plaque builds up inside an individual's arteries,[55] accounts for 50% of mortality in the U.S. and is the primary cause of heart attack (myocardial infarction) and stroke.[61] Studies have shown that environmental (e.g., stress, immunologic factors, toxins, viruses) and social (e.g., social isolation, lack of social support) factors may be related to the development of atherosclerosis and subsequently CVD.[61] Genetic predisposition does explain a significant amount of risk for the

development of CVD risk factors, such as lipid metabolism, hypertension, obesity, and diabetes.[61] However, two potential pathways, based on interactions with the environment, can explain which of these genetic factors are expressed. The first is a behavioral pathway, where psychosocial factors (e.g., stress, depression, hopelessness, social isolation) are associated with health behaviors (e.g., smoking, diet, physical activity), and the second is a neuroendocrine pathway, where feedback loops from the brain dictate physiological systems relevant to CVD.[61] These two pathways interact to result in higher blood pressure, atherosclerosis, and ultimately, higher rates of CVD.

Hormone-Related & Pregnancy Complications. Specific to women, hormone and pregnancy-related risks can also contribute to CVD. For example, women experiencing early menarche as well as those who are post-menopausal are at increased risk for CVD.[62,63] During pregnancy, women who experience preeclampsia are at two-times the risk of developing CVD in later life; women developing gestational hypertension or gestational diabetes[64] or who experience a spontaneous pregnancy loss or a preterm birth also appear to have increased future CVD risk.[65,66]

Health Behaviors. Beginning in utero, individual-level exposures over the life span affect CVD risks.[67] These exposures continue through childhood and affect subsequent CVD risk in adulthood. For example, technological advances, urbanization, economic issues, and other factors have contributed in increased childhood obesity by affecting physical activity and eating behaviors in childhood that affect health into adulthood.[68] These lifestyle factors hold a major place in developing CVD risk, particularly diet, physical inactivity, and smoking. Each of these personal lifestyle factors involves a complex relationship between an individual and their environment. Diet has both cultural and socioeconomic facets that relate to food availability and consumption,[69] and what a person chooses or can afford to eat directly affects CVD risk. For example, those who eat

diets high in trans-fats are at a three-fold risk of sudden cardiac death.[70] Physical inactivity is also strongly related to CVD outcomes; inactivity can lead to a 45% increased risk of coronary heart disease, a 60% increased risk of stroke, a 30% increased risk of hypertension, and a 50% increased risk of type 2 diabetes.[71] Overall, physical inactivity accounts for 13% of all premature deaths in the U.S..[71] Finally, smoking is largest health behavior-related risk factor for CVD. Nearly 50% of premature mortality associated with smoking in the U.S. is from CVD. Smokers are two-times more likely to develop coronary heart disease and ten-times more likely to develop peripheral artery disease.[72] The role of these lifestyle factors re-emphasizes the modifiable nature of CVD risk; however, health behaviors should be considered within the cultural, social, and natural environments that may dictate aspects of behavior change that are important to understand the reduction of CVD risk.

Socioeconomic Factors. Socioeconomic factors have also been consistently connected to CVD health outcomes.[73,74] While some researchers argue that income and education are on the pathway of other risk factors (e.g., diet), studies have shown that socioeconomic factors account for CVD risk beyond these risk factors.[69,73] Low socioeconomic status (SES) individuals are more likely to experience increased CVD events as well as to have poorer associated outcomes,[73] and income appears to play a greater role in CVD outcomes than other related demographic factors, such as race, education, marital status, or employment status.[75] Low SES individuals carry a substantial amount of CVD burden compared to their higher income counterparts, and as women are overrepresented among those in poverty, [73] the role of SES in CVD risk will be particularly important to understand from a gender/sex-specific lens.

Psychosocial Factors. A growing body of literature discusses the role of psychosocial factors in relation to the cardiovascular (CV) and physical health of women, including factors that take place in childhood or in midlife and may result in negative health outcomes later in life. In particular, studies explore the role of stressful life events and chronic stress throughout the life course with physical and CV health, such as adverse childhood events,[76] intimate partner violence,[77] and stressful social roles.[78] These sources of stress throughout the life course have been linked to chronic inflammation (i.e., through measuring inflammatory biomarkers such as interleukin-6 [IL-6] or C-reactive protein [CRP], which predict future CV events) and increased burden of atherosclerotic plaques. In particular, CRP, which tends to be higher in women throughout the life course,[79] is a stronger predictor of CV events in women than in men,[80] which suggests a greater role of inflammatory processes;[57] these processes may be connected to disrupted ovulatory cycles due to stress[81] or ventricular dysfunction related to prior severe emotional stress,[82] further supporting the role of hormonal or reproductive factors.

Other psychosocial factors, such as depression (which is twice as common among women),[83] anxiety,[84] and negative emotions (e.g., hostility, anger)[85] also may play an important role in CV risk for women as well as men; differences for future exploration exist among these negative emotions as well, with anger suppression having a more important role and hostility playing a less important role in CV risk among women compared to men.[57,86]

Interpersonal Level

Social Roles. To explore the depth of the types of stress women face, researchers have begun to consider the various roles women play socially that may contain forms of stress (e.g.,

marital stress, job stress, and caregiving stress) that affect them differently from men.[78] Studies designed to better understand the effects of social relationships on CV risk have mixed results; one recent study shows an association between a stressful social role in midlife with later-life atherosclerotic burden with no mitigating effects from social role rewards,[78] though other studies have discussed the potentially protective role of high marital satisfaction.[87,88] While these conflicting results warrant future exploration, researchers continue to suggest that frequency of social interactions may play a greater role in generated stress and CV risk than the types of roles, suggesting the importance of understanding stress accumulated across the interpersonal domain.[57]

Social Networks, Supports, & Isolation. An individual's social networks can also affect CVD health. For example, as families share both genes and environmental exposures, individuals who are related to someone with CVD are at increased risk,[89] and individual health behaviors may be influenced by the behaviors of partners, family, and peers. Literature on the relationship between social supports and CVD outcomes has mixed results, but in recent studies, higher social integration (i.e., contacts with family/friends and involvement in social activities) and lower social strain (i.e., negative social relationships) have been associated with reduced CVD incidence and mortality.[90-92] Age has also been associated with increased CVD risk and increased social isolation. As people live longer, more individuals experience periods of time living alone with reduced social interactions.[93] Chronic social isolation has been associated with an increase in high blood pressure, smoking, obesity, and ultimately increased morbidity and mortality. One systematic review showed that across 16 prospective longitudinal studies, social isolation was correlated with a 29% increased risk of coronary heart disease and a 32% increased risk of stroke.[94] Social isolation may

be particularly important to women, as emergence of heart disease tends to lag about 10 years behind men, manifesting in older women with higher rates of comorbidities.[57]

Community & Environmental Level

Natural Environment. As interactions with the environment affect how genetic factors are expressed, understanding the role of environmental exposures contributes to understanding the pathways through which women are at increased risk for CVD outcomes.[69] The natural environment increases CVD risk; for example, studies have shown the role of: time of day effects (e.g., heart attacks are three-times more likely to occur in the early AM hours),[95] seasonal effects (e.g., 53% more cases of heart attacks are reported in the winter than the summer),[96] altitude effects (e.g., individuals permanently living in high altitude environments have improved CVD health),[97] and the presence of greenspaces, which can increase mental and physical health.[98]

Pollution. Pollution and environmental noise also affect CVD risk. While fine particulate matter has mostly been linked to cancer and respiratory health outcomes, 70-80% of premature deaths tied to fine particulate matter are due to CVD cases.[99] Environmental noise pollution also affects sleep and stress, and minor noise reductions (~5dB) could improve hypertension and coronary heart disease outcomes by 279,000 fewer cases per year in the U.S.[100]

Social & Built Environments. The social and built environments can also affect CVD risk through the characteristics of the neighborhoods in which people live. Previous studies on ways social and built environment factors affect CVD risk show a strong spatial association between CVD mortality and markers of social deprivation such as poverty and social isolation.[101] Social cohesion, neighborhood identity, and stigmatization have also been linked to cardiovascular (CV)

health.[102-104] The pathways through which social environment factors operate are less clear but likely include mechanisms such as resource cost, availability, transportation, and healthcare access. Additionally, studies show complicated interactions between health access and socioeconomic status, supporting access as a multi-dimensional construct.[105] County-level analyses across geographic regions in the U.S. also show rates of improvement in CVD mortality lagging in low-income communities.[106] Much of the literature on built environment effects on health, including those that affect CVD, focuses on urban communities; however, across the rural-urban continuum, factors such as crime rate, income inequality, and race play a role in cardiac and obesity risk among low-income women.[107,108] Studies assessing rurality through land use found that women living in an area of low land use mix (i.e., more rural communities) have a 19% greater 10-year risk for coronary heart disease (CHD) than those in high land use mix areas (i.e., more urban communities).[107]

Exercise & Food Environment. Studies not explicitly focused on the health of women show mixed results for the roles of factors in the exercise or food environments on CV-related health outcomes. Several studies have noted a significant negative relationship between the number of facilities and physical environment characteristics (e.g., walkability, traffic) with body mass index (BMI) and CHD risk.[107,109-111] Generally, the availability and proximity to recreation facilities,[112,113] as well as living in neighborhoods with high densities or a variety of residential land use (e.g., parks, play areas),[114,115] have been associated with an increase in physical activity. For rural residents, the few studies on the exercise environment show traffic safety, recreation facilities, and trails are most consistently associated with physical activity behaviors.[116,117] In the food environment, factors, such as fast food density and presence of full-service grocery stores,

show less conclusive results, which may be related to the complex interactions of cost, food quality, convenience/access challenges, as well as nutritional value or portion sizes;[107,118] however, national survey measures have shown a significant relationship between food insecurity and risk for diabetes, hypertension, and higher odds of 10-year CVD risk, with particularly consistent and strong associations among females.[119,120] Overall, these factors create vulnerabilities in populations through increasing stress and reducing food, exercise, and health resource access.[69]

1.4 Appalachian Context: Social-ecological and Sociocultural Factors

In addition to the documented factors that affect the CVD risk among women, studied social-ecological and sociocultural factors from the Appalachian region shed light on the CV health of women in the region. Based on Appalachian cancer research and other literature throughout the region, individual, interpersonal, community, and policy level factors likely combine to affect CVD prevention among rural Appalachian women.

Individual Level. For Appalachian women, identified individual-level factors affecting preventive screening behaviors include: knowledge (e.g., causes of disease,[121] uncertainty of guidelines,[122] and misinformation about disease[123,124]), perceptions (e.g., need for privacy;[124-128] lack of perceived need for screening;[127-130] emotional reaction to the screening process, including fear, worry, and embarrassment;[46,126,128,130-132] and lack of control over disease[131]) and skills (e.g., ability to manage and negotiate uncertainty[122]). In rural areas, closer-knit communities and the desire to not have an acquaintance involved in health-related decision-making increase body

discomfort and worry of stigma, which supports the elevated need for privacy.[125,133] However, studies show the majority of demographics do not predict the receipt of certain types of screening by this population[46] and a gap exists between knowledge, attitudes, and beliefs and screening behavior. These findings support a shift from individual-focused knowledge-based interventions to the inclusion of social and contextual factors.[122,123,126]

Interpersonal Level. At an interpersonal level, studies assert important figures in social networks, such as friends, family, or providers, influence preventive screening decision-making by Appalachian women.[124] Studies often cite the interpersonal factor of provider recommendation and engagement,[46,125,133] which can improve upon a knowledge-only approach.[50] Patient-provider interaction extends beyond messaging content to include factors that impact levels of trust and comfort, such as provider gender and communication method.[122,123,126,134] Family history and previous experiences with disease also play a role in screening decision-making.[50,127,129] Over time, health experiences of family or friends may build-up an individual's emotional response, such as fear or worry, and in aggregate, exacerbate lack of screening at a larger familial or community level.[131] In addition, family and providers play an intersecting role in screening decision-making; while family may provide the origin of behaviors, providers influence behavior in a more proximal manner.[50] Further research should seek to understand the role of social factors and to determine how social relationships interact with individual and structural factors.[126,133,135]

Community & Policy Levels. Regional health disparities research identifies several community-level challenges that prevent women from receiving screening, such as cost of screening procedures and follow-up,[46,50,124,126,130] access to insurance,[50,124] and access to transportation.[123,129] Effects of geographic isolation, such as high numbers of health professional

shortage areas, affect whether women in the region receive preventive screenings.[136] Factors like primary care physician to county population ratios also predict higher rates of adverse outcomes for women in the region.[137] However, in Appalachian PA, with greater resources than many other areas in the region, studies directly connect higher mortality rates to lower receipt of preventative screenings.[51] This suggests access challenges alone may not provide the solution to decreasing chronic disease health disparities or may involve complicated relationship with other aspects, such as health insurance access and affordability.

Researchers should consider community-level factors within the health policy landscape. For example, recent cervical cancer studies discuss how changing screening guidelines in 2012, which reduced overall lifetime screening for women, affects perceived competency and trust in providers by Appalachian women.[122] Additionally, while programs, such as PA Department of Health's WISEWOMAN and HealthyWoman provide free screening services to women at or below 250% of the federal poverty guidelines,[138] these programs only reach a fraction of those eligible. Unlike many Appalachian states, PA successfully passed Medicaid Expansion in 2015.[139] Subsequently, the number of women using these programs declined, and preliminary studies by PA Cancer Control, Prevention, and Research Advisory Board (CAB) members suggest increased access to health insurance is a major contributor to the decreased need for supplementary screening.[140] Newly insured women are able to go to providers that accept Medicaid, and anecdotal evidence suggests that some of these women may be avoiding screenings in the anticipation that they would not be able to afford deductibles if treatment is needed. While Medicaid Expansion is beneficial for Appalachian women living in PA, particularly those without insurance through employment, women whose closest providers are across state-lines may gain policies that do not

carry across state boundaries. As a result, these women would have to travel farther to a PA provider to receive affordable services.[132] Understanding contextual policy-level effects on screening behavior will be vital, as the country's healthcare policy landscape continues to shift and may result in many women once again needing these screening services.

Sociocultural Factors

As Appalachia is a region with rich cultural heritage, social values, and a place-based identity, one must also consider how sociocultural factors affect both CVD risk and preventive screening decision-making by rural Appalachian women.

Socioeconomic Status. As previously described, residents of Appalachian counties remain economically disadvantaged with a per capita income at 74.3% the national average. Compared to the national average of 14.8%, 17.2% of residents are in poverty, with some counties with rates as high as 44.3%.[4-6] Overall, these counties also have lower high school and college completion rates and higher levels of unemployment than national averages.[7,8] Studies continue to show that community-wide income and education levels play a role in access challenges,[129] exacerbating existing difficulties with receiving affordable care, such as screenings tests, provided at an appropriate health literacy level.

Local Economies. Historically, many counties in this region had one-industry dominant economies, such as mining, forestry, agriculture, chemical industries, and other heavy industry, which have dissipated in recent years leaving an economic gap many communities have struggled to fill. In response to these concerns, the U.S. government formed the Appalachian Regional Commission (ARC) in the 1960s to build capacity and improve economic conditions in this area.[141]

The work funded by the ARC has addressed poor health precursors, such as geographic isolation, low incomes, and limited education.[142] However, despite these improvements, mortality rates for a variety of health outcomes, including those for CVD, continue to diverge from the rest of the country.[143] Following the economic recession of 2008, the Appalachian region lost all of the jobs it gained since 2000, which included a loss of 59,000 jobs in farming, forestry, and natural resources.[144] This lack of employment and stunted economic growth directly affects the poverty that many families in the region experience and increases stress that contributes to mental and physical health disparities, including CVD health outcomes among women.

Additionally, local industries often create health concerns and generate complicated relationships Appalachians have with major regional employers. For example, the top five U.S. states in tobacco production are in Appalachia, where it represents more than ten-percent of total crops.[142] Many families in these areas have a historical relationship with this industry, referring to tobacco as the "Christmas crop," and in some areas, more than 50% of individuals have some personal connection to tobacco productions, sales, or use.[142] Other local industries in the region also affect health, resulting in occupational hazards, unclean air, and toxic waste or farm run-off that can affect water quality. As a result, Appalachians often hold complex relationships with local industries, which are simultaneously creating health hazards and providing jobs that allow them to support their families and stay in their home region.[142] These jobs may also provide the health insurance that allows families to seek and afford healthcare. Health researchers working in the region should consider how these complicated relationships affect both preventive health-seeking behaviors as well as how it may affect subsequent treatment or intervention participation.

Race & Ethnicity. Individuals, both within and outside the region, often consider Appalachians to be a predominately white population with heritage tracing to Irish, Scottish, and German settlers.[144] While seven out of eight (~90%) of Appalachians are Non-Hispanic white, other races and ethnicities also make-up portions of this population, which varies across the region.[142] Although most non-white populations of the region live in Southern Appalachia, African Americans, Native Americans, Italians, Poles, Hungarians, French, Jewish, and other populations exist in various parts of Appalachia.[144] African Americans make up the largest minority group in the region. Bolstered by Frank X. Walker publishing "Affrilachia" in 2000, a culture supporting identity as both African American and Appalachian has a growing following, which includes poets, authors, and musicians, who demonstrate that they too are a part of this region while offering a uniquely African American perspective.[145] Latino populations are also growing in certain areas, particularly in the southern parts of the region,[144] and Native Americans live throughout the region including in the Appalachian portion of North Carolina, which is the home of the Eastern Band of the Cherokee Nation. Notably, Northern Appalachia is home to Amish and Mennonite communities, which have their own culturally distinct practices and beliefs.[144,146] Within the larger cultural characteristics of Appalachia, each of these races, ethnicities, and cultural groups have their own history and traditions that need to be considered in the provision of healthcare, including CVD screening, throughout the region.

Culture & Social Values. A cultural practice in Appalachia, storytelling may generate social norms for receipt of preventive measures, as the experiences of family, friends, and community members perpetuate over time creating negative perceptions of screening outcomes.[131] Additionally, while federal programs promote culturally competent care, physician shortages in

rural areas persist and often result in providers, some from outside the U.S., to fill positions in a transitory manner.[147] The cultural divide between providers and residents in the region reduces trust and increases miscommunication in health decision-making, such as preventive screening.[132] While not accurate for all Appalachians, male-dominated industries, such as mining and steel production, historically provided the major source of employment in the region. This structure created family roles with patriarchal heads of households;[148] aspects of this structure still manifest today, where some women remain reliant on male partners for income, transportation, and decisions to receive care.[132] However, for many Appalachians, economic and social changes have resulted in more egalitarian relationships, where patriarchal dominance is seen as a facet of previous generations.[149] Studies also reference high levels of religiosity as an important cultural facet; however, faith and religious affiliation are not barriers for receipt of healthcare or screening and, rather, provide a positive, protective factor for those with a disease diagnosis and in intervention development.[44,142] Finally, the region has a reputation for its mistrust of outsiders, which includes health care providers; [125,148] however, researchers have successfully built trust through displaying non-judgmental and respectful knowledge of Appalachian lifestyles and community-engaged methods.[148]

Studies also acknowledge the role of traditionally-identified Appalachian social values within the decision-making process for screening. Four relevant Appalachian characteristics are: independence, ethic of neutrality, familism, and personalism.[150] In health decision-making, self-sufficiency takes precedence, and in many cases, Appalachians view social programs as charitable causes to avoid.[148] Additionally, Appalachians value assistance from family, friends, or even churches over formal healthcare structures, and family takes priority over individual needs.[148] A

neutral ethic reflects the avoidance of interfering in other individuals' personal business and, in healthcare, can manifest as a reluctance to perform prescriptive behaviors, such as screening.[148] Finally, Appalachians value a person-based focus to health issues rather than a disease-focus. In some cases, this person-centered approach generates a present-day orientation to health issues that can be interpreted as fatalism; however, studies argue that life circumstances may justify this viewpoint as a rational response.[128,150] Importantly, while these values exist in aggregate in Appalachian populations, they do not necessarily transfer to the individual level,[148] and while these beliefs may affect a decision to preventive screenings, the complex interaction of circumstances requires fuller consideration of context.[128]

Appalachian Identity. A good portion of the literature on Appalachian culture is from the 1950s to 1970s, representing a dated perspective.[149] These works, such as by Thomas Ford in 1958, focus on characteristics that have become common place in describing Appalachian populations, such as the noted social values (e.g., fatalism, religiosity, individualism, and self-reliance).[149] Despite refuting the existence of fatalism and purporting the positive effects of religiosity in these earlier works, such studies influenced future researchers to focus on these facets in their work, some of whom still continue to depict Appalachia in research in inaccurate ways.[149] These characteristics, as well as a lack of modernization and isolation from the mainstream, have formed stereotypes present in media representations of the region (e.g. *Deliverance*, *Duck Dynasty*, *Here Comes Honey Boo*, etc.).[149] These "hillbilly" archetypes proliferate representations of Appalachian culture and identity[144] and serve to misrepresent the diverse and varying types of individuals that call this region home or who identify as from Appalachian families.

Appalachian identity holds unique characteristics. Researchers have chosen to define who is and is not 'Appalachian' differently based on either a place-based or self-identified definition. As a place-based identity, questions often remain for who truly is Appalachian and whether family heritage or residence play a more distinct or important role.[144] In ARC reports, all individuals living in an Appalachian county are considered to be of Appalachian identity; however, this loses the nuance of those who come from Appalachian heritage but moved to outside areas for work or education or those who live in the region but either recently located there or more strongly identify with other elements of their identities. For example, Obermiller has conducted extensive research on urban areas outside Appalachia that are home to individuals of Appalachian heritage who experience many of the same health disparities as those currently living within the region.[42,151] Many such individuals live in cities like Detroit, Cleveland, and Chicago due to familial migration on what has been called the "Hillbilly Highway," when millions of Appalachians moved north between 1910 to 1960 to find jobs in industry.

The complicated nature of Appalachian identity continues to develop in American culture, as seen by the success of J.D. Vance's recent best-selling novel *Hillbilly Elegy: A memoir of a family and culture in crisis*. While dominating the books sales market in the wake of the 2016 presidential election, reviewers and scholars familiar with Appalachian culture and identity spoke to the unfortunate effects of this limited view of Appalachia continuing to be represented in the mainstream media.[152] The pervasive nature of these stereotypes has led some researchers to find that individuals may initially object to being referred to as Appalachian in an effort to reject these unflattering depictions.[149] However, many individuals have great pride in their connection to this region, and a powerful sense of place attachment plays an important role for many who do identify

as Appalachian.[142] This important place-based connection in Appalachian identity should be considered by researchers when understanding the contributors to health behaviors for outcomes such as CVD as well as in the development of interventions to improve screening or treatment.

1.5 Cardiovascular Disease Screening

With a focus on risk factors broadly across populations rather than risk specific to women or the Appalachian region, the screening process for CVD typically involves a series of steps taken by providers in the context of a medical-related visit. This process generally involves: 1) asking about current lifestyle factors, such as smoking, diet, physical activity, and alcohol use; 2) conducting measurements of blood pressure as well as height and weight (BMI) or body fat to assess obesity; or 3) ordering blood tests to assess cholesterol and glucose levels.[17] See **Table 2** for a summary of the recommended screenings by the American Heart Association along with the frequency and age for beginning screening. The information gathered from these screenings can

Table 2. American Heart Association's Heart Disease Screening Recommendations (since 2014)

Recommended Screenings	***How Often?***	***Starting when?***
Blood pressure	Each regular healthcare visit or at least once every 2 years if blood pressure is less than 120/80 mm Hg	Age 20
Cholesterol ("fasting lipoprotein profile" to measure total, HDL and LDL cholesterol, and triglycerides)	Every 4-6 years for normal-risk people; more often if any you have elevated risk for heart disease and stroke	Age 20
Weight / Body Mass Index (BMI)	During your regular healthcare visit	Age 20
Waist circumference	As needed to help evaluate cardiovascular risk. This is a supplemental measurement if your BMI is greater than or equal to 25 kg/m2.	Age 20
Blood glucose test	At least every 3 years	Age 45
Discuss smoking, physical activity, diet	Each regular healthcare visit	Age 20

then be used to calculate a risk score. A variety of tools can be used to calculate this score; for example, the Pooled Cohort Atherosclerotic Cardiovascular Disease (ASCVD) Risk Equations, the Framingham Risk Score (FRS), and the QRISK®2/QRISK®3 are three commonly used measures.[153] These tools use differing source populations to generate a risk score for an individual. Most of these tools involve the input of age and sex, and some can adjust the score based on family history or ethnic origin. For example, the Framingham model uses a nationally representative sample, which performs well in white and Black populations but poorly among some other racial/ethnic groups.[153] However, these traditional risk algorithms tend to underestimate cardiac risk for women compared to men.[58]

For more in-depth CVD screening, physicians may also use imaging (e.g., CT scans or ultrasounds), electrocardiography, biomarkers (e.g., CRP, IL-6), or genetic screening; however, these are much more resource and time intensive. In recent years, subclinical measures have been utilized to assess coronary artery calcium (CAC) scores and the development of atherosclerosis; several measures can be used to capture different aspects of atherosclerosis progression, including carotid intima-media thickness (cIMT), adventitial diameter (cAD), and arterial stiffness via measures such as brachial-ankle pulse wave velocity (baPWV). Collectively, these measures can give researchers or providers a sense of an individual's arterial thickening and the presence of plaques.[78] While these measures are now frequently used in research, regular use for clinical purposes and their applicability across risk-groups as well as sex or racial/ethnic groups is still up for debate.[154]

One easy guide for CVD primary prevention is the American Heart Association's Life's Simple 7 index, which uses the major screening areas of: smoking, BMI, physical activity, diet,

total cholesterol, blood pressure, and glucose to calculate a patient's cardiovascular health.[155] Those middle-age patients who meet more of the Life's Simple 7 criteria have substantially lower lifetime risk of heart failure; a tool such as this, that does not involve more invasive or intensive testing, is valuable to inform lifestyle behaviors or other recommendations.[156] In addition to generating overall risk scores, healthcare providers use the screening test results to determine the necessary follow-up steps for patients using guidelines, such as those set by the U.S. Preventive Services Task Force (USPSTF), the American College of Cardiology, and the American Heart Association.[153] The rates of receiving these preventive screenings vary across type of screening and by population. For example, one study shows that only 56% of all adults and 93% of hypertensive patients had blood pressure screenings in the recommended 2-year span.[157] Additionally, cholesterol screenings at the recommend 5-year intervals vary in practices from 45 to 88%.[158] Notably, women receive screenings at lower rates than men across all risk levels.[153,159] Beyond the screening process itself, healthcare providers have no guarantee that patients will follow-up on any recommendations or referrals given to improve CVD risk.

Understanding the factors that affect the receipt of these screenings is key to unlocking the challenges in the subsequent referral and preventive health behavior pathways to reduce CVD risk. This is particularly important among women, who experience higher rates of asymptotic cases and simultaneously receive less screening from healthcare providers. In response to the high risk women face for CVD events, the CDC started the WISEWOMAN program in 2008. This program is available in the 19 states and two tribal organizations that participate in the NBCCEDP (National Breast and Cervical Cancer Early Detection Program).[160] Five of these programs exist in Appalachian states, including Pennsylvania, West Virginia, North Carolina, South Carolina, and

Alabama.[160] PA has 21 facilities throughout the state, including eight in rural counties (all Appalachian).[161,162] This program aims to improve heart disease and stroke prevention by focusing on risk factors, such as blood pressure control, by offering free screening in participating locations, free lifestyle programs through community-based organizations, and referrals to free or low-cost CVD resources.[160] As such programs are reliant on referrals made by health providers and community-outreach, understanding barriers and facilitators women experience related to receiving CVD screenings could directly inform the types of services that programs like WISEWOMAN offer to help alleviate challenges rural Appalachian women face in preventive health decision-making.

1.6 Theoretical Framework: Social Cognitive Theory and Grounded Theory

Currently, no specific theoretical frameworks exist that describe the complex interplay of the multilevel factors that contribute to CVD health among women in rural Appalachia. Individual, interpersonal, community, sociocultural, and biological experiences likely contribute to these outcomes, but little is known about the extent to which each impacts and interacts with one another or the primary determinants that contribute to these disparities. In the existing literature focused on the health of women in the region, authors cite a number of health theories with social and/or behavioral components to help explain the behavioral health patterning seen among rural Appalachian women. These theories range from: Social Determinants of Health,[163] the Integrated Behavioral Model,[123] Models of Service Utilization,[37] Consumer Information Processing Theory,[50]

Social Cognitive Theory,[23] Health Belief Model,[164,165] Transtheoretical Model,[135] and Theory of Communication and Uncertainty Management.[122] While all of these theories have merits, a theory like Social Cognitive Theory is able to connect the social, environmental, and personal factors together with behavior to reflect their relationships with health outcomes.

Social Cognitive Theory

A useful underlying theory to examine is the reciprocal determinism facet of Social Cognitive Theory. As described by Bandura's work in the 1980s, reciprocal determinism describes how a person's behavior both influences and is influenced by personal factors and the environment.[166] For CVD among rural Appalachian women, the behavior being assessed is receipt of preventive CVD screenings, which covers the previously described checks for health outcomes and self-reported behaviors,[16] including: labs/blood tests (e.g., cholesterol, blood glucose); body measurement screens (e.g., blood pressure, BMI, waist circumference); and checks of lifestyle behaviors (e.g., smoking, diet, physical activity).[17] These behaviors are mediated at an individual level by both personal characteristics, such as age, education level, race/ethnicity, health insurance status, and income as well as personal beliefs and attitudes, such as perceptions of barriers and facilitators to screening. Additionally, the behavior is affected by the external environment, which includes the physical environment, such as medical resources (e.g., hospitals, rural health clinics, and Federally Qualified Health Centers [FQHCs]) and preventive resources (e.g., spaces for physical activity, the presence of grocery stores and

affordable foods, and the social environment). See **Figure 2** for a visual depiction of how these elements relate to each other in a reciprocal fashion and lead to increased risk of CVD mortality.

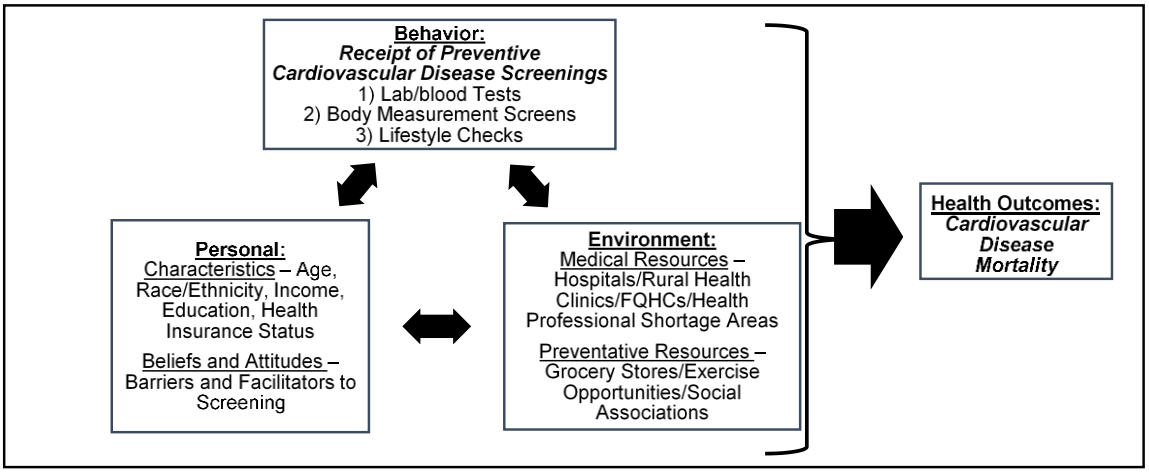

Figure 2. Reciprocal Determinism of Preventive CVD Health among Appalachian Women

Grounded Theory

Within the existing literature for women in the region, a number of studies utilized qualitative research approaches (e.g., interviews, focus groups) to study the health experiences of rural Appalachian women; however, only one of these articles focused specifically on heart disease within this population,[167] with a majority focusing on cervical cancer-related behaviors and experiences.[124,130,134,168] Without a specific theoretical framework in place for CVD risk and related social and behavioral experiences, grounded theory provides a platform for rigorously exploring an individual's perspectives and experiences. A grounded theory approach allows one to use an inductive and iterative approach to develop a conceptual framework, which is particularly useful when exploring concepts that do not currently have an existing framework.[169,170] Qualitative research utilizing a grounded theory approach can help to build a new, comprehensive framework based on the experiences of individuals. Such a framework would be useful to then provide a

guidebook for new interventions to increase preventive screening and to ultimately reduce CVD risk among rural Appalachian women.

1.7 Dissertation Aims

Dissertation Aims and Papers

This dissertation follows a three-paper format and includes six chapters: this introduction (chapter 1), paper 1 (chapter 2), research methods (chapter 3), paper 2 (chapter 4), paper 3 (chapter 5), and a discussion bringing together novel mixed method findings and future directions for research (chapter 6). The three papers reflect the three primary aims of this dissertation, which are:

Aim 1: Identify and summarize existing women's health research in Appalachia.

The second chapter includes the first paper, which is a rapid scoping review of peer-reviewed published articles on the health of women in Appalachia. The aim of this paper is to identify and summarize existing women's health research in Appalachia from 2000 to 2019, including health topics, study populations, theoretical frameworks, methods, and major findings. Understanding the current status of the range of health issues that affect women is important in developing needed programs and services, guiding future research, and creating a holistic view of women's health in the region. Due to the dearth of literature on CVD among Appalachian women, this scoping review provides overall context for the health of women in Appalachia with relevant thematic areas to explore specific to CVD in research.

Aim 2: Assess the association of county-level resource distribution, including medical, preventive, and socioeconomic factors, with CVD mortality for women in Appalachian PA.

The fourth chapter includes the second paper, which involves geographic information system (GIS) mapping and spatial analysis with secondary data to assess the spatial clustering of medical (e.g., hospital/clinic locations) and preventive (e.g., healthy food retailer density, recreation facility density) resources with CVD mortality for women. The aim of this study is to assess the association of county-level resource distribution, including medical, preventive (e.g., food and recreation environments), and socioeconomic factors (e.g., median household income), with CVD mortality for women in the Northern Appalachian PA counties. These analyses will identify differing patterns of resources and their role in the CVD mortality among women in the rural Appalachian counties of PA.

Aim 3: Uncover the range of perceived barriers and facilitators to CVD prevention and community-specific interventions among rural Appalachian PA women.

The fifth chapter includes the third paper, which utilizes concept mapping, a participatory mixed method, to explore the perceptions of women in three rural Appalachian PA counties (N=71)around factors that contribute to the CV health of women in their community. The aims of this paper are to identify: 1) the range of perceived barriers and facilitators to preventive CVD health by rural Appalachian PA women; 2) the relationship between individual, social, and environmental-level factors identified as important for CVD prevention; and 3) potential community-specific interventions to improve CVD prevention among Appalachian PA women.

2.0 Place, Power, and Premature Mortality: A Rapid Scoping Review on the Health of Women in Appalachia

2.1 Abstract

Appalachian women continue to die younger than in other U.S. regions. We performed a rapid scoping review to summarize women's health research in Appalachia from 2000 to 2019, including health topics, study populations, theoretical frameworks, methods, and major findings. We searched bibliographic databases and included articles that were: (1) on women's health in Appalachia; (2) published January 2000 to June 2019; (3) peer-reviewed; and (4) written in English. Two coders reviewed articles to create summary tables comparing variables of interest. This search revealed 81 articles, which primarily focused on cancer disparities (49.4%) and prenatal/pregnancy outcomes (23.5%). Many of these studies took place in Central Appalachia (e.g., 42.0% in Kentucky) with reproductive and/or middle-aged women (82.7%). Half of the studies employed quantitative methods, and half used qualitative methods, with few mixed method or community-engaged approaches (3.7%). Nearly half (40.7%) did not specify a theoretical framework. Findings included complex individual, interpersonal, and community-level factors across health topics. Future studies should: 1) systematically include Appalachian women across life stages from under-represented sub-regions; 2) expand the use of rigorous methods and specified theoretical frameworks to account for complex interactions of social-ecological factors; and 3) build upon existing community assets to improve health in this vulnerable population.

2.2 Introduction

Appalachian women face high proportions of uncontrolled risk factors, decreased life expectancy, and increased chronic illness compared to the nation as a whole.[10,11,13,18] Appalachian health disparities persist in part from limited research concerning the complex interaction of multilevel factors shaping the health of women across the Appalachian region. Advancing health equity in Appalachia rests upon understanding the foundational work in the current literature surrounding factors influencing Appalachian women's health. Uncovering the range of factors affecting the health of Appalachian women will contribute to the development of effective interventions capable of increasing life expectancy and improving health equity among women in this under-resourced region.

The Appalachian region includes 420 counties spanning 13 states from Mississippi to New York; the region's population is 42% rural, compared to 20% of the U.S. population.[3] Residents of Appalachian counties die younger from preventable causes than those from non-Appalachian counties; reports from the Appalachian Regional Commission (ARC) indicate premature mortality rates 25% higher in Appalachia than the U.S..[1,2] While progress has been made in the region on various economic indicators, challenges remain, including low income and educational attainment and high rates of poverty and unemployment.[2] As in many other largely rural areas, these socioeconomic disparities reflect, and contribute to, significant health inequities; however, the improvements in health outcomes across the U.S. from 2008 to 2014 outpace those in the Appalachian region, resulting in widening gaps from the rest of the country in areas like chronic disease and infant mortality rates. The Appalachian region has higher rates of heart disease, cancer,

chronic obstructive pulmonary disease (COPD), injury, stroke, diabetes, and suicide, with markedly higher rates of mortality due to poisoning (e.g., drug overdoses) than national averages.[2] In 2017, the ARC found that the Appalachian region performs worse than the U.S. as a whole on 33 of 41 health indicators. Additionally, Central Appalachia has particularly high premature mortality rates, which are 69% higher than the U.S. rate,[2] and across the entire Appalachian region, premature mortality rates are 40% higher in rural counties compared to metro counties and 42% higher in distressed counties compared to those that are non-distressed,[2] which further supports the exploration of socioeconomic, demographic, and contextually-based factors to understand health burdens, particularly in highly rural areas.

Due to a complex combination of individual (e.g., personal choice and characteristics) and contextual factors (e.g. socioeconomic and political environments), mortality rates among women are higher in the Appalachian and southeastern U.S. states than their counterparts.[171] For example, despite recent national attention to high levels of "diseases of despair" in Appalachia, including negative consequences from substance use such as alcoholic liver disease and cirrhosis as well as overdose from prescription and illegal drugs,[172,173] few studies examine the effect of these health burdens on women in the Appalachian region. While overdose burden is lower among females than males in the region, the disparity for overdose between Appalachian and non-Appalachian counties is even greater among females than males, including double the rate among those age 35-54 and a 92% higher rate among those age 25-34.[173] Such findings suggest researchers should include sub-analyses focusing on sex or gender-based differences in health burdens and include intentional elements in studies to assess the explanatory factors affecting burdens for women specifically.

Little is known about how barriers and facilitators to health in the Appalachian region, such as social and geographic isolation, affect women. As people live longer and rural communities become disproportionately older, more individuals, particularly women, experience periods of time living alone with reduced social interactions.[93] Chronic social isolation is associated with an increase in high blood pressure, smoking, obesity, and ultimately increased morbidity and mortality. Additionally, the effects of geographic isolation, such as health professional shortage areas (e.g., 39% of Appalachian counties lack the minimum number of primary care providers and 20% of counties do not have a hospital), often affect whether individuals in the region receive treatment or preventive screenings.[136] While policies, practices, and political power vary by state in the region, compared to men, women may be more greatly hindered due to lack of resources including employment opportunities and access to transportation and insurance.

Appalachian women's barriers for accessing health services may, in part, trace their origins to the male-dominated industries, such as mining and steel production, which historically have provided the major source of employment in the Appalachian region. For many residents, this structure created family roles with patriarchal heads of households;[148] aspects of this structure remain today, where some women may rely on male partners for income, transportation, and healthcare decisions.[132] However, for many Appalachians and rural residents, changing economic and social structures have promoted more egalitarian relationships.[149] As with many populations who have experienced underrepresentation in formal power structures, women in Appalachia are not regularly consulted on their health needs and present a relatively absent voice in the literature. Instead, perceptions of women in Appalachia often stem from stereotyped images of mountain matriarchs, isolated and self-sacrificing for their families, or of immoral and ignorant young

women who are frequently pregnant.[174] By not discussing the nuances of being an Appalachian woman, including diversity of lived experiences and corresponding health needs, public health professionals miss a vital opportunity to uncover important risk and protective factors as well as to develop interventions with the engagement of Appalachian women.

Long aware of the health concerns in their community, Appalachian women historically have been activists and advocates for health. Tracing roots back to lay-midwives, commonly referred to as 'granny women,' women served as birthing coaches and used herbal remedies for many health issues.[26-28] Similar to African American granny midwives of the southern U.S., granny women were highly respected in communities and provided vital, otherwise unavailable, care.[27,29] Successful efforts increased residents' access to care by using community-driven, culturally-sensitive approaches. The major health issues tackled by the efforts of Appalachian women include prenatal care, violence, alcoholism, basic health needs (e.g., clean water), chronic diseases (e.g., black lung and diabetes), and mental health issues, reflecting a number of challenges experienced in rural areas.

While the work of community advocates and a growing research literature have increased attention to the Appalachian region's health needs, little is known about the risks, protective factors, and population-specific interventions needed to improve the health of women. The most recent ARC report provides vital health statistics of the region; however, subgroup analyses by sex or gender are less frequently discussed, with the exception of some aspects of reproductive health (e.g., teen birth rates, sexually transmitted infections) and cancers that primarily affect females (e.g., mammography screening rates).[2] Understanding the current literature concerning the range of health issues that affect women is important in developing needed programs and services,

guiding future research, and creating a holistic view of health in the region. We performed a rapid scoping review of peer-reviewed literature to summarize the state of literature on women's health in Appalachia from 2000 to 2019, including health subjects, temporal patterns, study locations and populations, theoretical frameworks, and methods.

2.3 Materials and Methods

We conducted a rapid scoping review to identify relevant peer-reviewed articles. A scoping review serves a different purpose than a systematic review; scoping reviews are useful for providing an overview of available research, particularly for a topic that has not been explored in a comprehensive way or has diverse elements.[175,176] Rather than answering a specific question through the assessment of methodological rigor or evidence of best practices as in a systematic review, scoping reviews focus on emerging evidence and can be used to assess gaps in the literature or clarify questions for future systematic reviews.[177] Rapid reviews, with accelerated review processes and streamlined methods following the structure of a scoping review, are valuable in assessing what is known about existing policies, practices, and research in a timely manner while maintaining high quality standards.[178] Given the limited number of publications focusing on the health of Appalachian women and the dearth of existing reviews on this topic, we conducted a rapid scoping review to gain a novel scope of what exists in the current literature.

Data Sources

We obtained literature from three bibliographic databases: PubMed, PsycINFO, and Google Scholar. We selected these databases to capture literature focused on health and medicine (PubMed, which includes MEDLINE articles) as well as information on behavioral and mental health found in the social sciences, nursing, and related fields (PsycINFO); the inclusion of the Google Scholar search also allowed us to identify articles published in less renowned journals or smaller university presses that may not be indexed in traditional bibliographic databases,[179] which is consistent with the broad search goals of a scoping review. Our search included the terms: health services accessibility/access to health care, women's health/women's health services/maternal health services, female, Appalachian region/Appalachia, and Appalachian women (**Appendix A**). As the MeSH heading, a hierarchical heading used for indexing in PubMed, for 'Appalachian Region' pulls articles linked to any portion of the 13 states in Appalachia, we added search terms for 'Appalachia' in the title or abstract to eliminate the majority of irrelevant articles. We did not include specific health topics in this search to broadly capture research discussing health and health services among women in Appalachia.

In our search, we included the gender-based term 'women' and the sex-based term 'female' to capture as many articles as possible. We recognize these terms vary in meaning and should be used in differing contexts; we primarily use 'women' to be inclusive of all who identify as women, unless data sources specify a sex-based determination (e.g., death certificates). Additionally, we acknowledge that including the term 'Appalachia' in our search restricts our sample to articles with an intentional focus on the region and may miss studies conducted without that focus, even if the study occurs in an Appalachian-designated county.

After the initial literature identification, we searched article bibliographies for additional studies. The first author conducted the initial search and abstract review, and both the first and second authors read and abstracted information from the identified full text articles. The rapid search was initially conducted in February 2017 with subsequent rapid updates to identify additional recent publications in February 2018 and June 2019. We consulted with Public Health Informationists from our University's Health Sciences Library System for input and guidance regarding the search strategy.

Inclusion and Exclusion Criteria

Articles had to meet the following inclusion criteria: (1) focused on health behaviors, care, or services for women in Appalachia; (2) published from January 2000 to June 2019; (3) peer-reviewed; and (4) written in English. We excluded studies without reported data findings (e.g., literature review or commentary articles) as well as dissertations and non-peer-reviewed publications. Overall, we identified 81 articles that met the inclusion criteria (see **Figure 3**).

Data Extraction

In a scoping review, data extraction follows a data charting process, which includes general information about the study such as the population, methods, design, and important results.[175] As scoping reviews identify and describe the available research and do not assess the quality of methods or evidence,[175] we focused on charting data for major study categories. Two primary coders reviewed the final set of articles (JT and LR) with assistance from a third coder (MD). The

reviewers abstracted descriptive information from each study and entered the determined information into an excel document that served as a tracking sheet (**Appendix B**).

Data Synthesis

As scoping review data charting processes can be edited post hoc,[175,176] we co-reviewed a sub-sample of the identified articles to ensure consensus as well as to expand and refine the data charting categories and ways of documenting relevant information. The reviewers resolved any inclusion and coding concerns in collaboration. The collected descriptive information included: health topics of focus, years of publication, study locations (e.g., Appalachian state and rurality), study populations (e.g., age or health status), methods and theories utilized by the researchers, and major study findings. The latter we categorized according to the social-ecological framework levels (e.g., individual, interpersonal, community, and societal factors), as scoping reviews require a framework or thematic construction to present the important results[175] and the social-ecological framework provides an established way to depict a variety of multilevel factors affecting health outcomes. We then reviewed these categorizations to assess the co-occurrence of codes across multiple levels within articles to further describe the interconnectedness of factors.

2.4 Results

Health Topics by Year

Overall, articles focused on cancer disparities (49.4%) with a particular focus on cervical cancer (27.2%).[46,47,50,121,122,124,126,129,130,134,135,168,180-188] Many of the remaining articles focused on cancer-related risk factors, such as Human Papillomavirus (HPV; 16.0%),[123,131,184,189-194] smoking (16.0%),[163,195-203] or prenatal or gynecologic care (23.5%).[38,199-201,203-218] See **Figure 4** for a summary of the reviewed health topics divided by decade of publication; these topics are not mutually exclusive, as one article may discuss multiple health topics. Only ten articles (12.3%) focused on other chronic diseases such as cardiovascular disease and diabetes,[11,23,25,136,167,216,219,220] while increasing numbers of more recent studies focus on mental health (8.6%),[40,41,202,209,214] substance use (7.4%),[36,37,218,221,222] and intimate partner violence (6.2%).[38,39,215]

Locations of Study

Figure 5 provides information on the geographical distribution of studies included in this review, including the percent of counties in each state that are economically distressed or at-risk of economic distress (data for fiscal year 2020, as the most up-to-date information at the time of publication) as determined by the county economic classification updated annually for monitoring by the ARC.[223] Many of the included studies take place in Central Appalachia, where economic disparities and inequities are even higher than other parts of the region, including portions of states like Kentucky (34, 42.0%),[44,45,131,135,183,191,224] Tennessee (18, 22.2%),[199,200,205,206,211] Ohio (15, 18.5%),[46,47,134,168] and West Virginia (13, 16.0%).[23,201,225] Notably, none of the identified articles

take place in Southern Appalachia (e.g., Mississippi, Alabama, Georgia, and South Carolina), and very few take place in Northern Appalachia, with none in New York or Maryland and a small number in Pennsylvania (4, 4.9%).[48,49] Several studies include multiple states, with five covering the entire region. Additionally, reflective of the rural character of the Appalachian region, a large proportion of the identified studies (33, 40.7%) include a focus on rurality either within the population of focus or in implications for consideration from study findings.

Populations of Study

The population characteristics of the studies disproportionately focused on women's health at certain stages of life. The majority focus on those of reproductive or middle age; 82.7% of studies (67 of 81) include women between age 18 and 55. As study recruitment populations may intersect multiple age categories, approximately half of the articles also include women of over age 55, including many that generally recruited women over age 18 (46, 56.8%). However, few identified studies include individuals under the age of 18 (6, 7.4%). Reflective of the health topics covered, nearly one-third of the articles have inclusion criteria focused on reproductive status (25, 30.9%) or cancer history (12, 14.8%). Additionally, those articles that disclose a racial or ethnic breakdown are majority white with a few including a specific income-based inclusion requirement (6, 7.4%).

Methods Used

Across the 81 reviewed studies, half of the authors used quantitative methods (40, 49.4%), and half used qualitative methods (41, 50.6%). Those who employed quantitative methods

primarily used survey collection (29) with significantly fewer using surveillance methods (6), medical chart reviews (5), intervention studies (4), and spatial analyses (2). Those who utilized qualitative methods primarily conducted interviews (35) with fewer using focus groups (11), ethnographic case studies (1), and story circles (1). Some authors employed a mixed method approach (7), and few authors explicitly mentioned the use of community-engaged approaches (3).

Theoretical Frameworks

Authors referenced a number of health theories with social and/or behavioral components to help explain the health patterns of women in Appalachia. These theories included: Health Belief Model (5),[164,165] Social Determinants of Health (5),[163] Transtheoretical Model (5),[135] the Social Ecological Model (2),[183] the Integrated Behavioral Model (2),[123] PRECEDE-PROCEED (2),[126] Self-Regulation Model (2),[182] and Theory of Planned Behavior (2).[131,191] A large portion of the studies (33, 40.7%) did not specify any theoretical framework.

Major Findings in the Social-Ecological Framework

We organized results into distinct levels according to the social-ecological framework, as the levels of influence in this framework align well with intervention implications. We summarized the combination of individual, interpersonal, community, and society-level factors related to health outcomes and behaviors for women in Appalachia that were addressed in the studies included in our analysis. **Figure 6** illustrates how these thematic findings and implications fit into the levels of the social-ecological framework.

Individual Level. Study findings identified individual-level factors for health outcomes and behaviors including: medical knowledge (e.g., causes of disease,[121] uncertainty of guidelines,[122] misinformation about disease[123,124]), attitudes/perceptions (e.g., need for privacy;[124-128] lack of perceived need;[127-130] emotional reaction, including fear, worry, and embarrassment,[46,126,128,130-132] lack of control over disease[131]) and skills (e.g., ability to manage and negotiate uncertainty[122]). In rural areas, some studies suggested that the desire to avoid having an acquaintance involved in health-related decision-making increases body discomfort and worry of stigma, supporting the elevated need for privacy.[125,133] Additionally, authors referenced the role of health literacy,[37] one's medical history (e.g., pregnancy outcomes,[38,204,212,217] substance use,[37,218,222] mental health,[41,202,215,226] chronic disease[23,219,220]), and identifying oneself as Appalachian[182] as important determinants of health behaviors and outcomes. Authors also referenced the role of an individual's financial and employment status,[38] which can affect access to insurance,[50] transportation,[11] and childcare.[123]

Interpersonal Level. Study findings described important figures in social networks, such as friends, family, or providers, who influence the health of women in Appalachia.[124] Authors cited provider recommendation and engagement;[46,125,133] as well as nuances of patient-provider interactions impacting trust and comfort, such as provider gender and communication method.[122,123,126,134] Study results also suggested that family history and previous disease experiences play a role in the health of women.[50,127,129] Over time, health experiences of family or friends may build-up an individual's fear or worry and, in aggregate, exacerbate lack of preventive behaviors at the familial or community level.[131] Study findings described women's familial roles, such as caretaking responsibilities,[222] relationship history,[37] and power in relationships[221] as factors

that impact health. For those of older age, authors suggested that social isolation may be a complex concept, where women may prefer to age in their homes even if it means geographic or social distance from others.[227] In addition, family and providers played an intersecting role in health; while family provided the origin of behaviors, providers influenced behavior in a more proximal manner.[50] Generally, study results suggested further research should investigate social factors and determine how social relationships interact with individual and community factors.[126,133,135]

Community & Societal Levels. The study findings also included several community-level challenges that prevent women from receiving healthcare, such as policies specifying the cost of procedures and follow-up,[46,50,124,126,130] access to insurance,[50,124] and access to transportation.[123,129] Health professional shortage areas and other effects of geographic isolation also affected whether women in the region receive healthcare;[136] study findings described factors like primary care physician to county population ratios that predict higher rates of adverse outcomes for women in the region.[137] Additionally, researchers noted the lack of specialized services for women, including those affecting oral[214,228] or mental health.[41,202,215,226] Beyond access-related challenges, authors noted quality of care available to women as an important consideration.[125,134,202,216] Broadly, authors noted policies and industries affecting availability of economic opportunities and community assets that relate to population health. In conjunction with availability of services and resources, study findings showed that high levels of religiosity[182,205,218] and cultural practices[131,220,229] serve as protective factors for health issues and help women combat historical trauma and stigma at a community-level.[36,183,222,230] When considering these higher level factors, authors recommended place-based interventions and programs that take into account local policies, assets, cultural beliefs, and community characteristics.[51,222,227,229]

Co-occurrence of Levels. Across the sample of articles, authors most commonly explored the intersection between individual-level behaviors, health outcomes, or decision-making and the interpersonal factors listed above (e.g., influences related to family, partners, and providers; 49.4% of articles). The connections among individual-level factors and community-level factors, particularly those related to access (e.g., cost, transportation, health professional shortages), were also regularly investigated (25.9% of articles). Though less often explored, a few authors connect the interpersonal and community-level factors, particularly when discussing the influence of social isolation or social capital on women's health.[14,222,231] Occasionally articles exploring the intersection of individual health and societal factors (e.g., social norms, religiosity, and policies; 11.1% of articles) also investigated how interpersonal interactions shape the norms[36,123,213] that influence health behaviors among Appalachian women.

2.5 Discussion

Many of the studies included in this analysis focused on prenatal care and cancer-related factors, which reflect the priorities and stories of early healthcare providers and researchers. With the establishment of the Appalachian Leadership Initiative on Cancer (1992-2000), which led to the Appalachian Community Cancer Network, funding for cancer-related disparities research has greatly increased.[33-35] This increased support for cancer research is particularly applicable for cervical, colorectal, and lung cancers, cancers from which Appalachian population suffer disproportionately compared with non-Appalachian populations.[2,9] Research on substance use,

intimate partner violence (IPV), and mental health has increased in recent years, which could reflect increased prevalence and awareness of the conditions leading to enhanced national funding priorities and growing interest in "diseases of despair."[172,173] However, mortality in the region has diverged from national averages before, and outside of, the opioid epidemic,[2] which calls for additional research to more broadly understand health inequities affecting Appalachian women. Aside from studies on common risk factors associated with cancer (e.g., smoking), sparse research efforts have focused on other types of chronic disease, aging, and sexual health (e.g., menstruation, sexually transmitted infections, menopause).

Many health inequities exist between Appalachian and non-Appalachian portions of states across the region; therefore, researchers need to focus future work in Northern and Southern Appalachia to understand regional variation, as levels of rurality, types of economies, and demographic factors vary considerably across these subregions. However, given greater socioeconomic disparities and health inequities, greater research attention also should be paid to women's health in Central Appalachia. Additionally, as the study populations primarily consist of white women of reproductive or middle age, other subpopulations are underrepresented, involving both younger and older adults, racial/ethnic minorities, and sexual and gender identity minorities. The intersection of these characteristics is almost entirely absent from the review and represents an important area for future research.

The nearly exclusive use of survey and interview methods used in the reviewed articles leaves room for other research approaches. Research would be strengthened by the use of epidemiologic surveillance, chart reviews, or spatial analyses capable of capturing larger, quantitative trends for the women's health in the region. Additionally, while researchers may be

concerned about privacy among participants in group-oriented methods, focus groups and other methods that build on culturally relevant practices, such as story circles, may provide novel insights. Mixed methods also provide an ideal way to capture a combination of depth and breadth of health trends among women in the region, including the complexity of factors informing multilevel interventions, but have rarely been used in research focused on women in Appalachia. Finally, few articles discuss the importance of community-engaged research throughout the region. As residents of the region may mistrust outsiders, including health care providers,[125,148] researchers would benefit from employing community-engaged methods, which build trust, demonstrate non-judgmental and respectful knowledge of Appalachian lifestyles, and foster more nuanced understanding of participants' lives.[148]

The use of social and behavioral theories in the reviewed articles helps to ground their determined multilevel factors. However, currently, no specific theoretical frameworks exist that describe the complex interplay of multilevel factors contributing to health outcomes among women in Appalachia. Findings from the reviewed studies discuss how policies and social structures, such as those that affect access and quality of care as well as economic opportunities, can influence individual-level knowledge, attitudes, and financial status as well as interpersonal-level provider relationships and family roles. Considering the role of cultural practices and community assets is critical when addressing population health, including understanding power in relationships, attitudes toward aging in place, and ways to facilitate the inclusion of women in determining their own health priorities and needs. Together, the current literature elucidates how individual, interpersonal, community, sociocultural, and biological experiences influence health outcomes; however, most studies focus on a single level without exploring the co-occurrence of

multilevel factors. As a consequence, little is known about the extent to which factors across levels impact and interact with one another or the primary determinants that contribute to health inequities. Researchers should endeavor to include theory development and use available theories in future works to better inform women's health in this region.

As this is a rapid scoping review, more extensive studies could use more refined or expanded search terms or review additional databases, which could capture a more comprehensive array of research. Additionally, as this is a scoping review, we did not assess data or methodological quality;[175] however, such results can guide future systematic reviews by providing ideas for more refined, specific searches in which data quality can be analyzed. By limiting our search terms to include women or female participants, we may have excluded some studies focused on Appalachia that included a majority but not exclusively female population or conducted sub-analyses for women. We also acknowledge that our inclusion of the regional name 'Appalachia' may have excluded certain studies that could contain relevant information. However, we feel confident in the ability of our current inclusion to assess relevant trends, as the studies of focus include those specifically interested in the health of those in the Appalachian region. Based on available funding and research priorities across universities in and around the Appalachian region, our findings include, in part, articles from specific, productive research teams; however, these researchers span a variety of content areas and states in the region and do not dominate any one area in our findings. We also recognize that many of the health issues as well as barriers and facilitators to healthcare presented here also apply to men in the region; future work should seek to understand sex and gender-based differences on the variety of health burdens in the Appalachian region to determine how these differences can guide the development and implementation of future

research, interventions, and programs. Finally, the addition of dissertations, conference abstracts, or other types of work may have provided additional information and can be explored in future works.

2.6 Conclusion

These results present the state of research on the health of women in Appalachia by describing what has been studied over the past two decades and by identifying gaps for future public health research. We highlight health topics in need of further exploration, population characteristics (e.g., needs among youth/aging, race/ethnicity, gender identity, sexual orientation) to be included in future works, and ways to build theoretical frameworks and methodological approaches intended for this population. We discuss regional variation, including the need for more research throughout the subregions of Appalachia, and the need for broader, more cohesive and comprehensive representation of the needs of this population in the literature. We believe that future studies can improve upon what is known about the health of Appalachian women in a number of ways. First, due to excessive health burdens and underrepresentation in existing research, researchers can seek to ensure inclusion of Appalachian women to address current systemic biases. Second, the findings from this review show how factors affecting Appalachian women across health topic span multiple levels of the social-ecological framework; however, our review demonstrated a limited use of theoretically grounded and methodologically rigorous studies. Such studies are needed that can account for complex interactions of these factors. Third,

our review demonstrated the limited use of community-engaged research, an omission due to the influential role of community-level factors (e.g., cultural practices and assets) on health. To address this deficit, researchers can seek to build upon existing community resources to improve health in this vulnerable population and use community-engaged approaches to guide development of needed programs and services, future research, and a more holistic view of women's health in the region.

2.7 Acknowledgements

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2.8 Figures

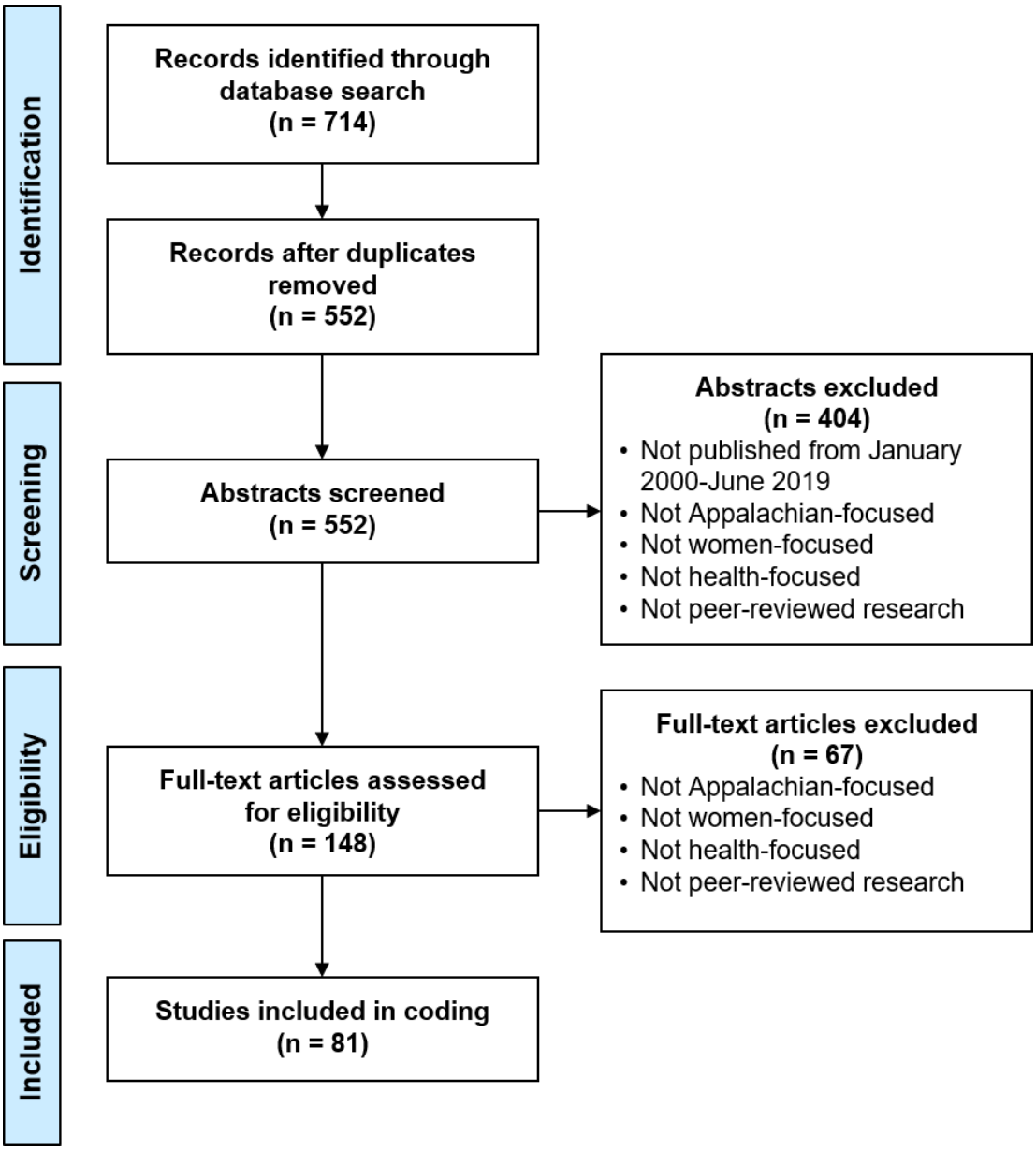

Figure 3. PRISMA Flowchart for Review of Research Articles on the Health of Women in Appalachia from January 2000 to June 2019.

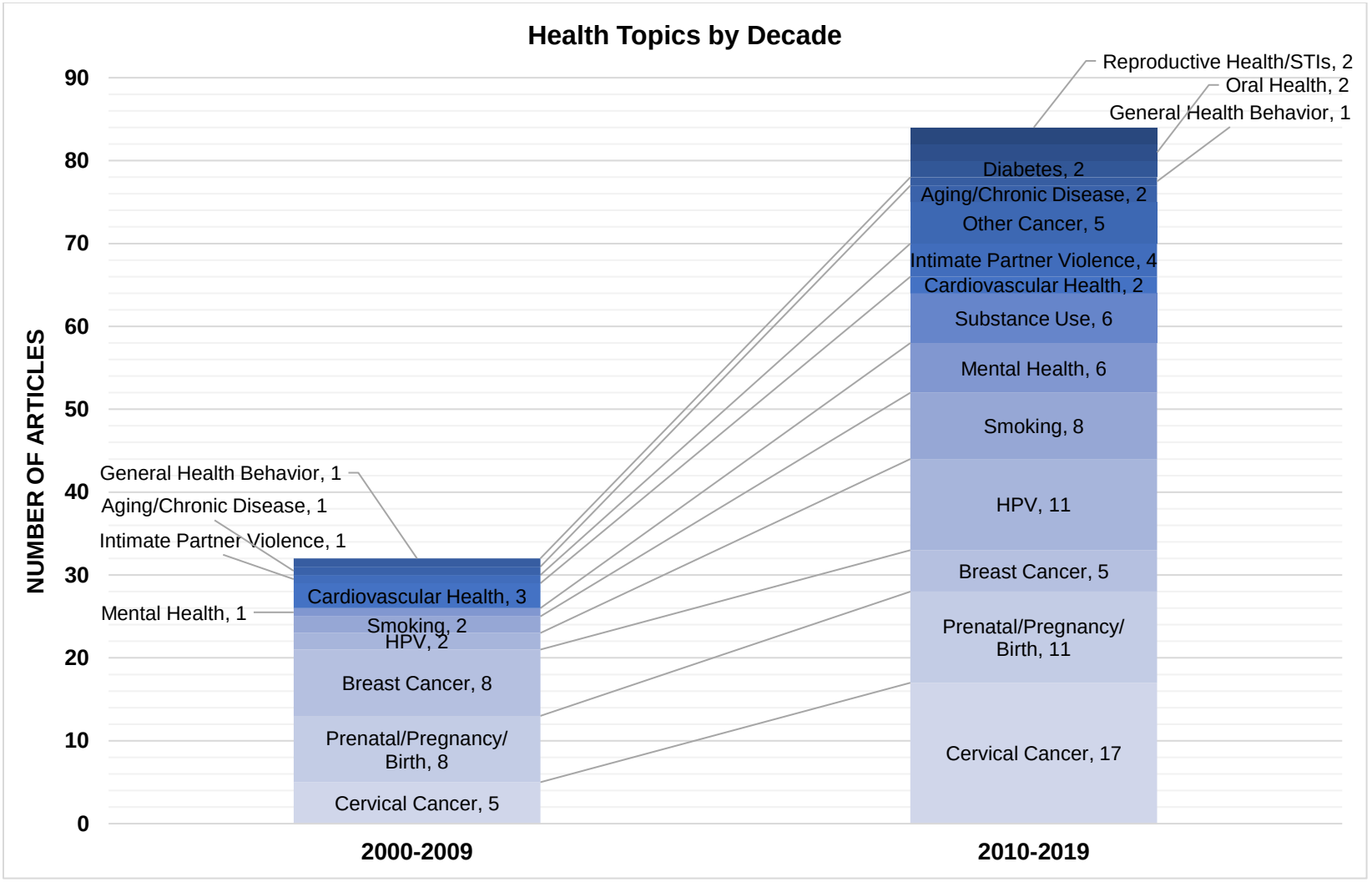

Figure 4. Bar Graph by Decade of the Health Topics Covered in the Articles.

(Note: Categories are not mutually exclusive.)

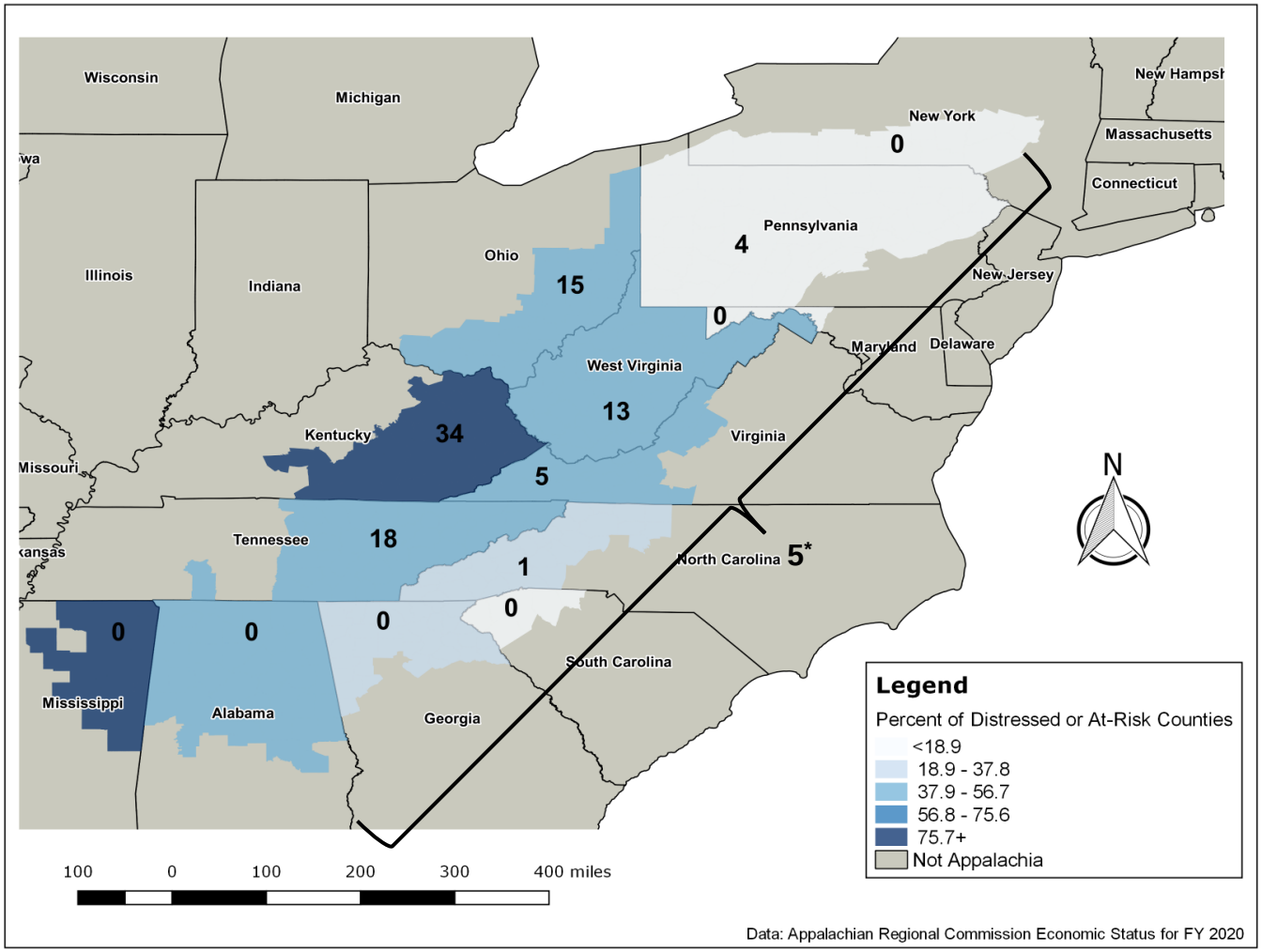

Figure 5. Map of the Study Locations in Appalachian States with Percent of Economically Distressed or At-Risk Counties.

(Note: Locations are not mutually exclusive. *Five studies take place across the entire region.)

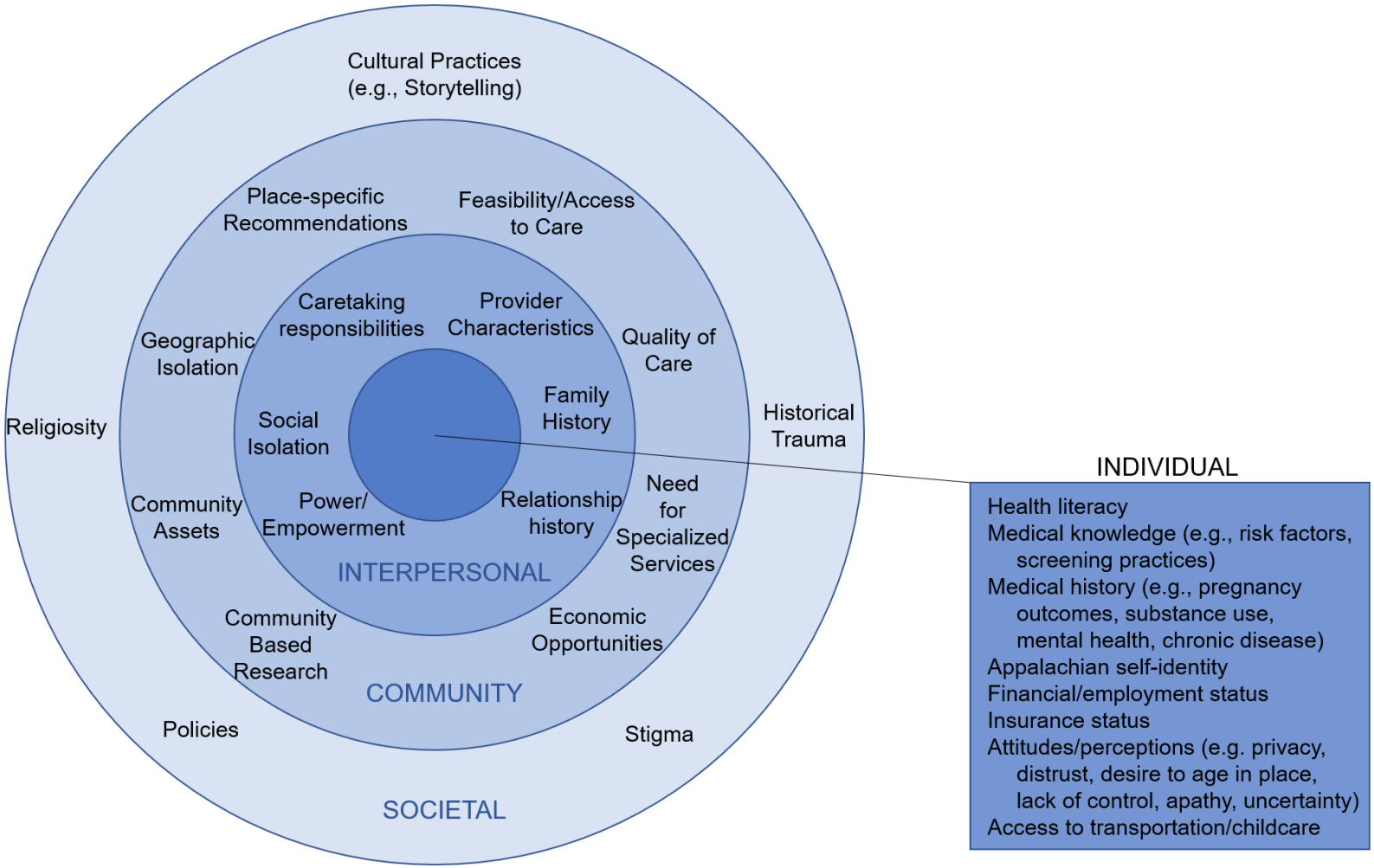

Figure 6. Summary of Included Articles' Factors Related to Women's Health in the Appalachian Region Organized Across the Social-Ecological Levels

3.0 Research Methods

3.1 Overall Methodological Approach

Based on the review of existing literature (Chapter 2) and an understanding of the broader state of research on the health of Appalachian women, there are several research gaps in need of further study: 1) location of the research including variations across regional areas such as Northern Appalachia, where a current lack of studies exists; 2) the role of social and contextual factors in CVD prevention, particularly due to the dearth of literature on factors related to CVD and related risk factors among this population; 3) how these social and contextual factors affect decision-making across preventive behaviors and screening types; and 4) the use of methods largely missing from the literature, such as mixed methods, community-engaged research, and systems science approaches, that include social and contextual components to build a framework for future research.

Systems Science

While the social-ecological approach in health behavior research, which suggests that a range of factors at multiple levels of influence interact and affect the health behaviors of individuals, is now widely accepted in health promotion,[232] the most potentially successful public health interventions based on this approach are not always apparent.[233] Despite growing use of systems science within public health, researchers continue to depend upon reductionist statistical models to assess cause and effect relationships between influencing factors and health behaviors.[234] Unfortunately, in the process of creating these models, researchers may fail to capture

the contexts within which health behaviors exist,[235] a necessity to understand potential interventions to increase CVD prevention.

In general, systems science refers to a range of tools and methods that allow for the study of complex systems, which have been developed and applied across a variety of disciplines. Systems thinking, which informs systems science approaches, has roots in disciplines such as biology, physics, psychology, management, and computer science and is often advocated for as an approach to encourage the consideration of systems in a variety of contexts, even without proceeding to a quantified simulation model.[236] Utilizing this type of approach may include the use of systems science methods (e.g., network analysis, system dynamics, or agent-based models) or, less formally, researchers from multiple disciplines and/or stakeholders in communities working together to address systemic issues. Using systems thinking processes to guide research can help to make assumptions explicit, raise new hypotheses, and generate large-scale solutions to contextually-driven health issues,[237,238] a valuable approach when complex, multilevel factors combine together to affect the CV health among Appalachian women.

Community-Engaged Research

Community-engagement in research varies based on study aims and design, where engagement may fall along a continuum spanning from community involvement to collaboration to fully shared leadership.[239] Community-Based Participatory Research (CBPR) is an approach at the far end of this spectrum, where community partners have an equal role to researchers in every step of the research process.[240,241] The strengths of a CBPR approach lie in its ability to promote capacity building, bi-directional leadership, and decision-making in communities that may not have historically had power or a voice on important issues.[242] This study falls in the area of

collaboration along the community-engagement spectrum. While initially seeking to carry out a CBPR approach, a combination of factors, including the amount of time to build partnership infrastructure and timely changes necessary due to the COVID-19 pandemic, led the study team to include community voices in the study design, data collection, and dissemination as much as possible, though falling short of fully shared partnership. Community partners who collaborated in and contributed to this study include: the PA Department of Health, Primary Health Network, Lawrence County YMCA, Susan G. Komen of Greater PA, as well as other local clinics and community sites. The use of concept mapping, as a participatory method capable of contributing helpful community insights across the community-engagement spectrum, further increases community participation in the study and grounds results in the perceptions and realities of community members.[243]

Mixed Methods

Mixed methods research involves the use of quantitative and qualitative methods, which permits researchers to assess the magnitude or frequency of constructs while also exploring meaning and understanding among study participants.[244,245] Pairing quantitative and qualitative elements allows researchers to draw on the strengths of each approach, to explore multilevel perspectives, and to study phenomena from both a deductive and an inductive view.[244] Typically, mixed method designs fall into one of three categories: exploratory sequential (i.e., collecting qualitative data to inform quantitative study), explanatory sequential (i.e., collecting quantitative data to be explored in more depth in qualitative elements), and convergent/parallel (both quantitative and qualitative elements conducted concurrently).[246] More recently, fully integrated designs have emerged as a fourth type of mixed method approach, where the quantitative and

qualitative elements interact with each other throughout the study, and the order of use will depend on the evolution of the research.[247,248]

This novel study uses methods in a nested approach, where a convergent mixed method (concept mapping) is paired with another quantitative method (spatial analysis); as the spatial analysis component precedes the concept mapping elements, the larger study most closely follows an explanatory sequential design. Explanatory sequential designs have often been criticized for underutilized or devaluing the qualitative elements, and in many cases, qualitative methods, most often interviews, are viewed as an afterthought to clarify the primary quantitative analysis.[248] By using a participatory method bearing equal weight to the quantitative component, this study is able to ensure that both elements build upon the strengths of the other. Additionally, the concept mapping results provide information for future exploration using both quantitative and qualitative methods, and as future steps are taken, this study may develop into a fully integrated design.

Selection of Methods

Mixed method approaches can generate essential community-specific results for future action. As tools in systems science, spatial analysis and concept mapping enable researchers to map existing systems and to understand the barriers and facilitators to large-scale change.[249] As geography plays a role in resource availability and subsequent receipt of screening,[137] spatial analysis provides a valuable lens to CVD prevention in a place-specific manner;[51] maps in the spatial analysis processes also provide useful representations of community assets and identify areas for community-specific interventions. These maps are helpful in the dissemination process to characterize the relationship between health outcomes and resource measures and to serve as a visual guide for probing community-specific questions. This process aligns well with the goals of

asset mapping, a community-engaged approach to work with community members to create and interpret maps to identify patterns within the community for programmatic or policy solutions that takes into consideration the assets of the given community.[250]

As a complement to CBPR, community-engaged research, and utilization-focused approaches, concept mapping allows researchers to visualize, analyze, and interpret factors in clusters and to uncover how they operate in complex networks.[249] Concept mapping is an intensive, structured conceptualization process that produces a framework for how a group views a specified topic; this participatory research method was introduced to public health researchers by Burke et al.[251] and has been used to address a range of complex health topics,[239] including women's perceptions of chronic disease prevention and screenings. The participatory elements also ensure community engagement in each step of the concept mapping process and improve feasibility and sustainability of resulting community-specific programs and interventions.[252]

Mixed methods allow researchers to develop studies to address public health issues, such as population-level disparities, behavioral health factors, poor adherence to treatment and recommendations, and translational health research.[253] By combining spatial analysis with concept mapping, study findings can provide depth and breadth of complex health issues in a visual and action-oriented manner to address inequities, such as those in CVD health for high-risk populations. While previously paired with qualitative methods,[254] the combination of spatial analysis with the structured method of concept mapping is unique. This method pairing provides a novel platform to uncover interconnections between personal characteristics and social and built environment factors to develop a needed comprehensive conceptual framework for addressing CVD inequities among rural Appalachian women in PA and across the region.

3.2 Overall Location of Research: Northern Appalachia

Much of the existing Appalachian health research takes place in Central Appalachia with less attention given to the Northern Appalachian region, including the 52 Appalachian counties in PA. The Appalachian PA counties mirror larger regional socioeconomic disparities and population trends. For example, if one considers the rural Appalachian PA counties of Fayette and Lawrence, both counties have high poverty rates (14.7% and 15.8% in 2018, respectively; comparatively, the U.S. rate was 11.8%), average incomes below the national average (73.8% and 81.0%, respectively), and declining populations (e.g., Lawrence had a -6.2% population change from 2010 to 2019).[4,5,255-257] In addition, these counties have alarming rates of CVD mortality when compared to the 2018 national rate of 422 per 100,000 individuals;[256,258] again, Fayette leads the way with a rate of 558.5 per 100,000 followed by Lawrence at 489.4 per 100,000 individuals.[256,259] Of the 52 Appalachian counties in PA, 46 have a rural designation; these 46 counties are the focus for the aims of this study due to the disparities found in the rural areas of the region.[4-8] The number of persons per square mile and the per capita income in the region is similar to that of the entire Appalachian region (158 vs. 123 and $42,595 vs. $37,260, respectively).[260] As with the larger region, access to health resources remains an issue connected to health outcomes. For example, despite the presence of major health care facilities available an hour away in Allegheny County, Greene County has just 46 physicians per 100,000 residents (the state average is 297) and ranks 66th of the 67 PA counties in health outcomes.[261]

3.3 Approach & Study Aims

This dissertation employed a mixed method approach to identify the individual, social, and environmental factors that inform CVD prevention among rural Appalachian PA women.[124,126] Based in the reciprocal determinism facet of Social Cognitive Theory (SCT),[166] personal characteristics (e.g., income, education, and perceptions) have a bidirectional influence with the built and social environment to shape behavior. **Figure 7** shows the overarching theoretical framework, based on reciprocal determinism,[166] combining personal factors (e.g., characteristics and perceptions), environment (e.g., medical and preventative resources), and behavior (e.g.,

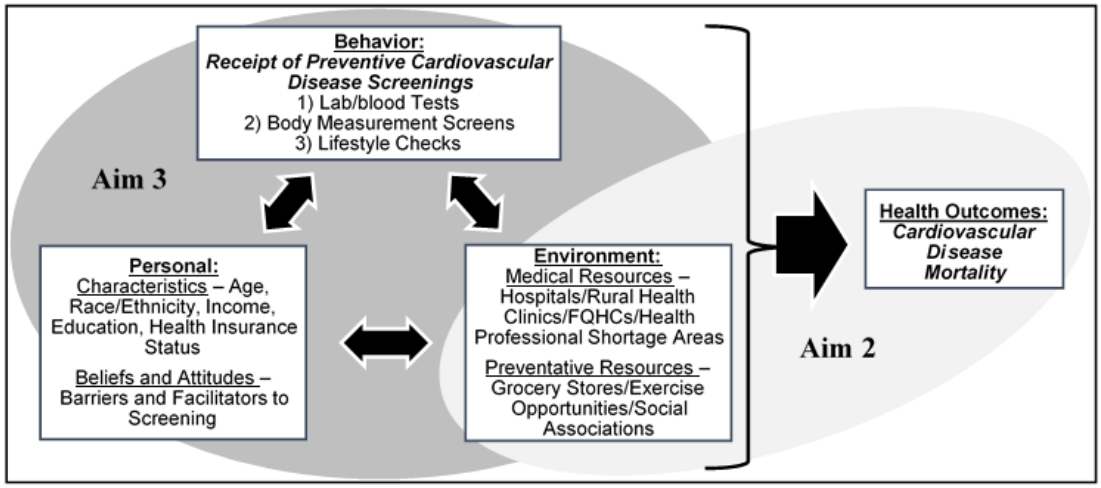

Figure 7. Reciprocal Determinism of Preventive CVD Screenings by Appalachian Women

receipt of preventive CVD screenings) for rural Appalachian women. The corresponding aims are also identified. Through these aims, this dissertation contributes to the literature to uncover which factors affect CVD prevention and how these factors interact or reinforce individual decision-making. The spatial analyses inform how geographic variation in CVD mortality relates to other patterns found at an environment level (Aim 2; Paper 2);[262] the concept mapping aim identifies community perceptions of relevant barriers and facilitators, including environmental factors

explored in the spatial analyses as well as social and individual characteristics, beliefs, attitudes, and behaviors that affect CVD prevention and influence CVD health outcomes (Aim 3; Paper 3).

3.4 Study Population & Recruitment

The study area of this dissertation encompassed the rural counties of the Northern Appalachian region of PA (spatial analyses) and three purposively sampled county-level case communities in that region (concept mapping sessions). Geographic information system (GIS) mapping and spatial analyses with secondary data were conducted to assess the spatial clustering of resource distribution alongside other socioeconomic predictors of resource patterns. Using these spatial analyses, three rural Appalachian PA counties with varying associations between resource levels and health outcomes were selected for concept mapping. The selected counties were located in Western PA for proximity to the study team and included: Butler County, Fayette County, and Lawrence County. In each selected county, a convenience sample of participants (total of N=71) was recruited. The overall study sample design is in **Figure 8**.

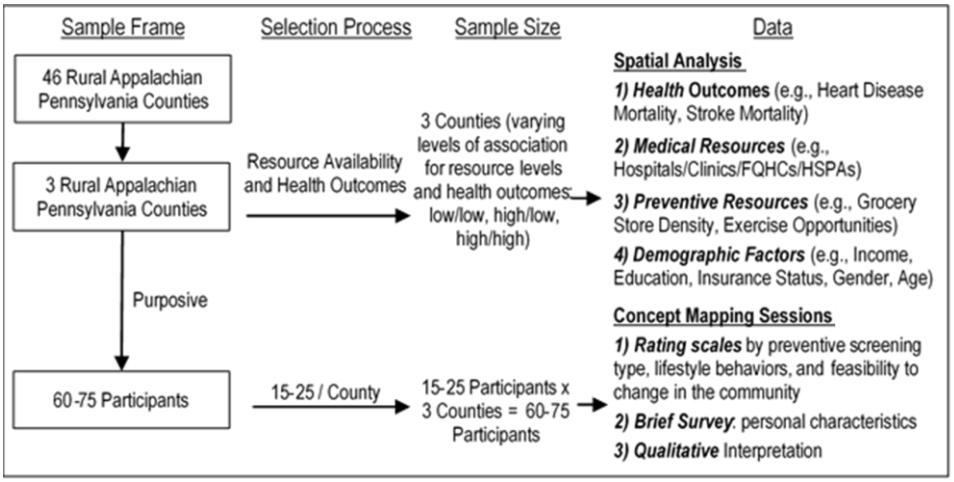

Figure 8. Sampling Frame, Data Collection, and Study Aims

Given restrictions and safety concerns from the COVID-19 pandemic, all recruitment and data collection occurred in an online format. We used three different online recruitment strategies to identify eligible participants. First, the study team utilized the University of Pittsburgh Clinical and Translational Science Institute Pitt+Me recruitment service available to Pitt faculty, staff, and students. This large registry of potential research participants has over 250,000 registrants, including more than 65,000 individuals in counties throughout Western and Central Pennsylvania. Pitt+Me staff identified and referred participants meeting the eligibility requirements to the study team. Second, we used a method employed by colleagues in the Department of Behavioral and Community Health Sciences for online social media recruitment through targeted ad placements on popular sites such as Facebook and Instagram, utilizing the Center for Social Dynamics and Community Health social media pages. These ads were specifically targeted for age, gender, and geographic location to reach potentially eligible participants; interested individuals clicked on provided links to learn more about the study and to communicate with the study team (**Appendix C**). Third, using a process successfully employed in work by Dr. Burke and colleagues, we identified participants through contacting relevant local organizations directly (e.g., clinics, community centers, local non-profit organizations) via existing community connections and internet keyword searches. We contacted and met with leaders of these organizations (e.g., Susan G. Komen Greater PA, Primary Health Network, Lawrence County YMCA, Cornerstone Care); the organization leaders shared recruitment materials to identify additional participants.

Participant eligibility included: 1) English-speaking; 2) female; 3) age 40-64 [target range for CVD screening programs[17]]; and 4) have lived in the case county (Butler, Fayette, or Lawrence) for ≥2 years. Participants also had to express willingness and ability to participate. At enrollment,

the study team collected contact information (e.g., email address, phone number) for each participant and obtained consent prior to data collection activities. The study team established a study phone number and email to facilitate communication between the Pittsburgh-based study staff and participants. All procedures were approved as an expedited study by the University of Pittsburgh IRB (#STUDY200550165).

3.5 Analysis Strategy

Aim 2: Spatial Analysis

As geography plays a role in resource availability and subsequent receipt of screening,[137] spatial analysis provides a valuable lens to CVD screening intervention in a place-specific manner.[51] Geographic information system (GIS) mapping and spatial analysis were conducted with secondary data from publicly available sources, such as the PA Department of Health, U.S. Census (FactFinder),[263] Robert Wood Johnson County Health Rankings,[264] Western PA Data Center,[265] PA Cancer Atlas,[266] and PA Spatial Data Access site.[267] The spatial clustering of socioeconomic predictors and resource patterns were also assessed along with interactions between these factors and CVD outcomes. See **Appendix D** for a list of measures and sources.

First, QGIS, a free and open-source geographic information system software package, was utilized to create maps for: 1) the health outcome measures, 2) the medical resource measures, 3) the preventive resource measures, 4) overlaying health outcomes and resources, and 5) the interaction of various risk factors, morbidities, socioeconomic factors, and demographic with the health outcome and resource measures. Next, using GeoDa, free and open-source spatial analysis software, Exploratory Spatial Data Analysis (ESDA) was conducted to visualize relationships

between health outcomes (e.g., CVD mortality) and resource measures by identifying patterns, clusters, and hotspots. County-level population demographics (e.g., median household income) and resource measures (e.g., medical resources, such as density of medical facilities, and preventive resources, such as healthy food retailer density) were also included; these data were used to assess Moran's I statistics of global spatial autocorrelation to determine spatial variation across the Appalachian PA region. Then, Local Indicators of Spatial Association (LISA) were used to determine local spatial patterning and to identify local clusters and hotspots for the health outcome and resource measures. Finally, multilevel linear regression analysis was used to determine which factors drive the relationship between resource measures and the cardiovascular health outcomes. The determination of these predictors shed light on which factors to prioritize in intervention efforts for women in rural Appalachian PA and were probed for in the concept mapping sessions.

With these calculations, the study team identified three counties (Butler, Fayette, and Lawrence) with distinctly differing patterns of resources and health outcomes (**Appendix E**). Fayette County has a relatively low median household income, moderate levels of preventive resources, and consistently poor health indicators compared to the larger Appalachian PA region, including the highest CVD mortality rates. Similarly, Lawrence County has a relatively low median household income and even lower levels of resources compared to Fayette County, but the county has performed better on health outcome measures, including CVD mortality, though these rates have been worsening in recent years. Butler County has the highest median income and levels of resources of the three counties, and though the county has higher CVD mortality rates than expected, these have been improving. Although all three counties are categorized as rural by the

state of PA metrics, these counties also represent different characteristics across the urban-rural continuum, with Butler as the most urban and Lawrence as the most rural.

Aim 3: Concept Mapping

As a participatory approach, concept mapping builds upon other qualitative methods widely used in community-engaged research and CBPR approaches by adding intentional participatory elements and an increased depth of data collection through built-in quantitative components. Outlined by Trochim and elaborated in subsequent works, concept mapping is centered around a focal question, which shapes the remaining steps with the data collection and analysis occurring over multiple sessions.[239,251,268] The study team conducted three sequential sessions for each county. As these sessions occur in a specific order, there were some longitudinal aspects to concept mapping data collection, but all participants did not have to participate in every element, as the goal is to reach group consensus on an identified topic. Including regular reminders to maximize participation, online concept mapping software created by Concept Systems, Inc.[269] was used to collect data from all participants (N=71), including demographic questions (e.g., age, income, insurance status).

Brainstorming (Session 1) involved participants generating a list of responses to the focal question: *What are all the factors, good or bad, that affect the cardiovascular (heart) health of women in your community?* The study team included probes to explore multiple levels covering individual, social, and environmental items. We compiled data from the brainstorming sessions for all three counties into a single master item list. This approach is consistent with Burke et. al.'s prior concept mapping research exploring context and women's health issues in multiple settings.[251,270-272] The participants then carried out a sorting and rating process of the master list

items (Session 2) using the online concept mapping software. The pile sorting process involved each participant grouping the items and labeling each pile. The rating process used Likert-type questions and asks participants to rate each factor on the three following scales: a) importance for receiving *preventive health screenings* (e.g., cholesterol, blood sugar, blood pressure); b) importance for *lifestyle behaviors* (e.g., smoking, diet, physical activity) and c) *likelihood for intervention opportunity in this community*.

The study team combined data from the sorting and rating sessions to analyze prior to the third session. We used non-metric multidimensional scaling, which uses similarity matrices, to create a spatial point map displaying the relative distances between the items representing perceived similarities and differences.[268] We included stress values for these point maps to reflect stability, which for 95% of concept mapping projects range from .205 to .365.[268] We then used hierarchical cluster analysis, based on the minimization of the sum of squares of the distances between all items, to create a cluster map illustrating group consensus regarding item categories.[268] The study team used the item ratings data to examine pattern matches for clusters and "Go Zone" bi-variate plots of individual items to see variation across each rating scale and, subsequently, to show if participants rate the clusters or items differently across rating scales; we displayed correlational values (r) for each direct comparison. The design of this three-county concept mapping study also allowed for the exploration of similarities and differences across counties and by participant demographic characteristics (e.g., age, income-level).

Finally, the study team brought these data to the participants for qualitative data interpretation (Session 3). These sessions typically follow the general structure of a focus group discussion, where participants view representative maps and patterns in a guided discussion to ensure contextually-specific and community-driven feedback of the results. We made adjustments

to increase safety from the COVID-19 pandemic by collecting all these data remotely. At the end of Session 2, the study team asked participants if they were interested in seeing the resulting data and participating in a discussion. We reached out to a sub-sample of participants from all three counties (N=16) to conduct group discussions. The discussion groups took place over Zoom, which allowed for sharing visual concept maps for discussion. In case participants did not have this technology available to them, we allowed phone participation and shared the results through an email.

During these conversations, the study team paid specific attention to exploring intervention opportunities and engaged participants in a discussion of existing community resources, including feedback for how to effectively implement associated intervention opportunities. In this way, the participatory aspect of concept mapping ensured that resulting programmatic, intervention, and policy-level recommendations remain grounded in community-specific needs and solutions. We also audio-recorded these discussions for qualitative analysis. We utilized a combination of approaches for the analysis of this data; we included thematic codes found in the scoping review and spatial analyses in order to cross-reference and explore the depth of results, and through a grounded theory approach, we used inductive content analysis to discover emerging themes;[169,170] Two independent coders conducted these analysis using NVivo 12; resulting themes were represented by illustrative quotes to capture participant language.

4.0 The Role of Place in Heart Health: Spatial Relationships of Resources and Cardiovascular Mortality for Women in Appalachian Pennsylvania

4.1 Abstract

Women living in Appalachian counties experience high mortality from cardiovascular disease (CVD), and CVD accounts for the largest portion of the gap in life expectancy between Appalachian women and women outside the region. This study aims to assess the association of county-level resource distribution, including medical resources, preventive resources, and socioeconomic factors, with CVD mortality for women in Appalachian Pennsylvania (PA) counties. Using publicly available data from 2011 to 2015, we conducted geographic information system (GIS) mapping to explore spatial clustering of medical and preventive resources with CVD mortality rates among women age 35 and over in the 52 Appalachian PA counties. We analyzed relationships between resources, socioeconomic factors, and CVD mortality among women in the region using multilevel linear regression. Using exploratory spatial data analysis (ESDA), we identified significant spatial autocorrelation of CVD mortality rates and resource variables, along with three regional clusters. Lower income, lower recreation facility density, and higher rates for CVD mortality in surrounding counties were associated with increased risk for CVD mortality among women in Appalachian PA. These findings suggest increasing access to recreation facilities and developing ways to overcome income-related barriers to cardiovascular health (e.g., healthcare costs, low-cost recreation facilities) among Appalachian women may help contribute to reducing CVD mortality rates between this population and those outside of the region.

4.2 Introduction

Women living in Appalachian counties of the U.S. experience high mortality from cardiovascular disease (CVD), prompting the need for further exploration of the factors driving this regional health disparity. The Appalachian region consists of 420 counties in 13 states, including 52 counties in Pennsylvania (PA); 42% of Appalachia is rural, compared to 20% of the rest of the US population.[3] Residents experience higher poverty rates[4-6] along with lower levels of educational attainment and higher levels of unemployment than national averages.[7,8] Reflected in the regional socioeconomic disparities, premature mortality rates are 25 percent higher in Appalachia than for all US counties.[1,2] Likewise, Appalachian populations have the most significant excesses, compared to national averages, in heart disease mortality.[9] Heart disease mortality is 17% higher than the US rate, which is mirrored by higher stroke mortality rates (14%) and CVD risk factors such as diabetes prevalence (11.9%), physical inactivity (5.3%), and smoking (3.7%).[2] Disparities also exist for the rural residents of the region, resulting in 40% higher premature mortality rates than their urban counterparts.[2]

Sex-specific risks emphasize the need for informing CVD prevention among women, particularly in Appalachia. Overall, heart disease is the leading cause of death for women in the US, and 65% of cases in women are asymptomatic.[10] Women have increased morbidity and mortality from CVD related events and are less likely to receive aggressive or invasive treatment.[11] Appalachian counties have high heart disease-related death rates for women,[12] and CVD accounts for the largest portion of the gap in life expectancy at birth between Appalachian women and U.S. women living outside the region.[13] High proportions of Appalachian women have uncontrolled CVD risk factors, such as hypertension and diabetes,[10,11,18] and four out of five women of reproductive age (age 18-44) have at least one risk factor for CVD.[20] Evidence suggests rural

Appalachian women are aware of CVD risks but may not act due to a complex combination of individual, social, and environmental factors, which may limit participation in prevention or screening recommendations.[23,25,224,273] A contextually-based approach to reducing CVD risks, which assesses place-based assets and barriers, can widen the prevention scope from individual lifestyle changes to include external factors.[11,167,274,275] Further research is needed to uncover which of these social and environmental factors contribute to reduced CVD prevention and, subsequently, health disparities for Appalachian women.

Previous studies of social and built environment factors demonstrate a strong spatial association between CVD mortality and markers of social deprivation such as poverty and social isolation.[101] Social cohesion, neighborhood identity, and stigmatization have also been linked to cardiovascular (CV) health.[102-104] The pathways through which social environment factors operate are less clear but likely include mechanisms such as resource cost, availability, transportation, and healthcare access. Additionally, studies show complicated interactions between health access and socioeconomic status, emphasizing access as a multi-dimensional construct.[105] County-level analyses across geographic regions in the US also show rates of improvement in CVD mortality lagging in low-income communities.[106] Much of the literature on the effects of the built environment on health, including those that affect CVD, focuses on urban communities; however, across the rural-urban continuum, factors such as crime rate, income inequality, and race play a role in cardiac and obesity risk among low-income women.[107,108] Studies assessing rurality through land use found that women living in an area of low land use mix (i.e., more rural communities) have a 19% greater 10-year risk for CVD than those in high land use mix areas (i.e., more urban communities).[107]

Studies not explicitly focused on the health of women show mixed results for the roles of factors in the physical activity or food environments on CV-related health outcomes. Several studies have noted a significant negative relationship between the number of facilities and physical environment characteristics (e.g., walkability, traffic) with BMI and CHD risk.[107,109-111] In the food environment, factors, such as fast food density and presence of full-service grocery stores, show less conclusive results, which may be related to complex interactions of cost, food quality, convenience/access challenges, as well as nutritional value or portion sizes;[107,118] however, national survey measures have shown a significant relationship between food insecurity and risk for diabetes, hypertension, and higher odds of 10-year CVD risk, with particularly consistent and strong associations among females.[119,120] Overall, these factors create vulnerabilities in populations through increasing stress and reducing food, exercise, and health resource access.[69] As geography plays a role in resource availability and subsequent preventive measures,[137] spatial analysis provides a valuable lens to CVD screening intervention in a place-specific manner[51] and enables researchers to map existing system configurations and to better understand barriers and facilitators to large-scale change.[249]

In the Appalachian region, spatial analysis studies have examined socioeconomic status,[276] neighborhood disadvantage with the food environment,[277] and racial disparities within CV health;[278] however, to date, studies have not explored built environment factors with CVD mortality among women. The aim of this study is to assess the association of county-level resource distribution, including medical resources (e.g., hospitals, rural health clinics), preventive resources (e.g., food and recreation environments), and socioeconomic factors, with CVD mortality for women in the Appalachian counties of PA.

4.3 Methods

We used geographic information system (GIS) visualization techniques to generate maps and conducted spatial analyses to assess the spatial clustering of CVD health outcomes and medical (e.g., hospital/clinic locations) and preventive (e.g., healthy food retailer density, exercise opportunities) resources for women in the Appalachian counties of PA. We also analyzed relationships between resources, socioeconomic factors, and CVD mortality among women in the region using multilevel linear regression.

Study Population

We included all 52 Appalachian counties in PA, excluding the 15 non-Appalachian counties located in the southeast corner of the state. According to definitions utilized by the PA state legislature, 46 of these 52 Appalachian counties have a rural designation.[279] The number of persons per square mile and the per capita income in the 52 counties is similar to that of the entire Appalachian Region (158 vs. 123 and $42,595 vs. $37,260, respectively).[260]

Variables

We collated secondary data from publicly available sources to create county-level indicators of CVD mortality rates among women, medical resources, preventive resources (e.g., food, exercise environments), and socioeconomic factors.[263]

CVD Mortality. We included the combined CVD mortality rates for women age 35+ from 2011 to 2015. We used data from the National Center for Health Statistics through ICD-10 codes.[256] These codes included: heart disease (I00-I09, I11, I13, I20-I51; underlying cause of death); coronary heart disease: (I20-I25; underlying cause of death); acute myocardial infarction

(I21-I22; underlying cause of death), cardiac dysrhythmia (I47-I49; underlying cause of death); heart failure (I50; deaths with heart failure mentioned in any of the 20 listed causes of death on the death certificate); hypertension (I10-I15; deaths with hypertension mentioned in any of the 20 listed causes of death on the death certificate); and stroke (I60-I69; underlying cause of death). We calculated the combined CVD mortality rate as a count per 100,000 based on population estimates by year from the American Community Survey (2011-2015).[257]

Medical Resources. The medical resource locations included are: 1) hospitals in PA (obtained from the Pennsylvania Department of Health[267]); 2) rural health clinics (also obtained from the Pennsylvania Department of Health[267]); and 3) Federally Qualified Health Centers (FQHCs; obtained from the US Department of Health and Human Services Health Resources and Services Administration [HRSA] Data warehouse[280]). Both the PA Department of Health and HRSA maintain GIS-based shapefiles of the geocoded point locations for these facilities. We created two additional indicators from this data: 1) a spatial lag variable, which reflects the role of medical resources in surrounding counties by calculating an average of medical resource density (number of medical resources per 100,000 population) of neighboring counties based on a queen continuity matrix, and 2) a percent of each county area with a medical resource within 10 miles, created using a 10-mile buffer around each resource.

Food and Recreation Environments. We included food retailers from the ReferenceUSA database of businesses based on North American Industry Classification System (NAICS) codes (445110 [Supermarkets and Other Grocery Stores], 445120 [Convenience Stores], 445230 [Fruit and Vegetable Markets], 452311 [Warehouse Clubs and Supercenters], and 722513 [Limited-Service Restaurants]).[281] Based on Centers for Disease Control and Prevention (CDC) classifications in the Modified Retail Food Environment Index (mRFEI), we generated a county-

level measure of healthy food retailer density per 100,000 population.[282] Likewise, we included point locations for recreation facilities from the ReferenceUSA database based on NAICS codes (713940 [Recreation Facilities]),[281] and we created a measure of recreation facility density per 100,000 population at the county-level.

Socioeconomic and Demographic Variables. We included variables representing demographic and socioeconomic factors available via the U.S. Census (American FactFinder): percent of the population age 65 and over, percent female, percent non-Hispanic white, median household income, percent of families below 150% of the poverty level, and percent with less than a high school education.[283] We included these variables at the county-level using the 5-year estimates from the American Community Survey (2011-2015).[257]

Analysis

GIS Mapping and Exploratory Spatial Data Analysis. We used QGIS,[284] a free and open-source geographic information system software package, to create maps displaying: 1) CVD mortality rates among women in 2011, 2015, and percent change of rates in the period (rates displayed per 100,000); 2) median household income at the county-level; 3) presence of medical resources (hospitals, FQHCs, and rural health clinics aggregated by county); 4) the preventive resource measures aggregated by county (e.g., healthy food retailer density per 100,000 and recreation facility density per 100,000). We explore patterns for the latter three measures in relation to CVD mortality rates among women.

Using GeoDa,[285] free and open-source spatial analysis software, we then conducted Exploratory Spatial Data Analysis (ESDA) to visualize relationships between health outcome and resource measures by identifying patterns, clusters, and hotspots. We used Global Moran's I

statistics to assess global spatial autocorrelation of CVD mortality to determine spatial variation across the Appalachian PA region, and we utilized Local Indicators of Spatial Association (LISA) to determine local spatial patterning and to identify local clusters and hotspots for the CVD mortality and resource measures.

Multilevel Regression Model. We then utilized multilevel regression analyses to determine which factors are associated with county-level CVD mortality rates. Due to access to five years of both independent and dependent variables, we conducted a longitudinal multilevel linear regression model (MLM) in Stata v14[286] to assess the spatial and temporal effects from 2011 to 2015 in the Appalachian PA counties. We used a two-level nested MLM, where time point (year) is the level 1 and county is the level 2 unit of analysis. Following the results from the univariate analyses and tests for multicollinearity, we included the four independent variables, including median household income, recreation facilities per 100,000 population, percent of each county with a medical resource within 10 miles, and a spatial lag variable generated from the weighted average of the CVD mortality rate among neighboring counties utilizing a queen contiguity weights matrix; we added to this an assessment of temporal effects by year. With *i* as the time point and j as the county, this MLM follows the form: $y_{ij} = \beta_{00} + u_{0j} + (\beta_{10} + u_{1j})T_{ij} + \epsilon_{ij}$, where y_{ij} is the CVD mortality rate among women, β_{00} is the average county mean at time 0, u_{0j} represents the county deviation from the average at time 0, β_{10} is the average slope of CVD mortality rate over time, u_{1j} represents the county deviation around the average slope, Tij is the temporal variable with time points by year, and ϵ_{ij} is the error term. We ran intraclass correlation coefficients (ICCs) during the model building process to assess the contribution of county-level clustering and contributions of variables to model variance.

4.4 Results

In our sample, the county-level statistics showed that, on average, approximately half of the population is female, 18.6% are age 65 and over, and over 90% of the population is non-Hispanic white. The 52-county region has an average median household income just under $50,000, with 23.5% of the population below 150% of the poverty level and 11.5% with less than a high school education. Additionally, the region has on average 62 primary care physicians, 28 healthy food retailers, and 7 recreation facilities per 100,000 population. The average overall CVD mortality rate for women in the region is 382.8 per 100,000, compared to the state and national rates among this population of 366.7 and 353.0 per 100,000, respectively. **Table 3** contains the county-level averages for demographics, socioeconomic factors, and resource distribution along with CVD mortality rates among women.

Exploratory Spatial Data Analysis (ESDA)

Figure 9 shows the exploration of CVD mortality rates between 2011 (**9a**) and 2015 (**9b**), including the percent change of the rates during this time (**9c**). The map of 2011 shows high mortality clusters in the southwest, northwest, and northeast with low rates in the central area of the state. Likewise, the map of 2015 further illustrates this same pattern, with slightly improved comparative rates in the northwest and slightly worsened rates in the northern portion of central PA. The map displaying the percent change of CVD mortality rates in this time displays these changes along with confirming counties in the southwest and northeast continue to have worsening rates. During this same period, the national percent change of CVD mortality rate among women age 35 and over was -4.7%, and portions of the southwest, northeast, and northern central PA not only do not decrease at the same pace as national levels but have increases in CVD mortality.

Next, **Figure 10** shows the comparison of CVD mortality among women with: median household income as a socioeconomic indicator (**10a**), medical resource presence (i.e., hospitals, rural health clinics, and FQHCs; **10b**), healthy food retailer density per 100,000 population (**10c**), and recreation facility density per 100,000 population (**10d**). When exploring the areas within the region with higher CVD mortality among women in 2015, three patterns emerge: 1) the northwest cluster has relatively lower median household incomes, higher medical facilities, higher recreation facility densities, and somewhat higher healthy food retailer densities; 2) the southwest cluster has relatively lower median household incomes, higher medical facilities, lower recreation facility densities, and mixture of healthy food retailer densities; and 3) the northeast cluster has relatively higher amounts of all four variables compared to other counties in the region. Additionally, in the low CVD mortality cluster in the center of the state, the counties have higher incomes, lower medical facilities, a mixture of recreation facility densities, and lower healthy food retailer densities. These findings suggest different drivers of CVD mortality in the various subregions, where income may be a primary driver in the northwest and southwest clusters of high CVD mortality as well as the low CVD cluster in central PA with less clear relationships between these variables in the northeast region.

Spatial Autocorrelation. All variables had significant global spatial autocorrelation values: 1) CVD mortality among women (Moran's $I = 0.37$, $p < 0.01$), 2) median household income (Moran's $I = 0.19$, $p = 0.01$), 3) spatially lagged medical resources (Moran's $I = 0.42$, $p < 0.01$), 4) healthy food retailer density (Moran's $I = 0.13$, $p = 0.02$), and 5) recreation facility density (Moran's $I = 0.09$, $p = 0.01$). These results indicate significant spatial clustering across the 52 counties for all variables, suggesting use of local spatial exploration to identify clusters.

For these same five variables, we also conducted Local Indicators of Spatial Autocorrelation (LISA) to view high and low cluster areas across the Appalachian PA region. **Figure 11** contains the visualizations for these resulting clusters, where high-high clusters indicate that a given county and its surrounding counties both have high values for a given variable and low-low clusters indicate the inverse. For the CVD mortality rate among women (**11a**), a six-county cluster emerged in central PA with low mortality rates and one county in the northwest with high mortality rates. For median household income (**11b**), we found a six-county cluster with low income in the northwest and two two-county clusters, one in the southwest and one in the northeast, with high income. For medical resource density (**11c**), two large clusters emerged, an area with high lagged medical resource density in the southwest and one with low density in the center of the state. For the healthy food retailer density (**11d**), one county had high density in the northwest, and one county had low density in the state center. Finally, for recreation facility density (**11e**), two three-county clusters emerged, one with high density in the center of the state and one with low density in the north. These results continue to suggest a complex relationship between these variables and CVD mortality; the findings for the central PA region indicate a potential relationship between increased access to recreation facilities and reduced CVD mortality and income continues to be a potential driver in the high CVD clusters in the northwest and southwest, while other subregions have varying patterns across these variables.

Multilevel Regression Model

The results of the full multilevel regression model, including spatial and temporal effects, are displayed in **Table 4**. The likelihood ratio test for this model showed significant improvement from a standard OLS model (LRT = 243.07, $p < 0.01$). Three of the county-level variables

indicated significant associations, including recreation facility density per 100,000 population (β = -1.05, 95% CI [-2.10, 0.00]), median household income (β = -15.12, 95% CI [-28.25, -1.98]), and the spatial lag term for CVD mortality (β = 19.57, 95% CI [10.72, 28.42]). These findings suggest the significant role of income and recreation facilities in CVD mortality rates among women, accounting for spatial and temporal trends. For example, these results indicated an increase of $10,000 in county-level median household income is associated with a decrease of 15 cases per 100,000 in CVD mortality; likewise, an increase of one recreation facility per 100,000 population is associated with a decrease in 1 case per 100,000 in CVD mortality. The significance of the spatial lag term also revealed the continued importance of location-based effects from surrounding counties to CVD mortality among women in this region, and the temporal effects indicated significant decreases over time in CVD mortality compared to the 2011 rate, which mirrors national trends. ICCs for these models (ICC = 0.7934) showed 79.34% of the variance found in CVD mortality rates among women was due to spatial clustering; in addition, when including the county-level covariates, a further 5.72% of variance is explained by income and presence of resources.

4.5 Discussion

While CVD mortality rates have decreased over time in Appalachian PA, reflective of larger national trends, mortality rates in Appalachia continue to diverge from national averages;[287] in 2015, the Appalachian counties of PA had a rate of 382.8 per 100,000 compared to the national rate of 353.0 per 100,000, with a number of counties displaying increasing rates of CVD mortality between 2011 and 2015. The exploratory maps we generated identified three clusters with high

CVD mortality in northwest, southwest, and northeast PA. The three cluster areas have varying patterns of resources and income, suggesting different prevention efforts may be needed based on which characteristics are driving CVD mortality rates. The local spatial autocorrelation results provide depth of understanding for the differences in the three clusters with high CVD, where, for example, the northwest has a significant low median household income cluster. The low CVD mortality cluster in the center of the state has high recreation facilities, indicating these assets may be important for prevention. The identification of these clusters reflect previous studies, where numbers of recreation facilities and characteristics of neighborhoods have an inverse relationship with CV risk;[103,107,109] likewise, the complex subregional differences in the food environment and medical facilities reflect previously described complex patterns between the existence of facilities and use due to factors like quality, access challenges, or perceptions involved in health decision-making.[105,118]

The exploratory patterns in the three areas with high CVD support the regression results, where low median household income and low presence of recreation facilities are associated with high CVD mortality rates among women in Appalachian PA. The significant role of income, where counties with lower median household incomes have higher CVD mortality among women, support previous studies in other areas that show social deprivation, poverty, and socioeconomic factors are associated with CVD mortality.[101,105,106] In the Appalachian region, where economic factors continue to lag behind the rest of the country,[4,5] the role of income and its relationship to CVD prevention efforts need to be further explored, including low cost screening options that account for access challenges (e.g., transportation, childcare) or easily accessed health information related to preventive health behaviors. The significant association of recreation facilities with CVD mortality among women provides another opportunity for potential prevention efforts, where

increased access to these facilities may play a role in improving CV health among women. Future studies would benefit from directly engaging with women in Appalachian communities to uncover intervention strategies that would build upon local community assets, such as parks or existing facilities, and strategies to ensure exercise opportunities meet the complex life needs many women balance with multiple social roles.

Our study has important limitations to acknowledge. First, while this study focuses within a single state, the pervasive extent of CVD in the Appalachian region supports this research as an important first step to capture contextual factors in a defined spatial area. Second, this study uses publicly available data, which greatly limits the flexibility in the format of the variables received. For example, as CVD mortality data is publicly available at county-level mortality rates, we were not able to use this dataset to pursue more granular exploration of relationship between resource availability and cardiovascular health outcomes. Third, the lack of association between the percent of the county with a medical facility within 10 miles and CVD mortality sheds light on an interesting limitation previously discussed in capturing the complexity medical resource access.[105] Without point locations for individual residence, county-level measures of access often do not account for variability in travel distance; additionally, patient choice as well as economic aspects of accessing care and differences in service provision suggest much more depth of information may be needed to accurately understand the role of medical resources in CVD prevention among women. Fourth, the lack of association between healthy food outlets and CVD mortality further supports the complex ways in which access and perceptions of quality affect utilization of these facilities and health behaviors. With such high levels of asymptotic cases, building future research that can capture the complex interaction of these factors to increase CVD prevention opportunities is particularly important for women to curtail premature mortality rates in this understudied region.

4.6 Conclusion

Overall, this study describes, through a spatial lens, the important role of income, recreation facilities, and location in affecting the CVD mortality among Appalachian women. Our findings support the need to understand the varying patterns in areas with low and high CVD and indicate the future use of methods to uncover the interconnected and systemic factors affecting CVD mortality. Future studies should explore additional spatial analyses, including a more granular scope and new ways to capture the complexity of measuring resource access. Additionally, researchers should utilize study designs, such as mixed methods or systems science, capable of gathering in-depth perceptions, prioritizing a range of barriers and facilitators, and uncovering connections between factors across the socioecological levels. Our results also inform prevention efforts, such as increasing access to recreation facilities and developing ways to overcome income-related barriers to CV health; while the findings support previous work, these relationships have not previously been described for women in Northern Appalachian counties. Finally, our analyses set the stage for subsequent study throughout the Appalachian region to understand the factors that affect women's health and CVD outcomes.

4.7 Acknowledgements

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4.8 Tables and Figures

Table 3. County-Level Average Demographics, Socioeconomic Factors, Resource Distribution, and Cardiovascular Disease Mortality for Women in the Appalachian Counties of Pennsylvania (N=52) and in 2015

Variable	***Mean (SD)***
County-Level Descriptors	
Population Density	162.91 (240.65)
Percent Female	49.63 (3.52)
Percent 65 and Over	18.60 (2.17)
Percent Non-Hispanic White	93.65 (5.66)
Socioeconomic Factors	
Median Household Income	47,100.65 (5,258.42)
Percent of Households Below 150% Poverty Level	23.51 (3.42)
Percent Receiving Disability	15.98 (3.02)
Percent Below High School Education	11.51 (2.80)
Medical Resources	
Primary Care Providers per 100,000 Population	61.63 (57.63)
Health Facilities Density per 100,000 Population	9.78 (11.08)
Percent of County Area with Medical Facility within 10 Miles	14.36 (9.60)
Preventive Resources	
Healthy Food Retailer Density per 100,000 Population	27.74 (7.69)
Recreational Facility Density per 100,000 Population	7.33 (4.73)
Cardiovascular Disease Mortality Rate for Women per 100,000	382.79 (33.61)

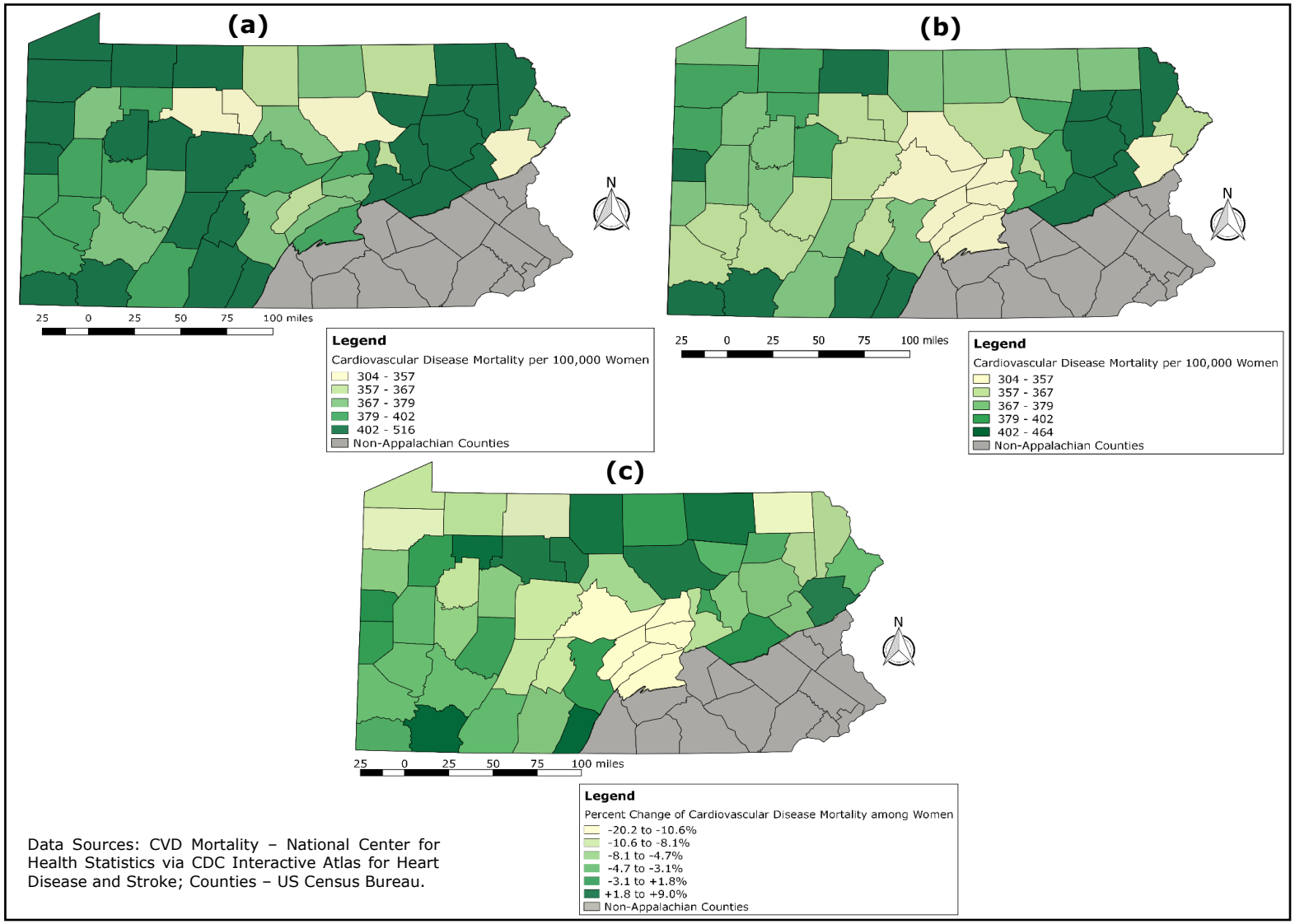
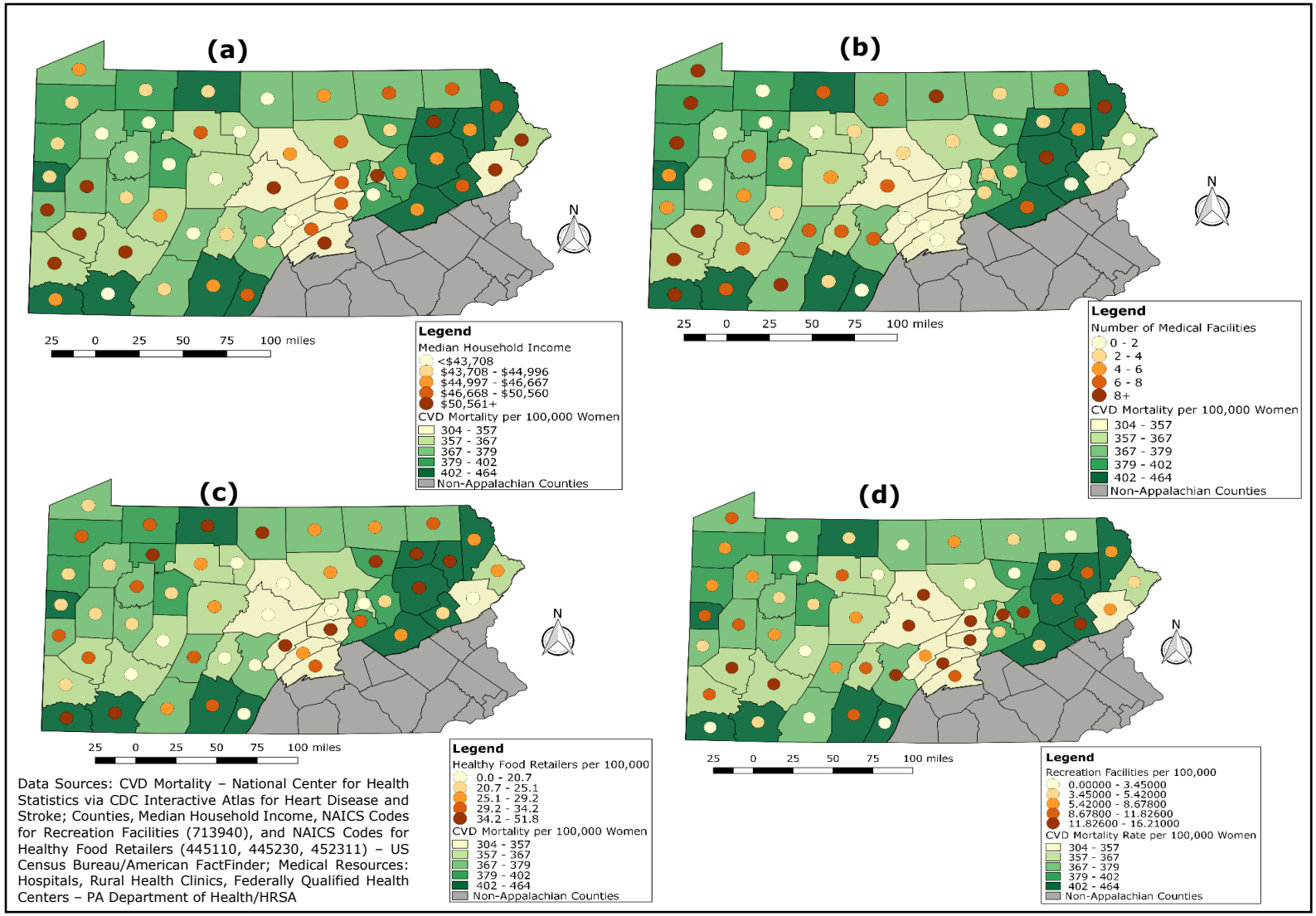


Figure 9. CVD Mortality Rates among Women in Appalachian PA (a) 2011, (b) 2015, and (c) Percent Change between 2011 and 2015.



Data Sources: CVD Mortality – National Center for Health Statistics via CDC Interactive Atlas for Heart Disease and Stroke; Counties, Median Household Income, NAICS Codes for Recreation Facilities (713940), and NAICS Codes for Healthy Food Retailers (445110, 445230, 452311) – US Census Bureau/American FactFinder; Medical Resources: Hospitals, Rural Health Clinics, Federally Qualified Health Centers – PA Department of Health/HRSA

Figure 10. CVD Mortality Rates among Women in 2015 with (a) Median Household Income, (b) Medical Resources, (c) Food Retailer Density, and (d) Recreation Facility Density

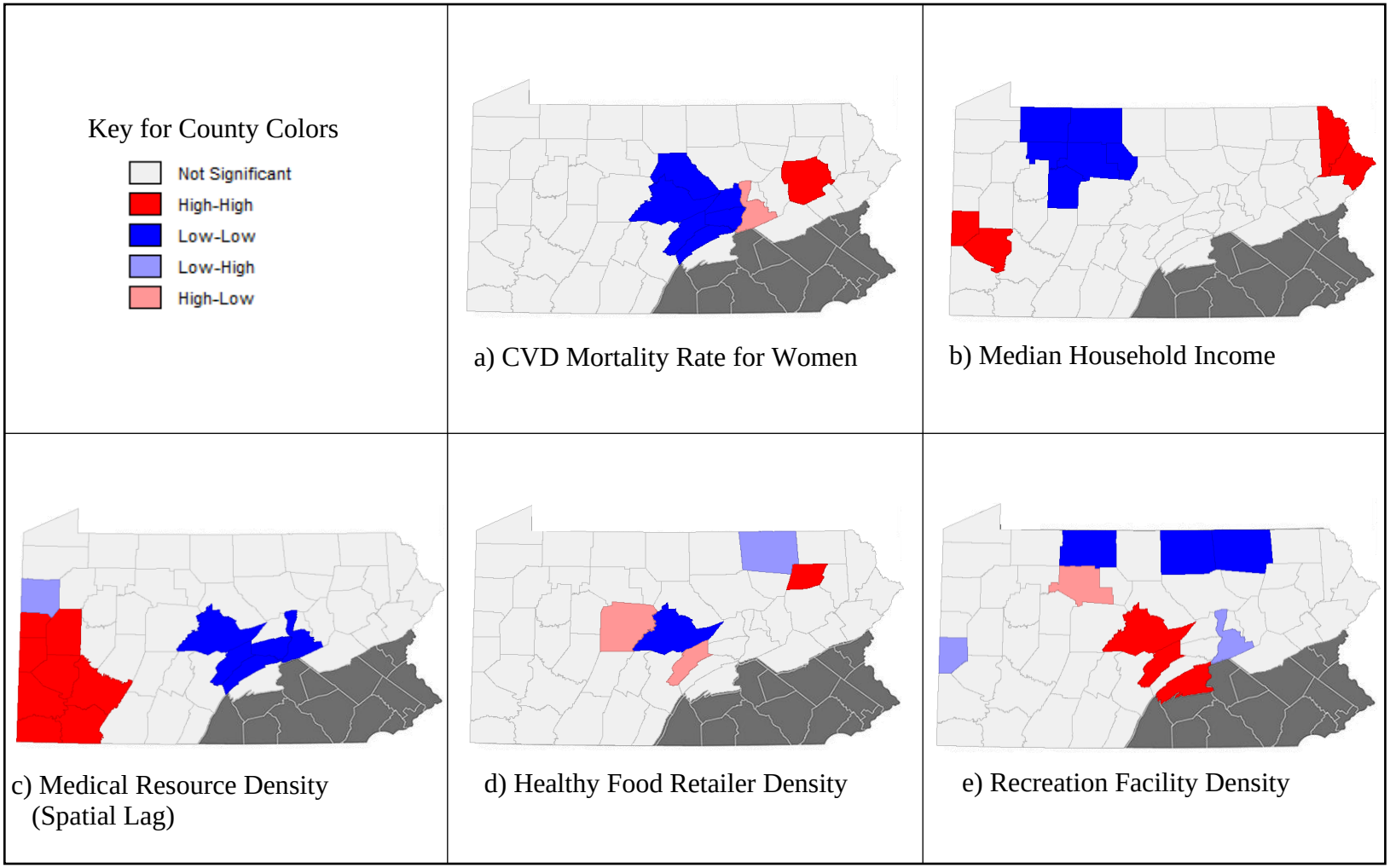


Figure 11. LISA Results for CVD Mortality Rate, Median Household Income, Medical Resource Density (Spatial Lag), Healthy Food Retailer Density, and Recreation Facility Density

(Note: The dark gray counties are Non-Appalachian.)

Table 4. Multilevel Linear Model for Predictors of CVD Mortality for Women in Appalachian PA (N=52) from 2011 to 2015

Variables	***Coefficients***	***95% Confidence Intervals***
Median Household Income (per 10k)	-15.12†	(-28.25, -1.98)
Percent of County Area with Medical Facility within 10 Miles	0.25	(-0.55, 1.06)
Recreation Facility Density (per 100k Population)	-1.05†	(-2.10, 0.00)
Spatial Lag Term (CVD Mortality for Women)	19.57‡	(10.72, 28.42)
Year (2011 Ref.)		
2012	-3.87	(-9.33, 1.59)
2013	-14.64‡	(-20.32, -8.96)
2014	-14.98‡	(-21.14, -8.83)
2015	-17.16‡	(-23.59, -10.73)

† $p < 0.05$
‡ $p < 0.01$

5.0 Heart Health Experiences of Rural Appalachian Women: A Community-Engaged Study

5.1 Abstract

This study assesses the range of perceived barriers and facilitators to cardiovascular health and identifies potential community-specific interventions to improve CVD prevention among rural Appalachian women in Pennsylvania (PA). With a sample of 71 women from three Appalachian PA counties, we conducted concept mapping, a participatory mixed method, including three online activities and a series of group discussions. We created point and cluster maps to build a conceptual framework of perceived barriers and facilitators in thematic areas. We then compared average cluster and item ratings on importance to preventive behaviors and feasibility to change in the community. We also performed qualitative data analysis on the discussion transcripts. Participants listed 96 perceived factors related to CVD prevention in their community. These factors grouped into six clusters spanning individual (Knowledge & Understanding; Lifestyle), social (Supportive People & Places; Work, Family & Life), and community-level factors (Obstacles to Healthcare; Difficult to Control Factors). Participants identified several intervention opportunities to prevent CVD: 1) non-traditional sources for health information; 2) holistic, consistent healthcare; 3) addressing workplace and facility policies and norms; and 4) positive media messaging. Participants also discussed the implications of the COVID-19 pandemic on their heart health-related behaviors. These results provide novel understanding of factors affecting CVD prevention among Appalachian PA women. We uncovered potential intervention opportunities, which build on social and community assets, promote holistic care, and utilize validating messaging. Future studies can explore regional variation and consider new or adapted interventions to improve the health of women in this understudied population.

5.2 Introduction

Residents of Appalachian counties, including those in the Northern Appalachian Region of Pennsylvania (PA), die younger from preventable causes, as premature mortality rates are 25 percent higher than for all US counties.[1,2] The Appalachian region consists of 420 counties in 13 states, including 52 counties in PA; 42% of Appalachia is rural, compared to 20% of the rest of the US population.[3] Appalachian residents have a per capita income that is 74.3% of the national average, along with lower levels of educational attainment and higher levels of unemployment than national averages.[7,8]

These regional socioeconomic disparities are then reflected in health inequities in chronic diseases, such as cardiovascular disease (CVD). Heart disease mortality is 17% higher in Appalachia than the US rate, which is mirrored by higher stroke mortality rates (14%) and higher CVD risk factors such as diabetes (11.9%), physical inactivity (5.3%), and smoking (3.7%).[2] Appalachian counties have high heart disease-related death rates for women,[12] and CVD accounts for the largest portion (27.5%) of the gap in life expectancy between Appalachian women and those outside the region.[13] High proportions of Appalachian women have uncontrolled CVD risk factors, such as hypertension and diabetes.[10,11,18] These sex-specific risks emphasize the need for CVD prevention among women, particularly in Appalachia.

Based on research for other health outcomes, structural, social, and individual factors likely combine in complex ways to affect CVD prevention among Appalachian women. Structural challenges may prevent women from receiving preventive screening, such as cost of procedures and follow-up,[46,50,124,126,130] access to insurance,[50,124] and access to transportation.[123,129] Income and education levels as well as primary care physician to county population ratios may also play a role in access challenges.[129,137] At an interpersonal level, provider recommendation and engagement

remains a frequently cited factor,[46,125,129,130,133] including trust and communication,[122,123,126,134] and family history with disease may also influence an individual's decision to receive preventive screening.[50,127,129] Individual-level factors affecting screening behaviors may include: women's knowledge,[124] perceptions (e.g., privacy;[124-128] perceived need for screening;[127-130] emotional reaction like fear, worry, or embarrassment;[46,126,128,130,131] and lack of control[131]) and skills (e.g., managing uncertainty[122]). In rural areas, body discomfort and need for privacy may also be higher from the desire to not have an acquaintance involved in health-related decision-making.[125,133] While traditionally-identified Appalachian beliefs of independence, present-day orientation, and religiosity may play a role in this process,[44,149,288] the complex interaction of circumstances indicate the importance of considering context[128] and the utilization of a holistic approach (i.e., consideration of the broad array of factors that affect receipt of preventive healthcare.)

Overall, these complex, multilevel factors support the use of methods and community-engaged approaches that highlight the social and contextual determinants of disease.[240] Through concept mapping, a community-engaged mixed method, this study assesses: 1) what is the range of perceived barriers and facilitators to CVD prevention by rural Appalachian women in PA; 2) what is the relationship between individual, social, and environmental-level factors identified as important for CVD prevention; and 3) what are potential community-specific interventions to improve CVD prevention among rural Appalachian women in PA?

5.3 Methods

Study Population & Recruitment

Of the 52 Appalachian counties in PA, 46 have a rural designation.[4-8] The number of

persons per square mile and the per capita income in Appalachian PA is similar to the entire Appalachian region (158 vs. 123 and $42,595 vs. $37,260, respectively).[260] The study team previously conducted spatial analyses (paper 2) to assess resource distribution with CVD mortality among women in the Appalachian PA counties. Using these analyses, the team purposively selected three counties with varying resource levels and CVD mortality rates: Butler, Fayette, and Lawrence. The selected counties were located in Western PA for proximity to the study team and existing community connections. Fayette County has a relatively low median household income, moderate levels of preventive resources, and consistently poor health indicators compared to the larger Appalachian PA region, including the highest CVD mortality rates. Similarly, Lawrence County has a relatively low median household income and even lower levels of resources compared to Fayette County, but the county has performed better on health outcome measures, including CVD mortality, though these rates have been worsening in recent years. Butler County has the highest median income and levels of resources of the three counties, and though the county has higher CVD mortality rates than expected, these have been improving. Although all three counties are categorized as rural by the state of PA metrics, these counties also represent different characteristics across the urban-rural continuum, with Butler as the most urban and Lawrence as the most rural.

From June to October 2020, we recruited a convenience sample in each county. The COVID-19 pandemic risk mitigation strategies were on-going during this period. Given restrictions and safety concerns, all recruitment and data collection occurred in a remote format. The study team used three strategies to identify eligible participants. First, we utilized the University of Pittsburgh Clinical and Translational Science Institute Pitt+Me registry of potential research participants, which has over 250,000 registrants throughout Western and Central PA.

Pitt+Me staff identified and referred participants meeting the eligibility requirements to the study team. Second, we used online social media recruitment through ad placements on popular sites such as Facebook and Instagram, which were specifically targeted for age, gender, and geographic location; interested individuals clicked on provided links to learn more about the study. Third, we identified participants through contacting relevant local organizations directly (e.g., clinics, community centers, local non-profit organizations). The study team met with the organization leaders, who shared recruitment materials (**Appendix F**) to identify participants.

Participant eligibility included: 1) English-speaking; 2) female; 3) age 40-64 [target range for CVD screening [17]]; and 4) living in a case county for ≥2 years to establish residency (**Appendix G**). Participants also had to express willingness and ability to participate. At enrollment, the study team collected contact information and obtained consent prior to data collection (**Appendix H**). All procedures were approved as expedited by the University of Pittsburgh IRB (#STUDY200550165).

Data Collection & Analysis

Concept mapping builds upon qualitative methods used in community-engaged research by adding intentional participatory elements and built-in quantitative components. The method's participatory nature allows researchers to uncover connections and to generate potential community-specific intervention opportunities to address health disparities.[239,251,252,270,272,289-292] Extensively used in program planning and evaluation, concept mapping as a research method allows researchers to uncover novel, exploratory findings around a topic of interest and to display the results in a visual, conceptual map useful for planning interventions, programs and services, scale development, and formative research for future studies.[251,252] Concept mapping is centered

around a focal question, which shapes the remaining steps of data collection and analysis; this iterative process occur over multiple sessions.[239,251,268] The study team conducted three sequential sessions, including four distinct activities, within each county. With regular reminders to maximize participation, we used the online concept mapping software created by Concept Systems, Inc.[269] for data collection, including demographic questions (e.g., age, income, insurance status; see **Appendix I**). Participants received $10 gift cards for each activity completed (up to $40 if participants completed all four activities).

Brainstorming (Session 1; **Appendix J**) involved 47 participants from across the three counties generating a list of responses to the focal question: *What are all the factors, good or bad, that affect the cardiovascular (heart) health of women in your community?* The study team included probes to explore individual, social, and environmental factors in their responses. We compiled data from the brainstorming sessions for all three counties into a single final item list. The participants then carried out a sorting and rating process of the final list items (Session 2; **Appendix K**). The pile sorting process involved 71 participants, including the 47 who had participated in the brainstorming session, working independently to group the items and labeling each pile. The rating process used Likert-type questions asking these participants to rate each factor on three scales: a) importance for receiving *preventive health screenings* (e.g., cholesterol, blood sugar, blood pressure); b) importance for *lifestyle behaviors* (e.g., smoking, diet, physical activity) and c) *likelihood for intervention opportunity in this community*, where responses ranged from 1 (not at all important/feasible) to 5 (extremely important/feasible).

With the combined sorting and rating data, we used non-metric multidimensional scaling to create a spatial point map displaying the relative distances between the items representing perceived similarities and differences.[268] We then used hierarchical cluster analysis to create a

cluster map illustrating group consensus regarding item categories.[268] The study team used the ratings data to examine pattern matches for clusters to see variation across each rating scale; we displayed correlational values (r) for each direct comparison.[268] The design of this three-county concept mapping study also allowed for the exploration of similarities and differences across counties and by participant characteristics (see **Appendix L** for additional concept maps).

Finally, we brought these data to participants for qualitative data interpretation (Session 3; **Appendix M**). We reached out to a sub-sample of 16 participants from the three counties for group discussions. These sessions followed the general structure of a focus group, where participants viewed representative maps in a guided discussion to gather community-driven feedback. The discussion groups took place over Zoom,[293] for the ability to share concept maps. We also shared the results through email and ensured participants could participate by phone, if needed. We audio-recorded these discussions and used the transcripts for qualitative analysis. First, we included thematic codes by cluster name to explore the depth of results, and second, through a grounded theory approach, we used inductive content analysis to discover emerging themes (**Appendix N**).[169,170] The first and second authors, as independent coders, conducted these analysis using NVivo 12 and double-coded 50% of transcripts with excellent levels of agreement (Cohen's kappa = 0.77; 98% agreement).[294] We identified representative quotes to capture participant language.

5.4 Results

Participant Characteristics

Reflective of eligibility criteria and regional demographics, the sample (N=71) had a mean age of 54.6 years and was majority white (83% of those who responded). Among those participants

reporting household income, approximately half were under $75,000, and 58% of participants identified that they or an immediate family member had a history of heart health problems (e.g., heart failure, heart disease). Across counties, the sample was similar, with slightly higher income and percent with private insurance among Butler County participants, reflective of county-level differences; while all three counties have a rural designation in PA, Butler County has the largest population and the highest median household income. **Table 5** contains a summary of participant responses.

Items & Clusters

Participants listed 96 unique factors that affect the heart health of women in their community. We generated a spatial representation of the similarities among the 96 items in a point map, which had a stress value of 0.2853 indicating a high level of stability.[268] The study team, utilizing hierarchical cluster analysis, found the items grouped thematically into six unique clusters spanning individual-level lifestyle behaviors, knowledge, and understanding; supportive people and places; difficult to control factors, including environmental, work, or life needs; and obstacles to healthcare. The 96 items grouped into the six clusters are in **Appendix O**, and the resulting cluster map is displayed in **Figure 12**. In the discussion sessions, participants developed cluster names based on the thematic similarity of items.

Cluster 1: Supportive People & Places. This cluster describes positive supports participants identified in their lives and communities, such as relationships and spaces for exercise or to buy healthy food. Within the items discussed by participants, relationships included supportive family relationships and support by other women, and places included local farms and farmer's markets, economical places to shop for food, gyms, and outdoor spaces for exercise such

as local parks. A few items (e.g., self-confidence, positive attitudes toward health) are at the individual-level; however, these items fit, as one participant describes:

> Having a positive attitude is a choice… even if you're around people who are negative, you have the choice to be negative or to be positive to try to influence them. So, if we're talking about supportive people and places, I think support begins with yourself. (Lawrence County)

One participant also connected the presence of community assets to pride of place and explains how these supports can contribute to positive attitudes in an interconnected manner:

> I would say pride of place because when we feel like our needs are being met then you're also going to… have a good self-image, feeling that you belong to a place that is willing to take care of you and then you may be willing to take care of it. (Fayette County)

Cluster 2: Knowledge & Understanding. This cluster discusses knowledge women identify as important to heart health behaviors. One participant called this cluster "myths and monsters" to reflect misinformation and the denial women may feel about hearth health issues affecting them. Participants described the need for "education from a young age, that would really help women understand themselves and not be in denial" (Butler County). Specifically, participants expressed interest in education to combat the narrative around heart health issues being primarily a male issue (e.g., male-specific symptoms) and stigma of help-seeking behaviors among women. One participant describes the need for education on "symptoms of heart disease in women compared to men… and I think too, maybe if women felt like, okay, you're not going to be a burden by saying that you don't feel well" (Lawrence County).

Cluster 3: Obstacles to Healthcare. This cluster contains challenges women encounter in healthcare, such as the monetization of care, insurance dictating processes and costs, and access in

rural areas, particularly to specialists and women's health providers. Insurance arose frequently in discussions, including the powerlessness women felt; as one participant states, "I think we all feel very helpless to change our insurance and like we're kind of puppets on strings. We can't change them, and they dictate what we do. Or don't." (Lawrence County). Another participant highlights the need for women to understand ways to "work the healthcare system" rather than accepting these barriers as the status quo; as she explains:

> I think women in my area, some of them don't feel welcome in healthcare facilities. I think they feel intimidated, especially if you're someone who comes from a lower socioeconomic status or if you're someone who comes from an isolated rural or mountain area… Maybe it's not explained to them… it's so overwhelming. (Fayette County)

Cluster 4: Lifestyle. This cluster includes lifestyle behaviors, including diet, physical activity, and alcohol use. Participants largely described two points-of-view: 1) women who choose not to engage in healthy behaviors and 2) acknowledgement of life circumstances and systemic barriers that make these behaviors challenging for many women. Several participants used the word "excuses" to describe choosing to not exercise or eat healthy, but as one participant explains, "processed foods, fast foods, alcohol abuse, lack of exercise… it's still a choice. Unfortunately, we don't choose to do the right things sometimes" (Lawrence County). On the other hand, some participants who felt aspects like poverty, which directly affect food and exercise choices, saw the language around "excuses" as blaming women for conditions that extend beyond behavioral decision-making; one participant states: "I just call this patient shaming… all about shaming" (Butler County).

Cluster 5: Difficult to Control Factors. Participants from the three counties agreed that the items in this cluster are difficult to control, ranging from personal health conditions like obesity

and diabetes to environmental concerns like air quality and poverty. Comments primarily focused on the lack of ability to change these items. For example, one participant describes: “A lot of these look like some of the things… I was like, it doesn’t matter. It’s not going to change anyway. [For example,] poverty. I wish I had the answer for that. That would be like the ultimate gift to the world…” (Fayette County). However, another participant described how acknowledging these challenges can benefit women:

> I think validating for women that it's not their fault would be a good place to start. Because all of this shows, it's not our fault. You have not failed as a human being because look at all the factors that are outside of your control that are contributing to the problem. So, it's not your fault. (Butler County)

Cluster 6: Work, Family, & Life. The items in this cluster relate to gender-based cultural norms around caregiving and the day-to-day challenges women face juggling work, family, and other life needs. Several participants discussed how caregiving norms play a role in deprioritizing their own health to focus on other life needs. As a participant explains:

> The whole women taking care of others before themselves… I still have a tendency to make sure that I have breakfast ready for my husband… which probably seems a bit old fashioned at this point, but I, of course, followed what my mother always did… I'm one of these people that it’s so hard for me to tell somebody ‘no.’ (Fayette County)

Participants also described complex decision-making because of financial, family, or work challenges; for example, if “we need to feed our families, and if we can't afford healthy food, we're going to get unhealthy fast food” (Lawrence County).

County-Level Variation

To shape county-specific interpretation sessions, we explored county-level variation in average cluster ratings across two of the scales: importance to preventive screening and feasibility to change in the community (**Figure 13**). While some similarities exist in the average cluster ratings, the correlations between these cluster ratings vary by county, ranging from r=0.39 (Butler) to r=0.70 (Lawrence). As similarities, participants across all counties rated cluster 3 (Obstacles to Healthcare) as most important to screening and clusters 2 (Knowledge & Understanding) and 3 (Obstacles to Healthcare) as the most feasible for change in their communities. In terms of differences, cluster 1 (Supportive People & Places) had a lower average cluster rating on both scales in Fayette County, and cluster 5 (Difficult to Control Factors) had a lower rating for importance to screening in Lawrence County. We utilized these similarities and differences to guide conversations around intervention ideas in each county-specific interpretation discussion.

Intervention Ideas

Based on county-level similarities and differences, participants identified potential community-specific intervention opportunities, including: non-traditional sources for health information; holistic, consistent healthcare; addressing workplace and facility norms; and positive media messaging.

Non-Physician Supports for Health Information. Participants identified the need for health information to be provided from sources other than a doctor's office. As regular touchpoints, participants described potential for pharmacists, fitness trainers, nutritionists, or churches as sources for information, particularly on women's heart health and for personalized health behavior instructions. One participant describes: "I think your pharmacist is your best advocate, you go

there and they tell you ‘you know you shouldn't be doing this. No, you shouldn't take this with this,’ and I don't think people utilize the pharmacists enough” (Butler County). Another participant speaks to the benefits of a personal fitness trainer:

> Like a gym membership, that's such an easy, accessible point that the trainer could be saying, okay, we're going to talk about, not getting on this treadmill to burn calories, but we want to get your heart rate up a little bit… and here's why. Because as a woman, that's your highest risk factor for death is a heart issue. (Fayette County)

Holistic, Consistent Healthcare. Participants described the need for more consistent and personalized healthcare, including the desire for doctors to see patients as a whole person, frustration that dental or optical care are not covered on primary insurance, and dissatisfaction with seeing a plethora of specialists. One participant states: “It's so chopped up into tiny little pieces… I'm looking at this toe, so I don't want to hear about what's going on with your heart… If you look at everybody and the whole patient, maybe that would work [to promote heart health]” (Fayette County). Due to short clinic visits with physicians and issues with patient-provider communication, participants expressed frustration about weight loss being a go-to health recommendation for heart health. Additionally, they described a lack of focus on health literacy (e.g., skills for taking concurrent medications or reading food labels to make healthy choices) within interactions with providers, resulting in inaccessible recommendations that may involve incorrectly assumed knowledge. A participant explains the consequences of poor communication:

> You have to look at the whole patient, including their dependents…telling a woman to work out more, eat better food, and get enough sleep when she's working three part time jobs, a single parent trying to cobble together a living, and you shame her for having a TV dinner or McDonald's takeout. She's not coming back to see you. (Butler County)

Workplace and Facility Norms. Participants also described the need for changing societal norms around caretaking, gender roles, and life priorities. For example, participants made recommendations to increase exercise opportunities through workplace policies to promote time for physical activity or for exercise options for those who may not work standard hours. As one participant discusses, "employers need to be encouraged to start encouraging all their employees to be more active, you know, I don't know, lunch hours instead of half hour lunch breaks" (Butler County). Participants expressed the need for workplaces, fitness facilities, and doctor's offices to meet life needs (e.g., childcare, transportation, times open) for women to build and maintain healthy behaviors, as one participant explains:

> I'm a mom. So, what do I do with my kid when I go to the gym… there isn't the chance I'm going to go to the gym after work or I'm going to get up and go real early… that doesn't work if you have a kiddo when you're the only one that's able to watch that kid because none of the gyms around here have childcare. (Fayette County)

Positive Media Messaging. Participants also suggested ways to address existing cultural norms around women and heart health through increased positive messaging in the media or an active presence on social media. Participants described the need to change "not me" attitudes involving denial of heart health issues to validating "not your fault" messaging that both acknowledges challenges and assists in finding ways to make healthy behaviors work despite these obstacles. Particularly, participants recommended media ads during primetime hours or via a key social media figure who could share useful, positive tips; one participant would like:

> An Oprah of women's healthcare, like a guru that women… [would] be able to trust enough to be able to say, okay, this is what we have to work with and this is how you can make a difference for yourself and your family. (Fayette County)

COVID-19 Considerations

In addition to intervention ideas, we noticed several brainstormed items contained specific references to the on-going COVID-19 pandemic, and women in the discussion groups regularly referred to ways in which their heart health behaviors have changed due to the pandemic. When inductively coding the transcripts, we decided to explore these findings thematically, including routines, mental health, and social supports.

Changes in Routines. Participants discussed ways they adjusted their daily routines because of the pandemic, including exercise, diet, and drinking behaviors. One participant describes options for women, particularly those with existing comorbidities or of older age:

> That gym membership jumps right to my mind… It's one of the things that, even though right now we're offered free memberships… there's no way I'm going with COVID. It's just too scary. Especially at my age. (Lawrence County)

Another participant directly conflicts the notion that being physically active is less likely at this time; as she explains: "I would have to say, I've gotten more exercise during COVID. We've never done more walks together, which has been nice" (Lawrence County). Participants also discussed this duality in diet and drinking behaviors, where some women have experienced higher levels of alcohol consumption or poorer diets since the pandemic began, while others are cooking or growing more food at home and going out less frequently to drink socially.

Effects on Mental Health. Participants also directly connected these behavioral changes to their mental health status. One participant explains: "I'm not going to the gym, and yeah, I've gained weight. I'm eating more potato chips, probably why I had a high cholesterol tests because I need a little more comfort food because, you know what, things suck right now" (Butler County). Participants who described poorer health behaviors in connection to the pandemic largely

discussed the need for ways to overcome or cope with stressors, putting their mental health as a higher priority than physical health; one participant explains how the pandemic has shifted her attitude toward life and healthy behaviors: “Before, I was like, oh, you know, happy and sunshine and everything else. Then, 2020 broke me [with] the existential crises I have gone through within this time period” (Fayette County).

Social Support. On the positive side, participants, such as those increasing exercise time outdoors, described ways in which they were experiencing higher levels of social support. Participants discussed going for walks in local parks with family members and enjoyment at seeing others out together using these spaces. Additionally, participants reflected on ways that using the internet has increased the ability to connect with others, including for physical activity. One participant described using online yoga videos with her husband at home; another discussed having her daughter set-up her computer for exercise videos and to stay in touch with friends and family. Overall, participants expressed higher levels of social support, including higher use of community programs, such as food distribution at churches. As one participant summarizes: “People have really come together and been supportive of each other” (Lawrence County).

5.5 Discussion

Our concept mapping activities identified a wide range of unique items that women in Appalachian PA perceived as a factors affecting the heart health of women in their community. These items grouped together into six clusters that spanned the social-ecological framework, including individual (Knowledge & Understanding; Lifestyle), social (Supportive People & Places; Work, Family & Life), and community (Obstacles to Healthcare; Difficult to Control

Factors) levels. By deriving cluster names from participant descriptions for why certain items grouped together, we uncover novel ways of viewing multilevel, complex factors affecting CVD prevention among women in this region.

Several identified clusters reflect findings in the previous literature, while others make novel contributions. Cluster 1 (Supportive People & Places) includes comments connecting community assets or positive interpersonal relationships to attitudes, both at an individual-level and to pride in the community, demonstrating aspects of the protective nature of social supports.[94,295] Cluster 2 (Knowledge & Understanding) highlights the need women feel to understanding risk factors and symptoms specific to women,[10,11] rather than the male-dominated narrative of heart health. Additionally, participants recommend looking beyond providing education, which implies a lack of knowledge among women; health professionals must also consider the roles of misinformation and stigma in help-seeking behaviors. Cluster 3 (Obstacles to Healthcare) identifies many expected barriers and challenges women face in seeking healthcare, including cost, access barriers, and the role of insurance.[46,50,123,124,126,129,130] Women use words like 'powerlessness' and 'intimidation' to describe interactions with healthcare providers, which reveals the importance of supporting women's efforts to work through systemic barriers (i.e., increase their "healthcare literacy"). Finally, the dual perspectives in cluster 4 (Lifestyle) fall in-line with locus of control theories[296] by distinguishing participants with internal attribution (i.e., lifestyle behaviors as a choice or excuse) versus external attribution (i.e., systemic factors superseding health decision-making). The items in cluster 5 (Difficult to Control Factors) and cluster 6 (Work, Family, & Life) summarize many factors that those with an externally-focused lens reference.

Participants identifying non-physician supports for health information aligns with previous discussion of Appalachian women likely preferring to receive information from social connections.[288] Future research should explore the potential for health information to be distributed by local pharmacists, fitness facilities, and churches; the latter has been successfully conducted with Appalachian women using community health workers to expand cervical cancer screening through faith-based locations[44] and could be adapted for CVD prevention. Additionally, the discussion of more holistic, consistent healthcare supports an increased consideration of a harm reduction approach to improving women's heart health-related behaviors such as diet and physical activity.[297] This perspective acknowledges that many factors, including those difficult to control in cluster 5 (e.g., poverty, existing co-morbidities), must be considered through humanizing patients, suggesting incremental changes rather than focusing directly on weight-loss, and allowing for an occasional step backwards in behaviors via a pragmatic lens.[297] This suggestion also relies on women's ability to build consistent connections with primary care providers rather than segmented healthcare experiences, which participants often connected to insurance companies dictating healthcare costs and processes or poor patient-provider communication.

Participants identified additional policies and systems that directly influence their heart health behaviors, including access to transportation and childcare. A shift in intervention approach that aligns with the literature includes advocating for greater resources to meet daily practical needs[123,129] and increasing information to women about existing resources. Similarly, by using the media or social media to combat gender-based norms around caretaking and social roles, a health communication campaign could utilize lessons learned from the success of breast cancer awareness; several participants expressed frustration or surprise at learning that heart disease is the leading cause of death among women because of the media presence breast cancer advocates have

created. Recent studies discuss suboptimal awareness and decreased engagement by women in existing successful heart health campaigns, such as the American Heart Association's Go Red for Women, compared to breast cancer campaigns like Breast Cancer Awareness month.[298,299] Such differences may be due in part to length of campaign (for these two examples, starting in 2004 compared to 1985) as well as the role of promotional industry interest in the breast cancer pink ribbon culture.[298] To increase women's engagement, an updated media campaign could incorporate a harm reduction approach that acknowledges the challenges women face and focuses on positive ways to improve behaviors working given these barriers.

Finally, the discussed changes in behaviors due to the COVID-19 pandemic captures the complexity of how future health outcomes will relate to behaviors during this time, where some women have improved health behaviors and others have worsened. These findings, including the relationship between mental health and behavioral decision-making, suggest the need for several strategies to encourage CVD prevention, including: promoting outdoor and online spaces for increasing physical activity options, offering intentional mental health supports to women, and encouraging positive ways to interact with members of families/COVID-19 bubbles to capitalize on the protective nature of these social supports. Those engaged in the development of media campaigns or policy changes should strive to include aspects that address potential behavior changes from the pandemic as well as mental health needs. Additionally, providers and those sharing health information should be sensitive to additional needs women may have because of recent circumstances.

We acknowledge several limitations in the design of this study. As we conducted the entire study remotely, the sample may skew towards participants with higher income or education, as these participants may have been more likely to have time to participate or technological access.

Our sample also had higher participation in Butler County, which is indicative of its larger population compared to the other counties (Fayette has 68.8% and Lawrence has 45.5% the population size of Butler). Additionally, we recruited many of our participants via an existing voluntary health research registry, so our sample may be biased towards those more likely to participate in research studies. While we collected data from three counties, our results may not reflect all of Appalachian PA nor the entire region, and future studies should seek to expand upon these analyses to capture similarities and differences throughout the region. While fairly robust for a concept mapping study, our sample size is small and is not meant to be generalizable, as concept mapping seeks to capture group consensus. Future studies should also consider race/ethnicity as well as gender-identity or sexuality; while we collected the former, we did not intentionally oversample to explore these differences in our analyses. However, our study utilizes a mixed method design that captures novel findings related to a range of complex, multilevel factors and is grounded in spatial analyses. Through this combination of methods, we have confidence in the previously undescribed perceptions about preventive CVD factors among women in Appalachia along with novel intervention ideas provided by participants.

5.6 Conclusion

Overall, by employing the participatory, community-engaged method of concept mapping, we identified 96 unique items that grouped into six thematic areas, which provide novel understanding to factors that affect the heart health of Appalachian women. By using county-level and demographic comparisons, we uncovered potential intervention opportunities to improve CVD prevention among women in Appalachian PA, which build on positive social and community

assets, promote holistic care, and utilize positive and validating messaging. Future studies can build on these results by exploring regional variation as well as differences by race, gender identity, or sexuality and by considering ways to implement new or adapted interventions to improve the health of women in this understudied population. Finally, by including participant comments on the COVID-19 pandemic, we provide a platform for continuing discussion for how behaviors in this time will affect future cardiovascular health.

5.7 Acknowledgements

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5.8 Tables and Figures

Table 5. Concept Mapping Participant Characteristics

Participant Characteristics	Butler (N=37) *Mean (SD)*	Fayette (N=14) *Mean (SD*	Lawrence (N=20) *Mean (SD)*	TOTAL (N=71) *Mean (SD)*
Age	55.79 (7.07)	52.00 (8.38)	54.06 (6.08)	54.61 (7.08)
	Frequency (%)	*Frequency (%)*	*Frequency (%)*	*Frequency (%)*
Race/Ethnicity				
White or Caucasian	33 (89.19)	11 (78.57)	16 (80.00)	59 (83.10)
Other	0 (0.00)	1 (7.14)	1 (5.00)	2 (2.82)
Did Not Respond	4 (10.81)	2 (14.29)	3 (15.00)	10 (14.08)
Health Insurance				
Private	25 (67.57)	7 (50.00)	12 (60.00)	44 (61.97)
Medicaid	4 (10.81)	2 (14.29)	1 (5.00)	7 (9.86)
Medicare	2 (5.41)	2 (14.29)	2 (10.00)	6 (8.45)
Affordable Care Act/Marketplace	3 (8.11)	0 (0.00)	1 (5.00)	4 (5.63)
Did Not Respond	3 (8.11)	3 (21.43)	4 (20.00)	10 (14.08)
Household Income				
<$25,000	4 (10.81)	3 (21.42)	5 (25.00)	12 (16.90)
$25,000 - $74,999	10 (27.03)	3 (21.42)	3 (15.00)	16 (22.54)
≥$75,000	19 (51.35)	5 (35.71)	8 (40.00)	32 (45.07)
Did Not Respond	4 (10.81)	3 (21.42)	4 (20.00)	11 (15.49)
Family History of Heart Health Issues				
Yes	21 (56.76)	8 (57.14)	12 (60.00)	41 (57.75)
No	13 (35.14)	4 (28.37)	4 (20.00)	21 (29.56)
Did Not Respond	3 (8.11)	2 (14.29)	4 (20.00)	9 (12.68)

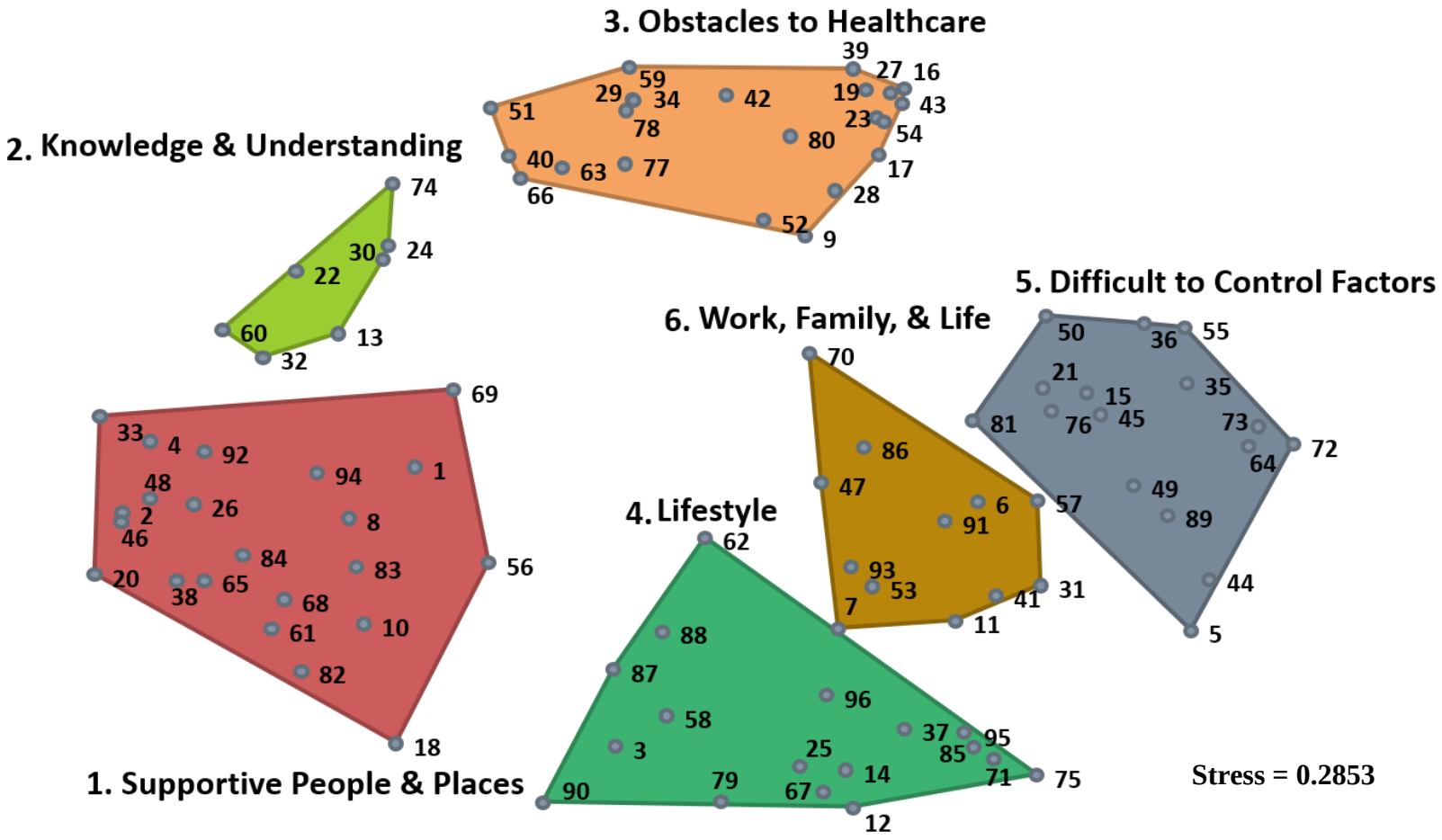


Figure 12. Six Cluster Solution for the 96 Brainstormed Items

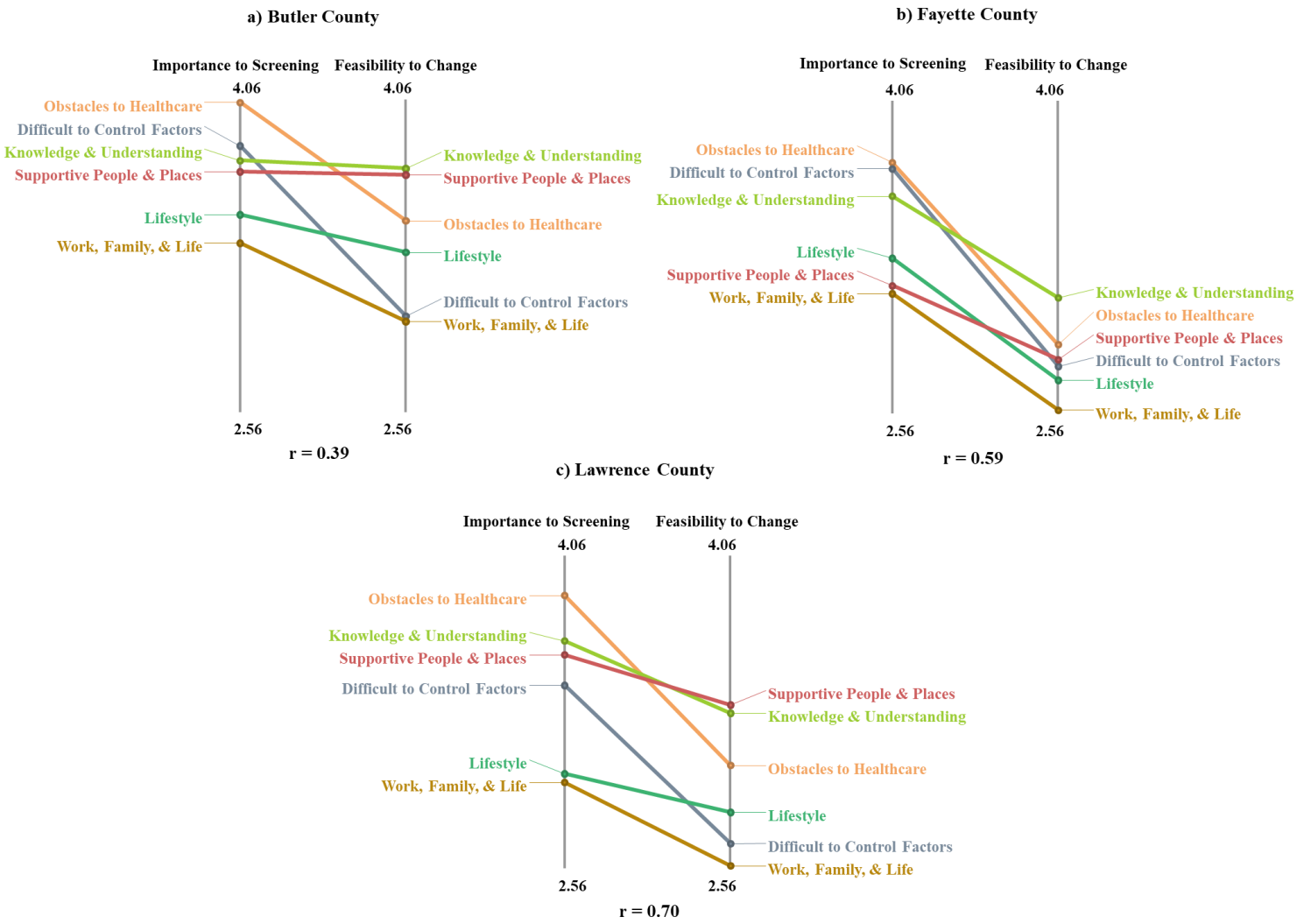


Figure 13. Pattern Matches by County – Screening Importance vs. Feasibility to Change

(Note: Utilized Likert-type rating scales, ranging from 1 [not at all important/feasible] to 5 [extremely important/feasible])

6.0 Dissertation Discussion

Overall, this dissertation, containing a rapid scoping review, spatial analysis, and concept mapping methods, provides an opportunity to explore how the findings of each element inform one another. Additionally, through the use of community-engaged methods utilizing a systems thinking approach, the findings generate the potential to transform this study into a fully integrated mixed method design through the identification of future additional spatial analyses, systems science approaches, and qualitative data collection to inform intervention development. Combined, these findings set the stage for future studies to fully capture factors to address to increase CVD prevention among women throughout the Appalachian region.

6.1 Summary of Findings

Combined, the three papers in this dissertation provide: 1) context for the current state and goals for future research on the health of Appalachian women, 2) the association of county-level social and environmental factors (e.g., income, medical facilities, healthy food retailers, and recreation facilities) with CVD mortality among women in the Northern Appalachian counties of PA, and 3) the perceptions of women within three of these counties on the important factors affecting CV health of women in their communities along with future potential intervention opportunities in rural Appalachian counties to improve CVD prevention.

Specifically, paper 1 presents the state of research on the health of women in Appalachia by describing what has been studied over the past two decades and by identifying gaps for future

public health research. In this work, we highlight health topics in need of further exploration, population characteristics (e.g., needs among youth/aging, race/ethnicity, gender identity, sexual orientation) to be included in future works, and ways to build theoretical frameworks and methodological approaches intended for this population. We also discuss regional variation, including the need for more research throughout the subregions of Appalachia, and the need for broader, more cohesive and comprehensive representation of the needs of this population in the literature. Additionally, this review demonstrates the limited use of community-engaged research, an omission due to the influential role of community-level factors (e.g., cultural practices and assets[131,220,229]) on health, suggesting the need to build upon existing community resources to improve health in this population and to support a holistic view of women's health in the region.

Next, paper 2 shows that CVD mortality rates among women in Appalachian PA remained higher than national averages from 2011 to 2015 with three regionally high clusters. The exploratory spatial data analyses indicate significant spatial autocorrelation of CVD mortality and identify regional variation across resource levels (e.g., income, medical facilities, healthy food retailers, recreation facilities). The exploratory patterns in the three areas with high CVD support the regression results, where low median household income and low presence of recreation facilities are associated with high CVD mortality rates among women in Appalachian PA. In the Appalachian region, where economic factors continue to lag behind the rest of the country,[4,5] the role of income and its relationship to CVD prevention efforts need to be further explored, including low cost screening options that account for access challenges (e.g., transportation, childcare) or easily accessed health information related to preventive health behaviors. The significant association of recreation facilities with CVD mortality among women provides another opportunity for potential prevention efforts, where increased access to these facilities may play a

role in improving CV health among women. Future studies would benefit from directly engaging with women in Appalachian communities to uncover intervention strategies that would build upon local community assets, such as parks or existing facilities, and strategies to ensure exercise opportunities meet the complex life needs many women balance with multiple social roles.

Finally, in paper 3, by employing the participatory, community-engaged method of concept mapping with 71 women in three Appalachian PA counties, we identify 96 unique items that affect the heart health of Appalachian women. These items group together into six clusters that spanned the social-ecological framework. By deriving cluster names from participant descriptions for why certain items grouped together, we uncover novel ways of viewing multilevel, complex factors affecting CVD prevention among women in this region. By using county-level comparisons, we also provide potential intervention opportunities to improve CVD prevention among women in Appalachian PA, which build on positive social and community assets, promote holistic care, and utilize positive and validating messaging. Future studies can build on these results by exploring regional variation as well as differences by race, gender identity, or sexuality and by considering ways to implement new or adapted interventions to improve the health of women in this understudied population. Additionally, by including participant comments on the COVID-19 pandemic, we provide a platform for continuing discussion for how behaviors in this time will affect future CV health among women in the region.

6.2 Novel Mixed Method Results

Through the use of novel mixed methods, including the pairing of spatial analysis and concept mapping, this study allows for the consideration of how each method's findings inform each other as well as the previously discussed factors identified in the rapid scoping review.

Intersection of Concept Mapping and Rapid Scoping Review Findings

As displayed in **Figure 14**, the concept mapping findings greatly overlap with the factors identified in the rapid scoping review. This overlap consists of factors across the social-ecological levels (items in bold). While a few factors in the review are minimally discussed or not mentioned (items in red), the concept mapping results also include several novel factors to add to the conceptual framework for understanding CVD risk among Appalachian women (items in yellow).

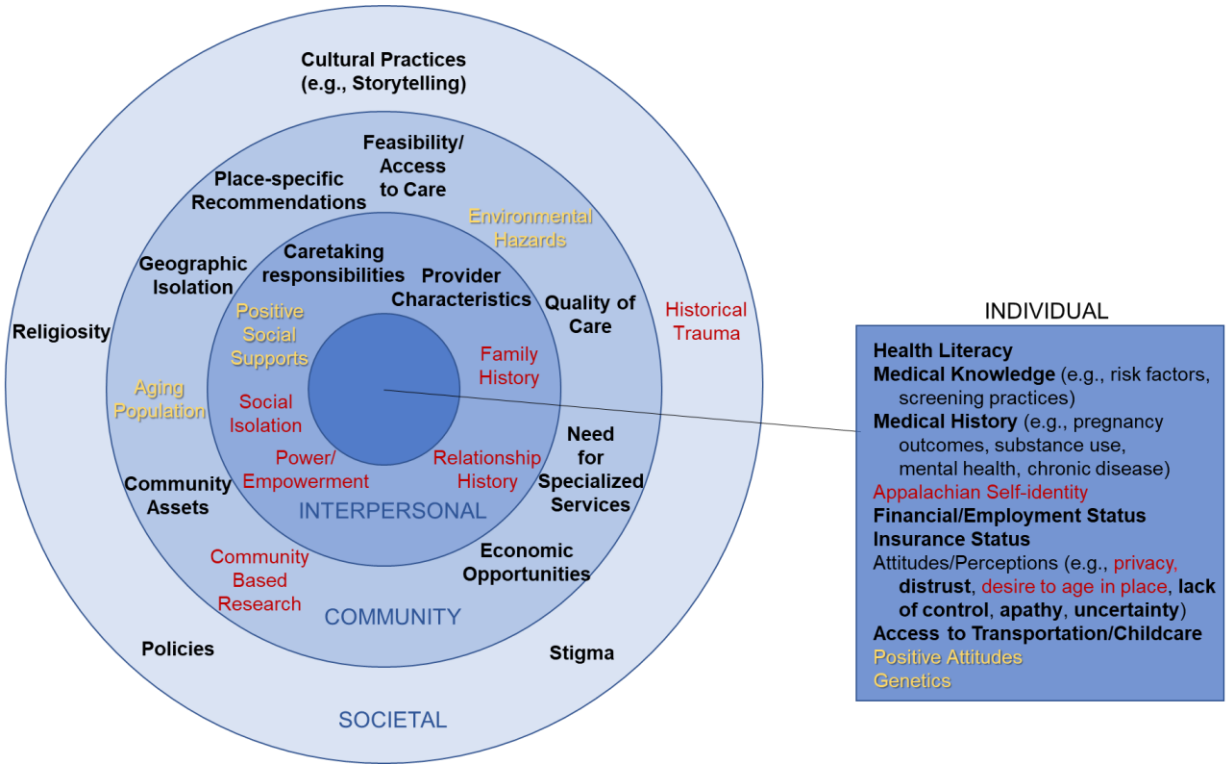


Figure 14. Intersection of Items from Concept Mapping Sessions and the Scoping Review

Individual Level. At the individual level, concept mapping participants discussed a majority of the previously identified factors. For example, participants regularly raised health literacy[37] and medical knowledge[121-124] within the conversation, as one participant describes:

> This assumes… medical or nutritional intelligence that a lot of people just don't have the privilege to have that access to. They look at pre-packaged lemonade. They're like, oh, it's lemonade. That's probably better for me, and they don't know to turn the label and see it actually has more sugar than the coke, but if you've never had that privilege of knowledge and education, then you're not going to know that. (Fayette County)

Likewise, participants frequently mentioned facing issues related to transportation, childcare, employment, and insurance.[50,123,124,129] Within attitudes and perceptions, participants tended to focus on distrust of the medical system[134] and lack of control[131] around CV health. One participant discusses feeling a lack of control around her health behaviors from life and work challenges:

> Because childhood experiences, you didn't pick your parents… You didn't pick where you live… You're too exhausted when you get home from your minimum wage job, which I work retail on concrete. At the end of an eight hour day shift, my feet hurt. (Butler County)

Additionally, in the concept mapping results, participants tended to discuss positive attitudes not previously covered in the literature. For example, participants listed items around gratitude, self-confidence, and positive motivators to be healthy. Likewise, participant brought up genetics as a Difficult to Control Factor not previously focused on in the literature. At this level, participants did not discuss privacy or the desire to age in place. They also did not actively describe themselves as having an Appalachian identity; however, participants expressed some of the same frustrations many individuals in Appalachia experience related to negative external perceptions. One participant explains:

> We get a lot of bad wraps in Fayette County. I mean, they still call us like Fayette-nam, and things like that. And I'm always quick to correct people whenever I'm on my own, and I don't feel that way about it because I've lived here my entire life. (Fayette County)

Interpersonal Level. At this level, participants mainly focused on the combination of caretaking responsibilities of women in their communities and experiences related to provider characteristics. Caretaking responsibilities[222] tended to fall into the categories of logistical barriers (e.g., how to exercise when childcare is not available) and constraints related to social norms. For example, one participant states, "I do think though that women care for others before themselves as a general rule. Not everybody, but many women do" (Butler County). Provider characteristics[122,123,126,134] also fell into multiple areas, including communication challenges such as biases toward focusing on weight loss rather than life challenges, a lack of a focus on prevention, and gender concordance. Related to the latter, one participant describes, "In the outer reaches and the smaller towns that is just so evident that the doctors are, you know, they're old men, and they don't explain things to women, and women don't know to ask" (Butler County). In terms of differences, participants largely only discussed issues of power in the context of patient-provider relationships; they rarely touched on aspects of partners and relationship history, such as intimate partner violence or negative facets of family history with CVD. As with the individual level, participants focused on positive aspects missing from the literature, including an entire cluster on Supportive People & Places; this cluster included items such as supportive family relationships, a good relationship so you can work on it together, and support by other women.

Community and Societal Levels. Across these broader levels, participants touched on almost all of the mentioned factors in the review. For example, many of the items in the cluster on Obstacles to Healthcare focus on access to care (e.g., availability of women's health care

services),[14,137] need for specialized services (e.g., availability of specialist doctors in the community),[40,214,215,228] quality of care (e.g., doctors not spending enough time with patients),[127,134,202,216] and geographic isolation (e.g., resources to travel long distances to get care).[14] Likewise, the cluster on Supportive People & Places also contains community assets and place-specific recommendations[51,222,227,229] to improve CV health, such as outdoor places for physical activities, local farms that offer good produce, and availability of gyms. At the societal level, participants actively discussed cultural practices[116,207,216] and religiosity.[44,142] One participant describes ways that understanding the local culture affects CVD prevention efforts:

> So, to reach them in the way that we know how to do it right now, really isn't working, so like aspects of more community outreach, like churches… people go to church every Sunday and are very religious… So that would be a good place. (Butler County)

Participants also regularly discussed the role of stigma (e.g., around mental health issues, gender roles, and weight loss)[125,133] and policies,[122,132] particularly related to healthcare such as Medicaid Expansion and the Medicare Modernization Act. As one participant elaborates, "And our church actually started a healthcare initiative as one of our ministries, because there were so many people that needed more information [about the Medicare Modernization Act]" (Lawrence County). Another participant speaks to the challenges of healthcare policies differing across state boundaries:

> I'm right on the border of West Virginia. So, if you have Pennsylvania medical assistance, healthcare, you can't cross the border to Morgantown, so then you have to go to Pittsburgh, and people don't have accessible transportation for an hour away. (Fayette County)

Finally, while participants did not speak to research-related approaches or to historical trauma, they did describe local industries and the connection to environmental hazards (e.g., fracking and pollution from mills affecting water and air quality as well as roads not being friendly to walkers).

Intersection of Concept Mapping and Spatial Analysis Findings

Participants in the concept mapping sessions also provided insights into the patterns found in the county-level spatial analyses, including the role of income, medical facilities, healthy food retailers, and recreation facilities.

Income. The role of income arises in multiple of the participant generated concept mapping clusters. For example, in the cluster on Supportive People & Places, participants listed concerns around economical places to shop for food and the need for free parks with trails for outdoor exercise. Likewise, the cluster around Work, Family, & Life contains items on the high cost of healthy food compared to unhealthy or fast food, the need to work multiple jobs to support family, and the way changing local economies has caused small local markets to close; the cluster on Difficult to Control Factors also includes poverty, high unemployment, and household income. The majority of income-related items are in the cluster on Obstacles to Healthcare, which includes cost of medication, cost to maintain proper health screenings, restrictive insurance, and resources needed to travel to care.[45,50,124,126,130] The complexity of how income is interwoven into multiple categories sheds light on a large variety of ways that increasing median household income could improve CVD mortality for women in Appalachian PA. These strategies could include: increasing access to and reducing costs of healthy food and exercise opportunities; increasing access to full coverage insurance, screening opportunities, and low cost medications; and addressing broader structural economic issues, such as poverty and unemployment.

Medical Facilities. Concept mapping participants spoke in depth about issues related to healthcare and medical facilities, as found in the cluster on Obstacles to Healthcare. In addition to costs, participants spoke about availability of care, particularly specialized or women's health services, barriers that insurance procedures raise in seeking care, and provider characteristics affecting quality of care. The items in this cluster speak to why the medical facility variable in the spatial analysis may not capture the mechanisms that generate risk for CVD mortality. First, we included all major healthcare facilities (e.g., hospitals, FQHCs, and rural health clinics), regardless of the availability of specialist or women's health services. Second, aggregating the number of facilities per county does not speak to perceptions related to quality of care or procedural barriers insurance may create in seeking care. These findings support utilizing a collection of variables capable of capturing these additional elements in order to determine which of these areas to focus on for future healthcare-focused interventions.

Healthy Food Retailers. Food-related items also appear in multiple of the clusters created by concept mapping participants. In terms of retailers, the majority of these items fall into the cluster on Supportive People & Places, where participants list economical places to shop for food, local farms that offer good produce, farmer's markers/Community Supported Agricultures (CSAs) to get fresh vegetables, and community dinners at churches to provide healthy food. Additionally, participants identified food behavior items in the Lifestyle cluster, including food and drink choices, eating too much processed foods, portion control, exhaustion at the end of the workday makes prep of healthy meals into a chore, eating to fill the time during stay-at-home orders/COVID-19, and availability of fast food restaurants. While we included grocery stores, fruit and vegetable stands, supercenters, and limited-service restaurants in our healthy food retailer variable, we may have not found a significant result for similar reasons to the medical facilities,

where the presence of these facilities does not necessarily capture other aspects of food access (e.g., cost, quality of food, parking availability) or food-based perceptions that may influence behaviors when purchasing healthy foods.

Recreation Facilities. Similar to the food retailers, concept mapping participants listed items related to exercise and recreation facilities in the clusters on Supportive People & Places and Lifestyle behaviors. In the former, participants note outdoor places for physical activities like walking, hiking, or biking in rural areas; sports/exercise spaces (e.g., tennis courts, basketball courts, bowling alleys); free parks with trails and outdoor exercise equipment; availability of gyms; and community exercise programs at local parks. For the Lifestyle cluster, participants note lack of exercise; a sedentary, stay-at-home lifestyle (affected by COVID-19); roads that are not friendly to walkers or bicycle riders; and fear to go to the gym even though it is open due to COVID-19. Participants also included an item on insurance companies offering gym memberships to elderly people in the cluster on Knowledge & Understanding, and they included an item on childcare needs limiting time to exercise in the Work, Family, & Life cluster. In support of our significant finding that an increase in recreation facilities per population in a county will decrease CVD mortality among women, the concept mapping participants regularly selected exercise opportunities as an accessible intervention point. While COVID-19 specific comments may not apply to our spatial analysis data due to the utilization of data from prior to the pandemic, participants described desire for increased access to gym memberships, positive social experiences gained from exercising with others, and positive opinions of local parks, which may contribute to our significant findings.

6.3 Overall Study Strengths & Limitations

As previously discussed, each of the papers in this dissertation has associated strengths and limitations that can inform future studies on the CV health of Appalachian women. Through the rapid scoping review, we set the stage for future systematic reviews by providing ideas for more refined, specific searches in which data quality can be analyzed. Future literature searches could include expanded search terms, specific population demographics, or characteristics unique to Appalachian subregions. Additionally, future work can seek to understand sex and gender-based differences on the variety of health burdens in the Appalachian region to determine how these differences can guide the development and implementation of future research, interventions, and programs. In paper 2, we utilize publicly available data to explore novel relationships between resource availability and CVD mortality at a county-level in Appalachian PA, which provides a framework for similar studies throughout the Appalachian region as well as those with more granular data to explore more localized patterns. Likewise, in paper 3, we uncover perceptions among women in Appalachian PA regarding the factors that affect the CV health of women in their communities, and future research should expand upon these analyses to capture similarities and differences throughout the Appalachian region. Future studies should also consider race/ethnicity, gender-identity/sexuality, and experiences across the life course. Overall, our study utilizes a novel mixed method design capable of capturing previously undescribed findings related to a range of complex, multilevel factors affecting CV health among Appalachian women. Through this combination of methods, we have confidence in the previously undescribed perceptions about preventive CVD factors among women in Appalachia along with novel intervention ideas provided by participants, which can be utilized to promote future community-engaged, mixed methods studies among women in the Appalachian region.

6.4 Future Directions for Research and Practice

The findings of this dissertation suggest several areas for future research and practice, including additional spatial analyses, use of systems science approaches, and interventions for development to increase CVD prevention among Appalachian women.

Spatial Analyses

The concept mapping findings suggest several areas for future spatial analyses. First, as these analyses are limited by the outcome measure of CVD mortality being publicly available at the county-level, future studies would greatly benefit from the collection of local data from health departments and universities to capture rates at a more granular level, such as census tracts or zip codes. The concept mapping participants expressed great variability within their counties in terms of population density, cultural practices, and proximity to resources; the ability to conduct intra-county spatial analyses would greatly enhance the understanding of the role of social and environmental factors in the CV health outcomes among women in the Appalachian region. Additionally, the concept mapping results shed light on the complexity of measuring facets of medical facilities, healthy food retailers, and recreation facilities to assess the medical, food, and exercise environments, respectively. Future spatial analyses would benefit from including additional attributes about these facilities, including variety of services offered, cost, and perceived quality. Finally, the concept mapping participants suggest a number of locations that may be useful for intervention development, such as pharmacists, churches, and other outdoor spaces that may be useful for promoting physical activity (e.g., free exercise space) or healthy eating (e.g., organizing local farmer's markets) or for providing health information to community members.

An analysis of these sorts of potential intervention spaces would be helpful when developing CVD prevention efforts based on existing community assets.

Systems Science Approaches

As this mixed methods study is rooted in systems thinking, utilizing systems science methods would be a valuable approach to continue building a conceptual framework for factors affecting CVD among Appalachian women. The concept mapping results provide 96 items, grouped in six thematic areas, represented in a spatial, visual format for additional exploration. For example, group based model building (GMB) may be a particularly valuable tool to expand this conceptual framework through the development of a causal loop diagram (CLD) grounded in stakeholder feedback. GMB, a participatory approach grounded in systems theory, is utilized to promote shared understanding among stakeholders and to identify the core ideas of a system within a complex health topic.[300,301] This approach involves a combination of qualitative and quantitative data collection, where stakeholders first identify the important elements related to a health topic followed by showing the relationships between these items in a CLD. If desired, the CLD can then be shifted into a system dynamics model through quantifying the relationships between the identified components. GMB relies on facilitated group sessions, which may also be utilized to identify leverage points (e.g., intervention activities) to create change in the system; if the model has been quantified, the study team can test the quantitative effects that implemented intervention strategies have on the identified health outcome or behavior.

Intervention Ideas

The intervention ideas raised by participants in the concept mapping sessions reflect improvements in preventive CVD screening, health education, and policy changes. Next steps include working with community stakeholders and researchers to identify the best interventions to implement among Appalachian women, which includes two strategies: 1) the determination of which evidence-based interventions (EBIs) currently supported by the Centers for Disease Control and Prevention (CDC) for CVD prevention[302] map onto those identified by concept mapping participants and 2) the use of activities to better understand feasibility, availability of community assets, receptiveness of community members, and ways to adapt potential EBIs for this population.

Participant requests for non-physician supports for health information fall in-line with the CDC-supported utilization of community health workers (CHWs) in CVD prevention.[302] The use of CHWs has shown to be effective in cervical cancer prevention among Appalachian women,[44] which could provide helpful guidance in ways to structure a CVD prevention-focused intervention. Additionally, participants mentioned pharmacists among noted potential sources for health information. The CDC also supports the utilization of tailored pharmacy-based interventions;[302] while specifically targeting medication adherence, these interventions could be expanded in this population to include other behavioral or screening-related information. Likewise, participant requests for holistic, consistent healthcare somewhat align with the CDC-approved strategy of team-based care, which seeks to form a care team including nurses, pharmacists, dieticians, social workers, CHWs, and physicians to coordinate and streamline a patient's CVD-related care.[302] Participants also note the need for social media or other media-based resources. In this general area, the CDC promotes the use of mHealth and telehealth technologies to improve treatment and screening adherence.[302] While these uses of technology focus on medication adherence and self-

management goals, uses of applications or social media to increase access to health information or tracking systems could be further developed. Cost-based interventions may be another viable option for exploration, as recommendations include reducing out-of-pocket costs related to high blood pressure and high cholesterol; these interventions could potentially be expanded upon to include further financial incentives for improving access to other preventive measures. Finally, few of the CDC-supported EBIs fall at the policy level, so future studies could explore how policy-based interventions have been utilized in other areas of chronic disease, particularly those that affect workplace policies and the promotion of physical activity as well as those to increase access to transportation, childcare, or other supports for women with multiple social roles.

Use of human-centered design activities may be one way to determine details surrounding potential interventions in this population. Human-centered design methods bring stakeholders together with researchers and can be used to improve adoption, implementation, and maintenance of interventions, including those geared toward chronic disease prevention.[303,304] These activities provide an interactive way to ensure the selected interventions and subsequent adaptations are grounded in community insights and feedback, as well as practical concerns from providers and leaders who may be instrumental in creating and maintaining any intervention efforts.

Other Areas for Exploration

Finally, additional areas for exploration in future research studies include expanding upon this work to capture subregional variability across Appalachia. As economic factors, rurality levels, cultural practices, and availability of resources vary throughout the region, understanding subregional needs for women in CVD prevention will be a helpful contribution in the identification of community-specific interventions to improve CVD outcomes. Additionally, this dissertation

study was on-going at the onset of the COVID-19 pandemic. While adjustments were made to account for participant safety and to ensure the timely completion of data collection, we did not actively seek to assess all the effects or ramifications of the pandemic, beyond thematic areas in our concept mapping findings. Based on the comments we did receive from participants, future studies would benefit from the exploration of the effects from the behavior changes, mental health effects, and economic constraints affecting many throughout this time; these effects may have lasting effects on population health, including among the CV health of Appalachian women.

6.5 Conclusions

As a whole, the use of mixed methods in this dissertation, including the novel combination of spatial analysis and concept mapping, contributes to the understanding of the social and environmental contexts for CVD prevention among Appalachian women. Such a contribution is significant because it pushes the scope of understanding of CVD risk among Appalachian women from a focus on individual behaviors to vital social and environmental factors. By building a framework of the multilevel factors for women in this region, this study provides valuable guidance to better understand decision-making and the corresponding action-oriented, community-specific strategies to improve CVD prevention by rural Appalachian women. Research in Northern Appalachian PA counties not only provides regionally specific insights but is also an important first step to understanding the pervasive extent of CVD among women in the Appalachian region. As a whole, this dissertation focused on characterizing CVD among rural Appalachian women: a) supplements recent joint Appalachian Regional Commission and Robert Wood Johnson Foundation efforts[2] to describe Appalachian health disparities by adding a unique female-focused

lens and augment those efforts by informing local programs and policy; b) provides valuable community-based information for successful interventions;[46,126] c) informs Healthy People goals to assess health disparities related to gender, SES, and geographic location;[305] and d) addresses noted NIH critical challenges to explore sex/gender-specificity in research and to advance methods to characterize exposures population-level health differences in disparate populations.[306]

Appendix A. Scoping Review Search Terms

Example Search:

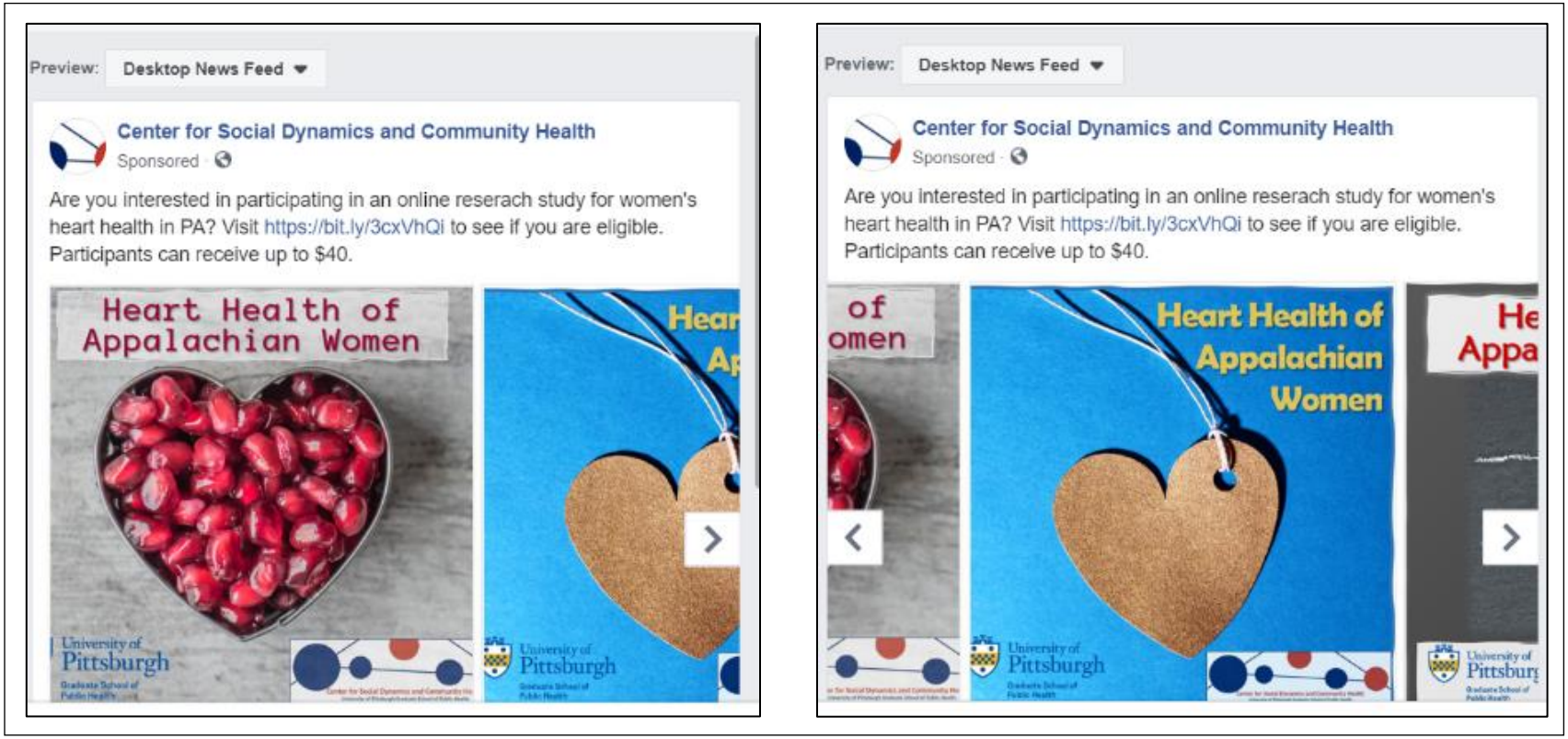
((((((("Health Services Accessibility"[Mesh]) OR (Availability of Health Services[tiab] OR Health Services Availability[tiab] OR Access to Health Care[tiab] OR Accessibility of Health Services[tiab] OR Health Services Geographic Accessibility[tiab] OR Program Accessibility[tiab] OR Contraceptive Availability[tiab])) OR (Availability of Health Services[ot] OR Access to Health Care[ot] OR Accessibility of Health Services[ot] OR Health Services Geographic Accessibility[ot] OR Program Accessibility[ot] OR Contraceptive Availability[ot])))) OR (((((women's health) OR women's health services) OR maternal health services)))) AND (((((((("Appalachian Region"[Mesh:noexp]) OR "Kentucky"[Mesh]) OR "Tennessee"[Mesh])) AND "Female"[Mesh]) OR "appalachian women") OR ("appalachia"[Title/Abstract]))

Appendix B. Example Scoping Review Data Charting Abstract Screening Form

Appendix Table 1. Example Scoping Review Data Charting Form

Authors	Year	Journal	Title	Topic	Source	Reviewer	Include	Exclusion - Reason	State(s)	Popu-lation	Theory (if listed)	Method	Major Findings	Suggestions/ Implications
Stubbs B, Hoots V, Clements A, Baily B.	2019	Addictive Behaviors Reports	Psychosocial Well-being and Efforts to Quit Smoking in Pregnant Women of South-Central Appalachia											
Clements AD, Cyphers NA.	2019	J Prev Interv Community	Prenatal substance use: Religious women report lower use rates, but do they use less?											
O'Donnell J, Goldberg A, Lieberman E, Betancourt T.	2018	Reprod Health Matters	I wouldn't even know where to start": unwanted pregnancy and abortion decision-making in Central Appalachia.											
Mark KP, Crosby RA, Vanderpool RC.	2018	J Rural Health	Psychosocial Correlates of Ever Having a Pap Test and Abnormal Pap Results in a Sample of Rural Appalachian Women.											
Staton M, Ciciurkaite G, Oser C, Tillson M, Leukefeld C, Webster JM, Havens JR.	2018	Subst Use Misuse	Drug Use and Incarceration among Rural Appalachian Women: Findings from a Jail Sample											
Oza-Frank R, Conrey E, Bouchard J, Shellhaas C, Weber MB.	2018	Matern Child Health J	Healthcare Experiences of Low-Income Women with Prior Gestational Diabetes.											
Snell-Rood C, Merkel R, Schoenberg N.	2018	Med Anthropol	Negotiating the Interpretation of Depression Shared Among Kin.											

Appendix C. Example Social Media Recruitment Ads



Appendix Figure 1. Example Social Media Recruitment Ads

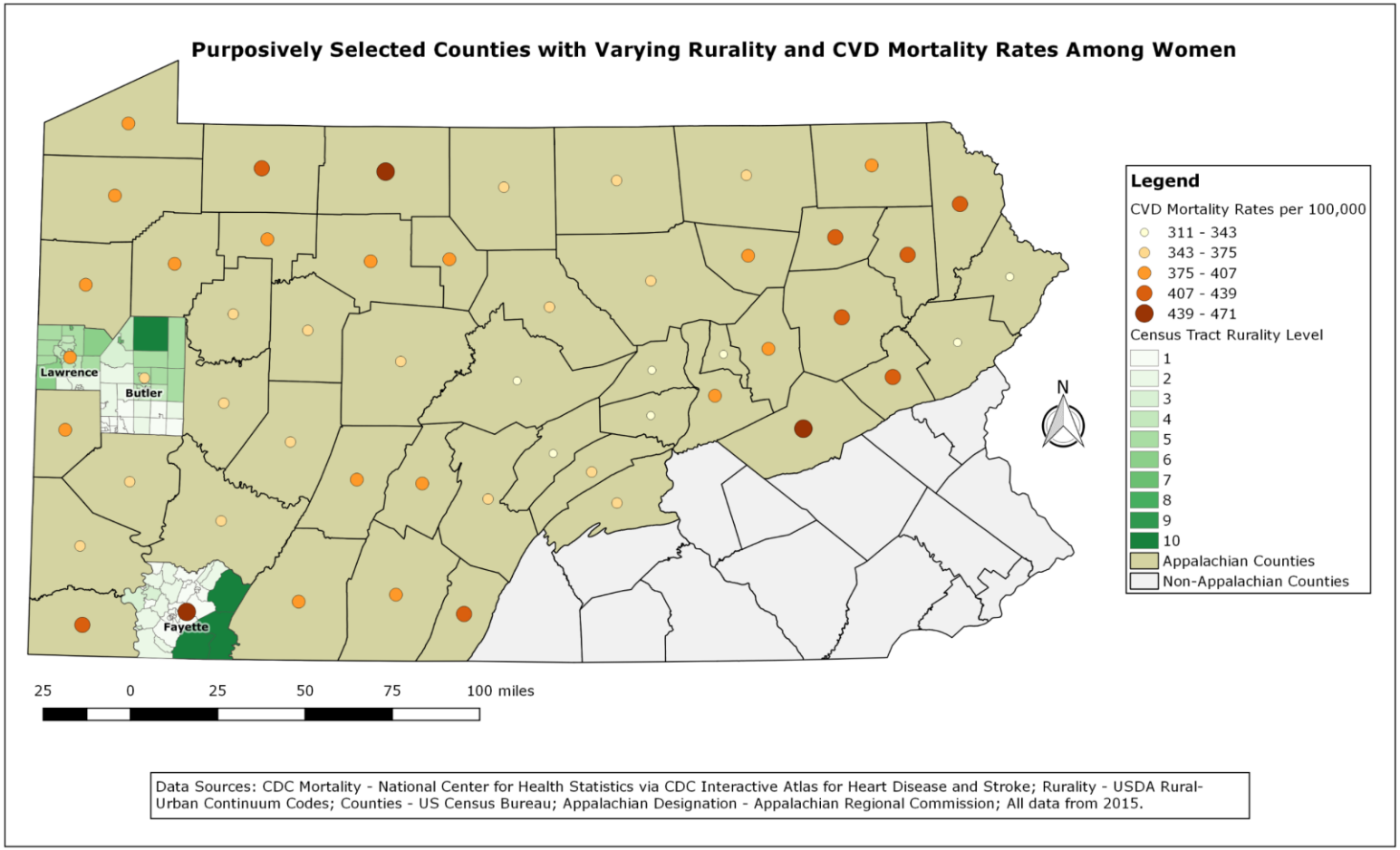
Appendix D. Table of Spatial Analysis Data Sources

Appendix Table 2. Spatial Analysis Data Sources

Construct	Category	Item	Source	Used in Final Analyses
Health Outcomes (DV)	***Mortality***	Heart Disease Mortality	NCHS Compressed Mortality[1]	
		Stroke Mortality	NCHS Compressed Mortality[1]	
		Overall CVD Mortality	NCHS Compressed Mortality[1]	Y
Resources (IV)	***Medical Resources***	Physician Rate per 100,000	RWJF County Health Rankings	Y
		Specialists Rate per 100,000	RWJF County Health Rankings	
		Health Professional Shortage Areas	HRSA	
		Hospital Locations	PA Department of Health	Y
		Rural Health Clinic Locations	PA Department of Health	Y
		Federally Qualified Health Centers	USHHS	Y
	Preventive Resources	Grocery Stores per 1,000 Residents	USDA Food Environment Atlas	
		Healthy Food Retailers per 100,000	NAICS Codes (445110, 445230, 452311)[2]	Y
		Access to Exercise Opportunities	RWJF County Health Rankings	
		Recreation Facilities per 100,000	NAICS Codes (713940)[2]	Y
		Social Associations per 10,000	RWJF County Health Rankings	
Risk Factors & Morbidity	***Medical Risk Factors***	Diabetes Prevalence	NCCDPHP, Div. Diabetes Translation	
		Smoking Prevalence	RWJF County Health Rankings	
		Obesity Prevalence	RWJF County Health Rankings	
SES & Demographic Factors	***Health Insurance***	% Under 65 without Insurance	RWJF County Health Rankings	
	Economic	Median Household Income	American Community Survey	Y
		% Households Below 150% Poverty Level	American Community Survey	Y
		County Economic Status	ARC	
		% Receiving Disability	American Community Survey	Y
	Education	% At Least Some College	RWJF County Health Rankings	Y
	Rurality	Rurality Status	ARC/USDA	
		Population Density	US Census/American FactFinder	Y
	Demographics	% Female	US Census/American FactFinder	Y
		% Non-Hispanic White	US Census/American FactFinder	Y
		% Over Age 65	US Census/American FactFinder	Y

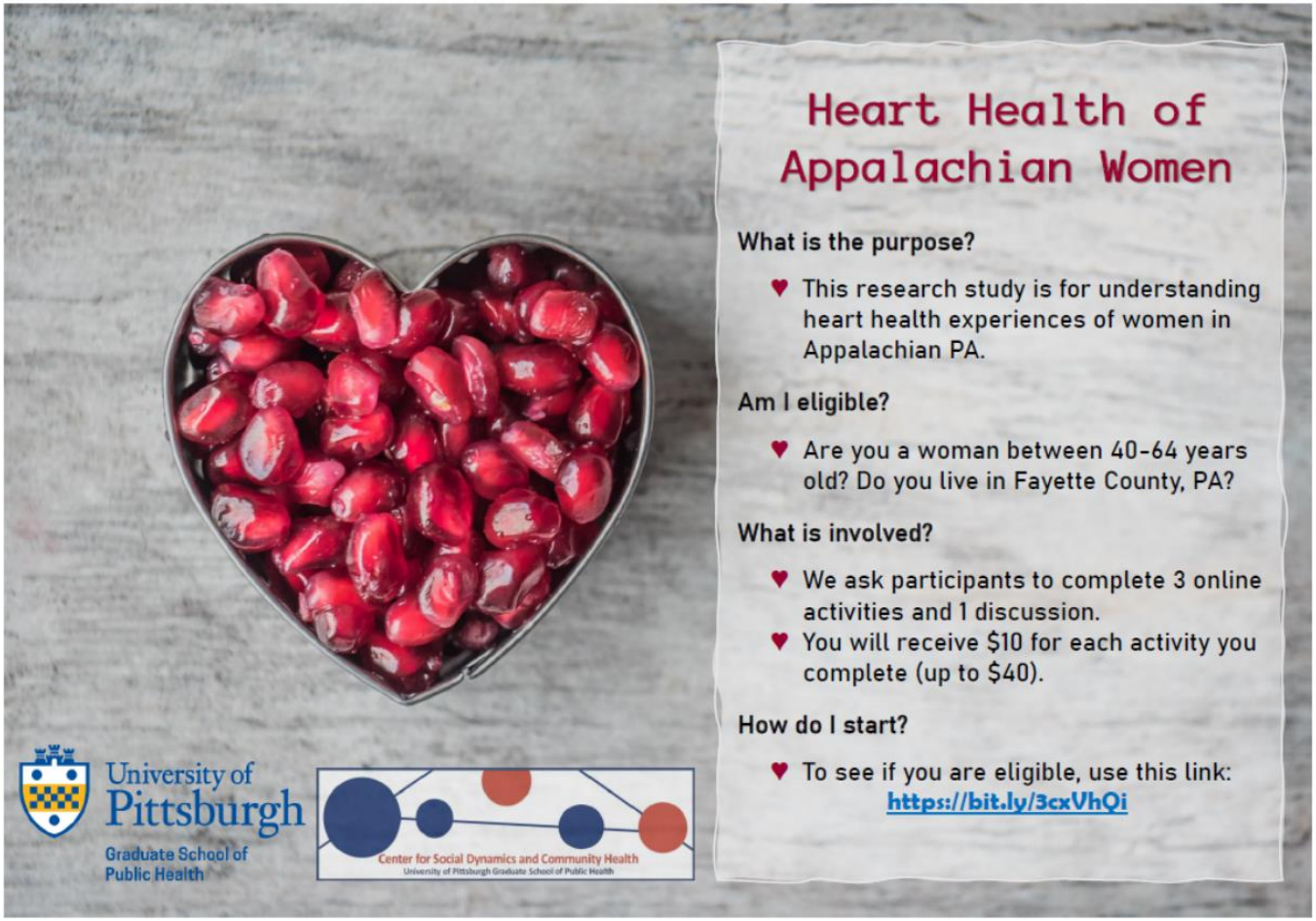
[1]Obtained via the CDC Interactive Atlas of Heart Disease and Stroke: https://nccd.cdc.gov/DHDSPAtlas/
[2]Obtained via ReferenceUSA database through the Carnegie Library System: http://clp-ezp.carnegielibrary.org/login?url=http://www.referenceusa.com

Appendix E. Map of Purposively Selected Counties for Recruitment



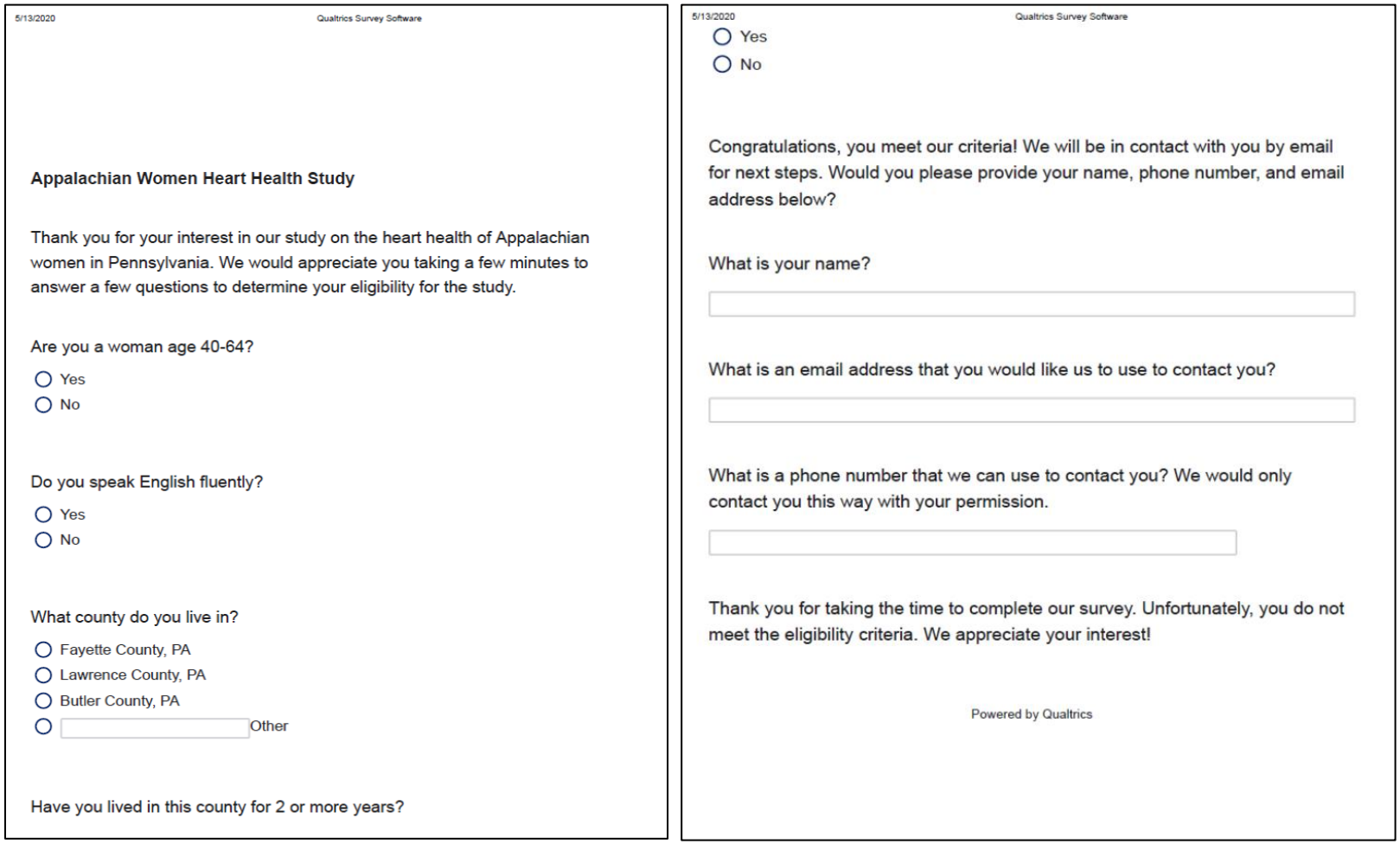
Appendix Figure 2. Map of Purposively Selected Counties for Concept Mapping

Appendix F. Example Concept Mapping Recruitment Flyer



Appendix Figure 3. Example Concept Mapping Recruitment Flyer

Appendix G. Concept Mapping Eligibility Screener



Appendix Figure 4. Concept Mapping Eligiblity Screener

Appendix H. Concept Mapping Consent Language

Welcome to the Heart Health of Appalachian Women Concept Mapping research study! We appreciate your input and value your participation. Thank you for your time!

This research study is designed to gather your honest thoughts about experiences women in your community have with heart health. The results of this study will be used to: a) range of perceived barriers and facilitators to heart health by women in Appalachian Pennsylvania; b) relationships between individual, social, and environmental factors identified as important for various preventive CVD screenings; c) potential community-specific interventions to improve heart health among Appalachian women in Pennsylvania.

You may return to the home page at any time by clicking on the "home" icon, which you can find at the top right side at the top of the page. Please be sure to save your responses frequently as you go by clicking the "save" icon that will appear near the top right portion of the page once you begin an activity.

Please select "Login" to enter your username and password. This username and password has been emailed to you. Please remember to keep your username and password in a safe place to use for future sessions.

What will participation involve?

Your participation involves the completion of 3 online concept mapping data collection activities and 1 discussion/interview.

- **Brainstorming Activity:** You will be asked to contribute information and insight into your experience with making heath a shared value. This activity will take approximately **15 to 60 minutes** to complete. This activity will be available for 4 weeks.
- **Sorting Activity:** You will be asked to sort responses into categories that make sense to you. This activity will take approximately **30 to 60 minutes** to complete. This activity will be available for 4 weeks.
- **Rating Activity:** You will be asked to rate each response on a scale in 3 areas: 1) the importance to your decision to receive heart health screenings, and 2) the importance to your lifestyle behaviors, and 3) how likely it is that change can be made in your community. This activity will take approximately **30 to 60 minutes**. This activity will also be available for 4 weeks for completion.
- **Discussion/Interview:** If you complete the 3 online activities, you will be asked if you are interested in participating in a discussion where we will share combined results and get feedback. This activity will take approximately **60 minutes** to complete and will be scheduled with you at a convenient time.

Your input and perspective is important, and we greatly appreciate you contributing your time and insight to the project. You will receive a **$10 gift card for each activity** that you complete (**up to $40**).

Before moving ahead, please remember that:

- There is the small but possible risk that you may feel some emotional discomfort when participating in the project activities. You do not have to answer any questions or provide any information that may make you uncomfortable.
- You can withdraw from the study at any time. If you choose to withdraw, we will retain your data from prior to your withdrawal but will remove your information and no longer include you in future activities.
- Computer use can be monitored and is impossible to be completely clear. If you are concerned about your safety related to this project, exit the webpage and clear your browser history.
- We will not use your name or any other personally identifiable information to identify your project records or any related documentation. Instead, we will assign you an identification code (study ID). Your responses will be kept private and confidential and no personally identifiable information will be linked to your responses.
- All records related to your involvement in this project will be stored on a password-protected file only accessible to the project team. All study staff will be trained in responsible conduct of research and human protections.
- The research team is committed to the open and timely dissemination of research outcomes. The outcomes generated in this grant will be presented at local and national conferences and published in a timely fashion. Investigators in the proposed activity recognize that promising new methods and strategies may arise during the course of the research. The Investigators are aware of and agreed to abide by the principles for sharing research resources as described by NIH in "Principles and Guidelines for Recipients of NIH Research Grants and Contracts on Obtaining and Disseminating Biomedical Research Resources." Proposals from external investigators wishing to develop manuscripts and grant proposals using study data will be considered by the investigative team on a case-by-case basis.
- This research study is covered by a Certificate of Confidentiality from the National Institutes of Health. This means that the researchers cannot release or use information, documents, or samples that may identify you in any action or suit unless you say it is okay. They also cannot provide them as evidence unless you have agreed. This protection includes federal, state, or local civil, criminal, administrative, legislative, or other proceedings. An example would be a court subpoena. There are some important things that you need to know:
    - 1) the Certificate DOES NOT stop reporting that federal, state or local laws require. Some examples are laws that require reporting of child or elder abuse, some communicable diseases, and threats to harm yourself or others.

- 2) The Certificate CANNOT BE USED to stop a sponsoring United States federal or state government agency from checking records or evaluating programs.
- 3) The Certificate DOES NOT stop disclosures required by the federal Food and Drug Administration (FDA).
- 4) The Certificate also DOES NOT prevent your information from being used for other research if allowed by federal regulations.
- Finally, researchers may release information about you when you say it is okay. For example, you may give them permission to release information to insurers, medical providers or any other persons not connected with the research. The Certificate of Confidentiality does not stop you from willingly releasing information about your involvement in this research. It also does not prevent you from having access to your own information.

- Once the data analyses are complete, all data will be destroyed according to institutional guidelines.
- **This concept mapping project is being conducted by Jessica Thompson of the University of Pittsburgh. If you have any questions about the study, concept mapping, or the software, please email: jrthompson@pitt.edu or call (412) 624-3610.**

Appendix I. Participant Characteristic Questions and Response Options

Thank you for participating in our concept mapping activities! We appreciate your time. We'd like to know a bit more about the participants who have participated in this study. As with all the other information we collect, your responses will remain anonymous.

1) What is your age? (Please respond in years.) _____

2) What is your race/ethnicity?
   a. Black or African American
   b. White or Caucasian
   c. Hispanic, Latinx, or Spanish origin
   d. American Indian or Alaskan Native
   e. Asian
   f. Other: _____

3) What is your annual household income level?
   a. $14,999 or less
   b. $15,000 to $24,999
   c. $25,000 to $34,999
   d. $35,000 to $49,999
   e. $50,000 to $74,999
   f. $75,000 to $149,000
   g. $150,000 or more
   h. I don't know
   i. I prefer not to answer

4) What form of health insurance do you have?
   a. Private Health Insurance (e.g., UPMC Health Plan, Allegheny Health Network)
   b. Medicaid
   c. Medicare
   d. Affordable Care Act Marketplace
   e. Military Healthcare (TRICARE/VA/CHAMP-VA)
   f. Indian Health Service
   g. Single Service Plan (e.g., Dental, Vision, Prescriptions)
   h. I do not have health insurance coverage
   i. I don't know

5) Do you or anyone in your immediate family have a history of heart health problems (e.g., heart attack, heart failure, etc.)?
   a. Yes
   b. No or not to my knowledge

Appendix J. Concept Mapping Brainstorming Script

Session 1: Brainstorming/Idea Generation (Activity 1)

Thank you for your time and attendance, and welcome! This activity is designed to gather your honest thoughts about experiences women in your community have with heart health. Before we get started, we would like to go over the ground rules for the session today:

As a reminder, there is the small but possible risk that you may feel some emotional discomfort when participating in the concept mapping activities, but you will not be required to answer any questions or provide any information that makes you uncomfortable. Also, there is a potential risk of an accidental breach of confidentiality; therefore, we have taken the following steps to maintain your confidentiality: All records related to your involvement in this research study will be stored in a password-protected secure folder accessible only by the researchers. Your identity on these records as well as on any related study documentation will be indicated by your study identification number rather than by your name, and the information linking your subject identification number with your identity will be kept separate from the research records and interview responses. No identifiers, such as your name, will be shared. Your participation is voluntary, and you may withdraw from the study at any time. Please understand that there are no right or wrong answers, and you will not be judged for your opinions or ideas. You should feel free to make negative or positive comments. We just ask that you share how you honestly feel and that you respect the opinions of others.

This activity may take you from **15 to 60 minutes.** You will receive a **$10 gift card** for completing this activity.

All of you have expressed an interest in discussing what is going on related to heart health in this particular community, and you may be wondering, "why are you interested in **my** community?" We have invited women like you throughout rural Appalachian counties of Pennsylvania to participate in these activities to understand why this area has high rates of heart disease and stroke for women. We hope that by speaking with you that you can help us to understanding what could be happening in your community and what we can do to improve these rates.

To help you think about this spectrum, we've provided you a table of what we mean when talking about "heart health screenings." Generally, these are things that you would have checked at a visit with a doctor or other healthcare provider. These include: your blood pressure, your cholesterol levels, your weight (which when taken with your height you may be told your Body Mass Index, or BMI), your waist circumference (or using a tape measure to see the size of your waist), your blood sugar (or glucose), and checks on your smoking, physical activity (or exercise), or diet (or food-related) habits. We would like you to think about these different types of heart health screenings.

Recommended Screenings	*How Often?*	*Starting when?*
Blood pressure	Each regular healthcare visit or at least once every 2 years if blood pressure is less than 120/80 mm Hg	Age 20
Cholesterol ("fasting lipoprotein profile" to measure total, HDL and LDL cholesterol, and triglycerides)	Every 4-6 years for normal-risk people; more often if any you have elevated risk for heart disease and stroke	Age 20
Weight / Body Mass Index (BMI)	During your regular healthcare visit	Age 20
Waist circumference	As needed to help evaluate cardiovascular risk. This is a supplemental measurement if your BMI is greater than or equal to 25 kg/m2.	Age 20
Blood glucose test	At least every 3 years	Age 45
Discuss smoking, physical activity, diet	Each regular healthcare visit	Age 20

We also recognize that each community is unique, and we'd like for you think about the wide range of things that could be going on in your community specifically, which can range from individual factors to larger cultural or social issues. By hearing your thoughts about these factors, we will be able to develop a comprehensive list that we will use in the future sessions together. We hope to use these lists, and the activities and discussions based on them, to inform how service providers in the area approach heart health screening and programs that are specific to the needs of your community.

With all of this in mind, here is the question we'd like you to consider. As a reminder, there are no right or wrong answers, and we are interested in all that comes to mind. The goal of this session is to come up with a list of responses to the question and to explore the full scope of responses.

FOCAL QUESTION: What are all the factors, good or bad, that contribute to the cardiovascular (heart) health of women in your community?

Probes:

- What about for different population groups in your community?
- What might be unique to your community/to you?
- What is missing?
- What about for other types of screening (blood tests, body measurements, lifestyle checks)?

Thank you! We really appreciate your input. The next step in this project is for our research team to review the lists and to prepare a master list for use in the next step. The final list of items will include responses from all the participants throughout the rural Appalachian counties in Pennsylvania, so if you continue to participate, you may see items added that you all did not mention. At the next activity, you will be asked to share your thoughts about the similarities and differences between the items and their importance.

Thank you again for your time! We greatly appreciate your time and participation.

If you have any questions about today's session or your participation, please feel free to reach out to me, Jessica Thompson, at jrthompson@pitt.edu or (412) 624-3610.

Appendix K. Concept Mapping Sorting and Rating Script

Session 2: Sorting & Rating (Activities 2 & 3)

Thank you for your time and welcome! These activities are designed to gather your honest thoughts about experiences women in your community have with heart health. We will be following up on the list of items that we gathered from women like you in the last session.

As a reminder, there is the small but possible risk that you may feel some emotional discomfort when participating in the concept mapping activities, but you will not be required to answer any questions or provide any information that makes you uncomfortable. Also, there is a potential risk of an accidental breach of confidentiality; therefore, we have taken the following steps to maintain your confidentiality: All records related to your involvement in this research study will be stored in a password-protected secure folder accessible only by the researchers. Your identity on these records as well as on any related study documentation will be indicated by your study identification number rather than by your name, and the information linking your subject identification number with your identity will be kept separate from the research records and interview responses. No identifiers, such as your name, will be shared. Your participation is voluntary, and you may withdraw from the study at any time. Please understand that there are no right or wrong answers, and you will not be judged for your opinions or ideas. You should feel free to make negative or positive comments. We just ask that you share how you honestly feel and that you respect the opinions of others.

Are there any questions before we begin?

Part 1: Sorting

In this activity, you will categorize statements, according to your view of their meaning or theme. To do this, you will sort each statement into groups that make sense to you. Group the statements for how similar in meaning or theme they are to one another. Give each group a name that describes its theme or contents. People vary in how many categories they create (e.g., 5 groups to 20 groups). If you have any questions about this activity, please contact Jessica Thompson or at jrthompson@pitt.edu or (412) 624-3610.

Reminder – The statements were developed in response to the focal prompt listed below. These statements are the combined responses of all participants of the brainstorming activity.

Focal Prompt*: *What are all the factors, good or bad, that contribute to the cardiovascular (heart) health of women in your community?

Instructions:

1. Read through the statements in the "Unsorted Statements" column on the left.
2. Drag statements from the column into the window on the right. If you drag a topic to any empty space in the window, the computer will prompt you to name a new group which that topic is going to be a part of. If you drag a topic into a group that's already there, it will become a part of that group.
3. Please note that the group names should reflect the reason that you sorted the responses together into the same pile (e.g., "citrus fruits" and "leafy vegetables" might be good pile names for a food-related

concept mapping project). If you have a response that does not seem to relate to any others, please put it in its own group.

4. Do NOT create categories according to priority, or value, such as "Important" or "Hard to Do."
5. Do NOT create categories such as "Miscellaneous" or "Other" that group together dissimilar statements. Put a statement alone in its own category if it is unrelated to all other statements. Make sure that every statement is put somewhere. Do not leave any statements in the "Unsorted Statements" column.

To save your information, click the "save" image at the top of the screen. To return to the sorting and rating main page, click the "home" icon. You will be able to see your progress on the left side of the screen. This activity may take you up to **60 minutes.** You will receive a $10 gift card for completing this activity.

Part 2: Rating

In this activity, you will rate each response on a scale of importance in 3 areas: 1) the importance to your decision to receive heart health screening and 2) the importance to your lifestyle behaviors; and 3) the likelihood of changing the item in your community.

Reminder – The statements were developed in response to the focal prompt listed below. These statements are the combined responses of all participants of the brainstorming activity.

Focal Prompt*: *What are all the factors, good or bad, that contribute to the cardiovascular (heart) health of women in your community?

This activity may take you up to **60 minutes.** You will receive a $10 gift card for completing this activity.

Rating Scales (3 Scales):

First, please respond to the following questions and rate each statement on a scale of 1 to 5, where 1 is not at all important and 5 is extremely important:

1) ***How important is each of these items to your decision to receive heart health screenings (e.g., cholesterol, blood sugar, blood pressure)?***
2) ***How important is each of these items to your lifestyle behaviors (e.g., smoking, diet, physical activity)?***

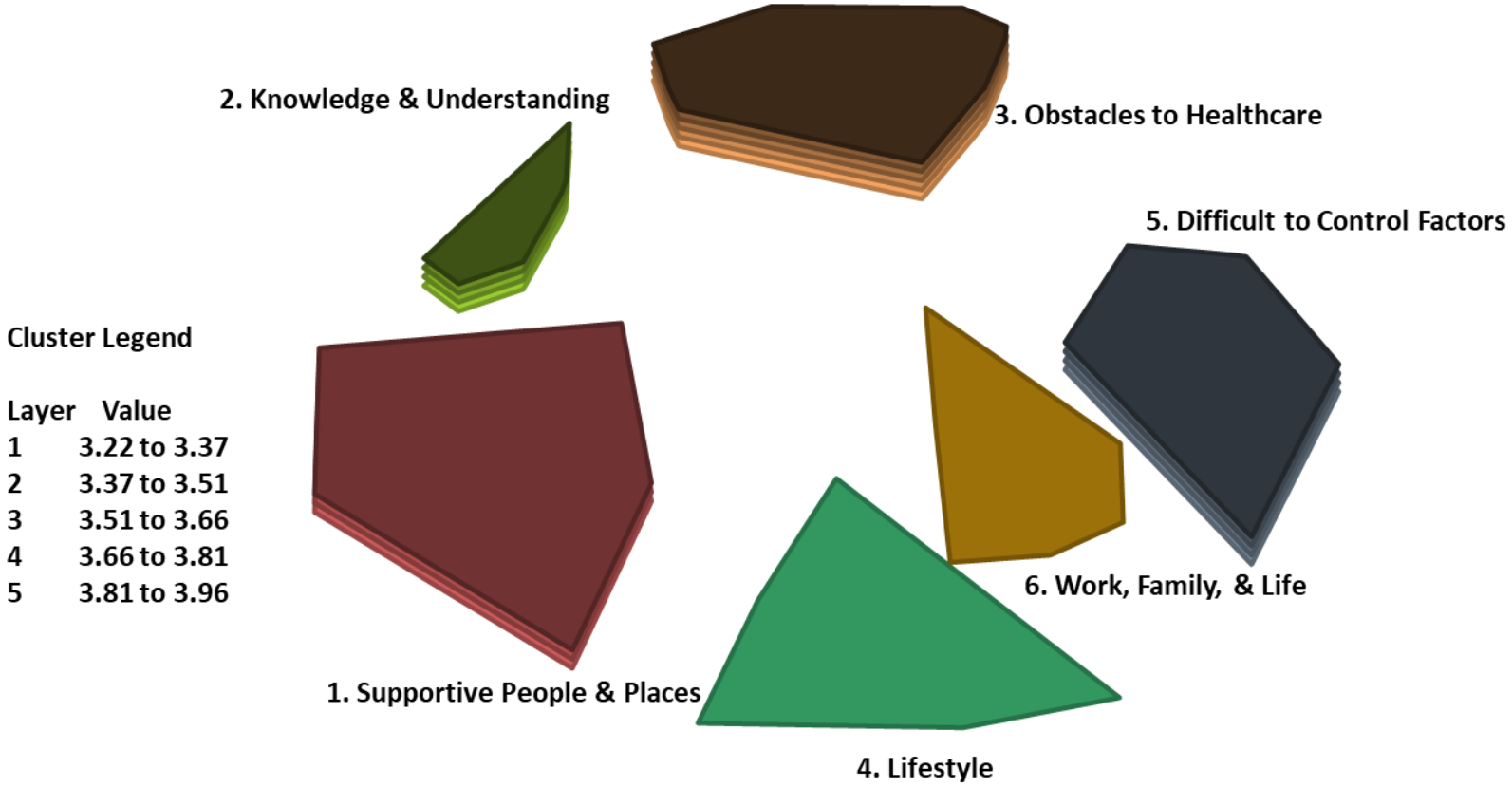
Next, please respond to the following question and rate each statement on scale of 1 to 5, where 1 is not at all feasible and 5 is extremely feasible.

3) ***How feasible is it that each of these items could be changed in your community?***

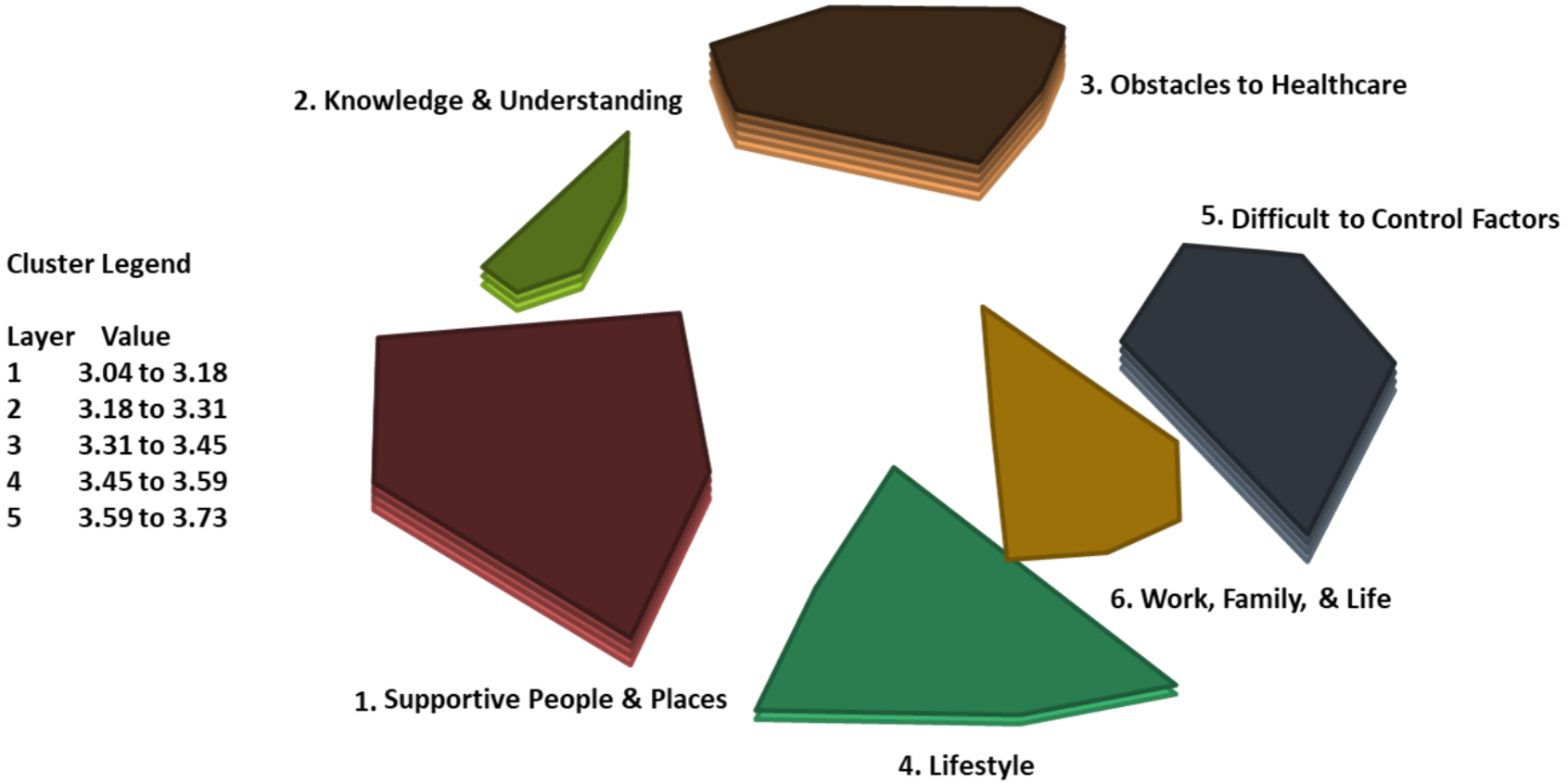
Thank you again for your time! We greatly appreciate your time and participation. If you have any questions about this activity or your participation, please feel free to reach out to Jessica Thompson or at jrthompson@pitt.edu or (412) 624-3610.

Appendix L. Additional Concept Maps

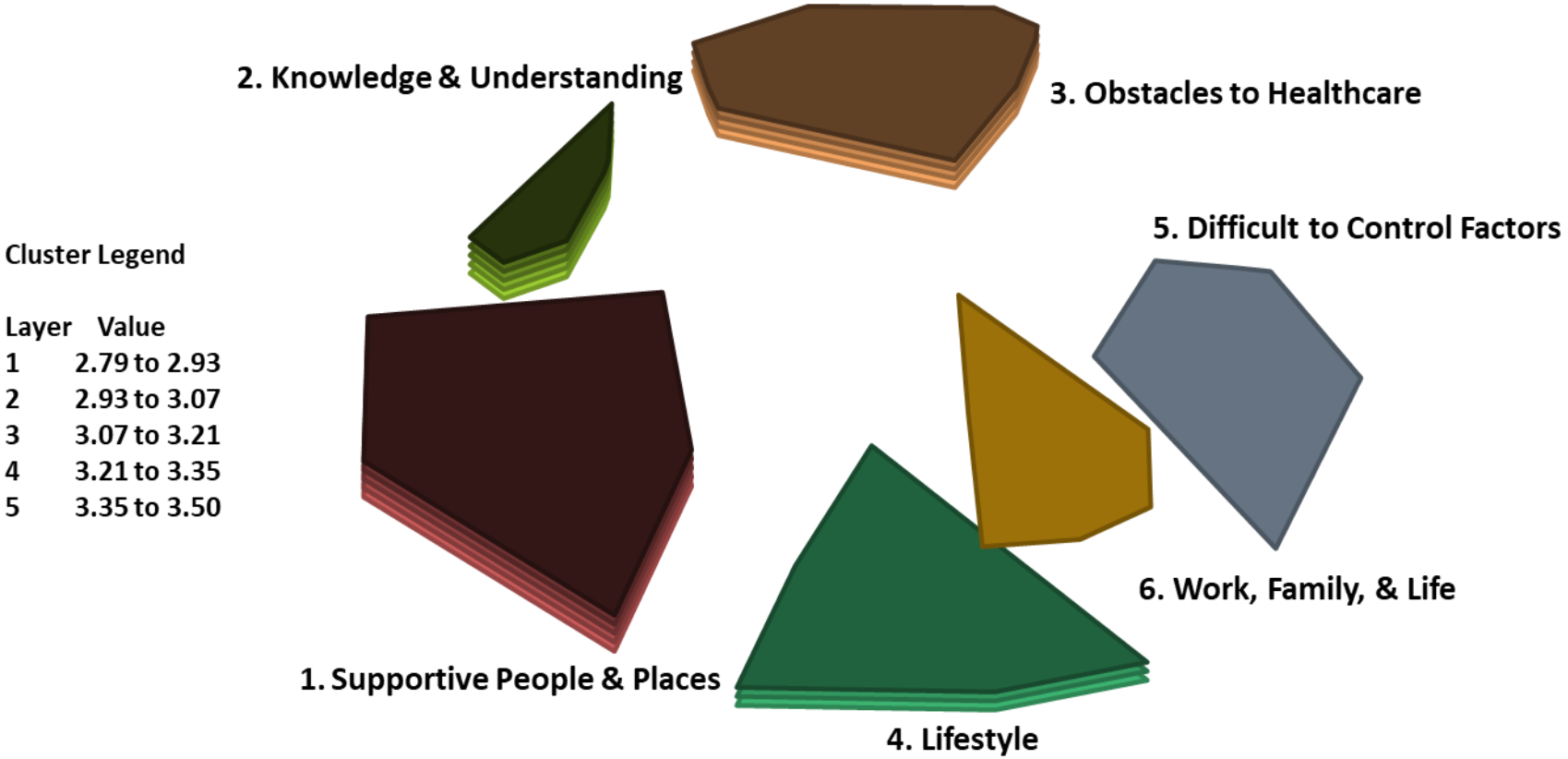
L.1. Cluster Rating Maps: Likert-type ratings from 1 (not at all important/feasible) to 5 (extremely important/feasible)



Appendix Figure 5. Cluster Rating Map for Importance to Screening

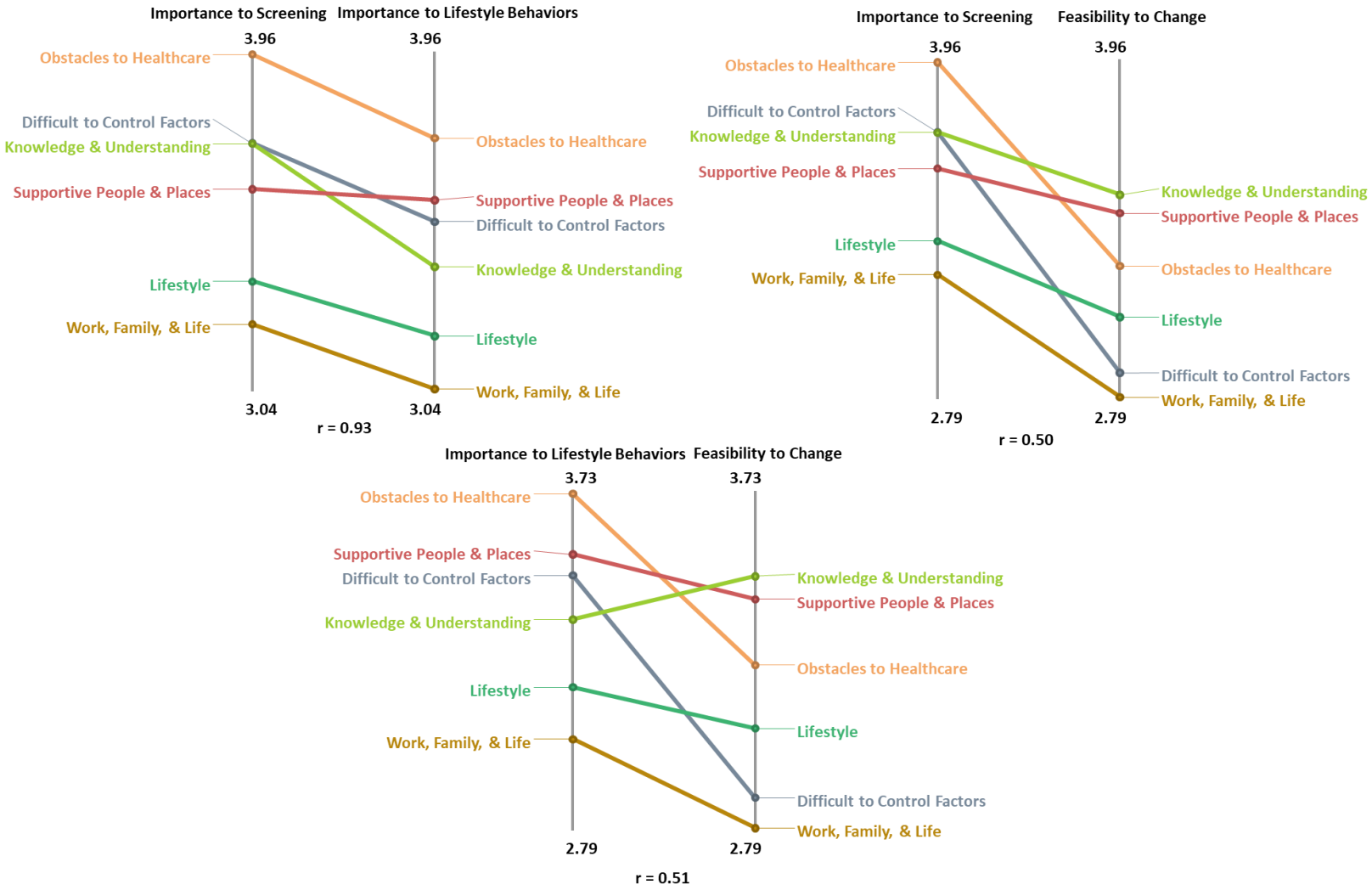


Appendix Figure 6. Cluster Rating Map for Importance to Lifestyle Behaviors



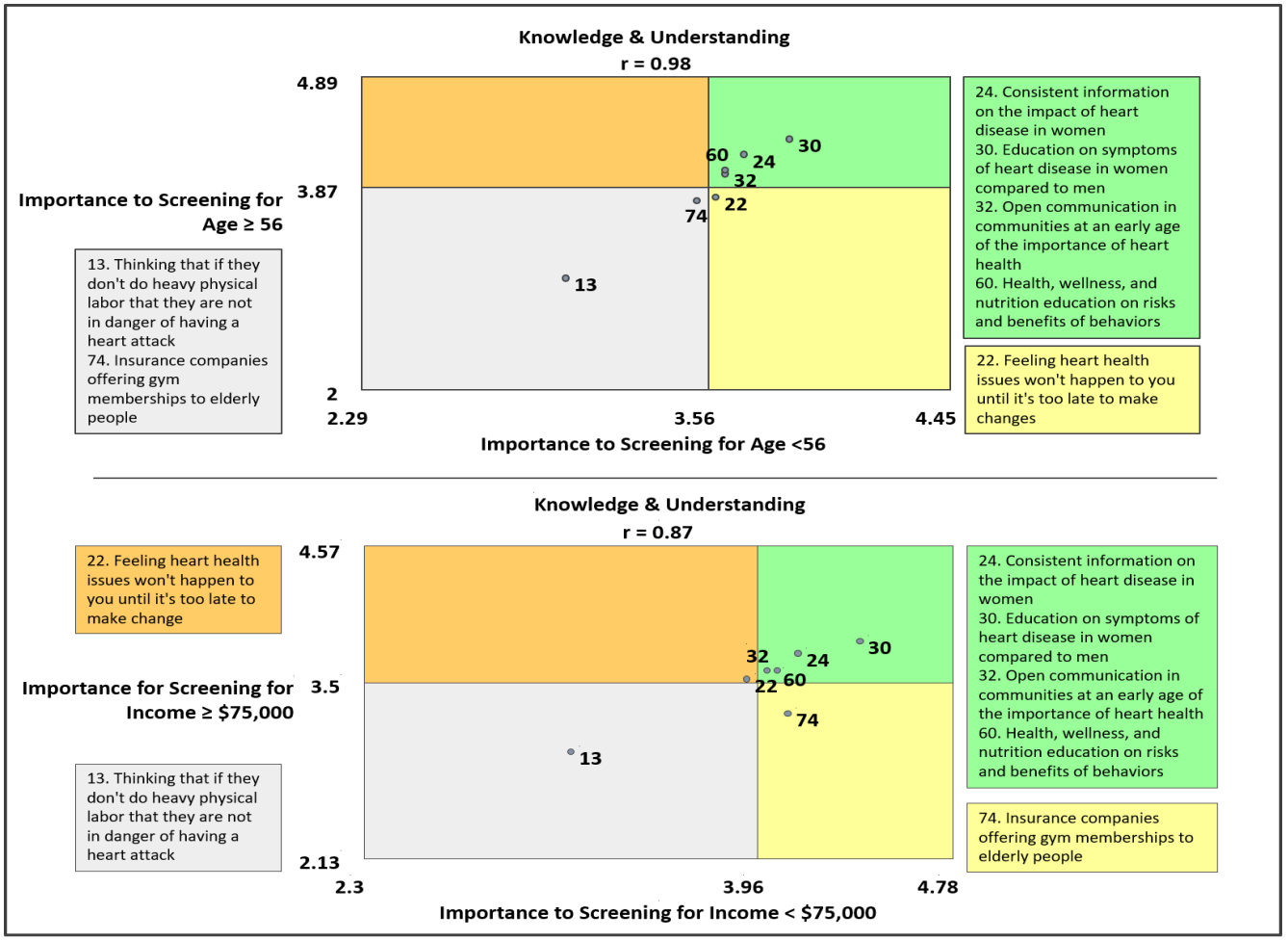
Appendix Figure 7. Cluster Rating Map for Feasbility for Change in the Community

L.2. Patterns Matches: Likert-type ratings from 1 (not at all important/feasible) to 5 (extremely important/feasible)

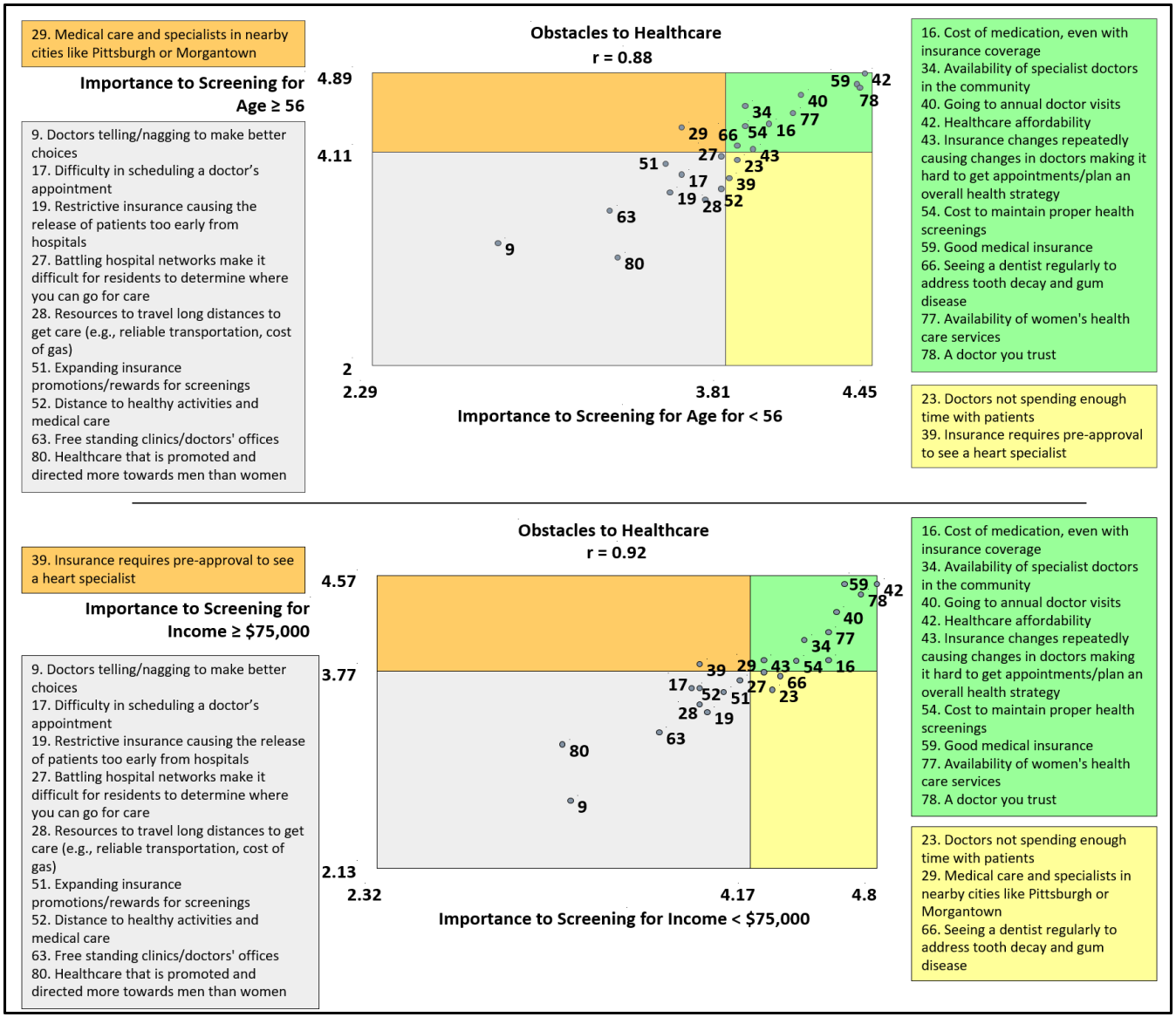


Appendix Figure 8. Pattern Matches for Average Cluster Ratings

L.3. Example “Go-Zone” Bi-variate Plots for Importance to Screening Rating by Age and Income-Level for Clusters 2 and 3



Appendix Figure 9. "Go-Zone" Plot for Cluster 2 (Knowledge & Understanding) by Age and Income-Level



Appendix Figure 10. "Go-Zone" Plot for Cluster 3 (Obstacles for Healthcare) by Age and Income-Level

Appendix M. Concept Mapping Interpretation Script

Session 3: Interpretation

Wait a few minutes for all to join

Give RA recording access and make her a co-host

Share slides in the chat

Thank you for your time and attendance, and welcome! Today's session is designed to gather your honest thoughts about experiences women in your community have with heart health. We will be following up on the list of items that were sorted and rated from community members like you in the last session. We used the responses to make concept maps that we will be sharing with you today.

Quick introductions of PI and RA; have others say their name before recording starts – ask how they have joined/if they have the materials

- As a reminder, there is the small but possible risk that you may feel some emotional discomfort when participating in the concept mapping activities, but you will not be required to answer any questions or provide any information that makes you uncomfortable.
- Also, there is a potential risk of an accidental breach of confidentiality; therefore, we have taken the following steps to maintain your confidentiality: All records related to your involvement in this research study will be stored in a password-protected secure folder accessible only by the researchers. Your identity on these records as well as on any related study documentation will be indicated by your study identification number rather than by your name, and the information linking your subject identification number with your identity will be kept separate from the research records and interview responses. No identifiers, such as your name, will be shared.
- Your participation is voluntary, and you may withdraw from the study at any time.
- Please understand that there are no right or wrong answers, and you will not be judged for your opinions or ideas. You should feel free to make negative or positive comments. We just ask that you share how you honestly feel and that you respect the opinions of others.

Are there any questions before we begin?

We will be taking notes and the discussion will be recorded. This is only to ensure that we don't miss anything said. No names or identifying information will be associated with what is discussed here today. We respect your right to privacy, and will not share this information with anyone outside of our team. We will generate and share reports summarizing the results from this project.

Is it alright with everyone if we record this session?

This session will last approximately **60 minutes.** You will receive a **$10 gift card** for completing this session.

Start the recording of the main room

Share my screen; mention the link in the chat.

Part 1: Discussion of Point and Cluster Maps (10 minutes)

- Remind participants of the data collection so far and study aims.
- Share the point and cluster maps for questions and discussion.

Stop for questions

Part 2: Naming of Clusters (30 minutes)

Assign participants to breakout rooms; PI group 1 & RA group 2

Start recordings in each breakout room - NOTE: these will go to our computers not the cloud.*

20 minutes while in the breakout room and come back to main room

- Form 2 breakout groups of 2-5 participants.
- One group assigned clusters 1, 3, 5; other assigned 2, 4, 6.
- Directions: Read through the items in each cluster and discuss:
    - What do these items have in common?
    - What would you call this cluster?
    - Which items stand out to you as particularly important?
    - Which of these items do you think has been particularly affected by COVID-19?

Probes/facilitation for PI & RA:

- Read items aloud to start the discussion (and for those on the phone) – what do these have in common and what would you call the cluster?
- Let participants discuss.
- When it sounds like they've come upon a name; repeat it back and verify you got it.
- Help them move along to another cluster if they are getting stuck. They can come back to a particularly hard cluster or have them compromise on a name (it's okay for it to be called 'this' & 'that')
- Try to make sure everyone participates -if there is a quiet person, try to ask them what they think at points.
- Monitor the time. If they get to 8 minutes on a single cluster, they need to move along to make sure they get through all 3.

Come back together for report out – what are your cluster names and why did your group pick that name? (10 minutes)

- We'll alternate back and forth so the clusters are in order.

Part 3: Discussion of Ratings/Intervention Opportunities by County (20 minutes)

- Show cluster pattern matches for screening importance and feasibility to change.

Part 1:

- Full group discussion of clusters 3 & 5 (or 5):
- Why do you think these clusters were rating highly important for heart health screening?
- Why do you think these clusters were not rated highly for change in your community?
- Looking across the items, which of these could potentially be addressed?

Probes for PI & RA:

- A doctor you can trust – how do you go about finding a doctor you can trust? What might be standing in the way?
- Good medical insurance/cost of medicine even with insurance – How has this affected women in your community? Do women have to prioritize other needs over medication?
- Family history with heart health – How do families talk about heart health?

Part 2:

- Full group discussion of clusters 1 & 2 (or 2 & 3):
    - Why do you think these clusters were rating highly feasible for making changes in your community?
    - Looking across the items, which of these would you recommend addressing?
    - What would that look like in your community (e.g., is there a way to build on existing assets already in your community?)
    - What considerations would need to be made for COVID-19?

Probes for PI & RA:

- Education on symptoms in women/consistent information on impact in women – What would an educational program or materials look like? How would you like to learn this information?
- Keeping up a regular exercise routine/outdoor places for exercise – How can women in your community do this? What resources already exist?
- Buddy system for motivation/support from other women – What would this look like for women in your community? How could we build support?

Thank you again for your time! We greatly appreciate your time and participation.

Appendix N. Concept Mapping Qualitative Codebook

Appendix Table 3. Concept Mapping Qualitative Codebook

Codes	Sub-Codes	Definition
Cluster Codes		
Cluster 1		Quotes specifically about cluster 1
Cluster 2		Quotes specifically about cluster 2
Cluster 3		Quotes specifically about cluster 3
Cluster 4		Quotes specifically about cluster 4
Cluster 5		Quotes specifically about cluster 5
Cluster 6		Quotes specifically about cluster 6
Inductive Codes		
COVID-19		Effects of the current pandemic
Women-specific		Factors or effects specific to women (as compared to men)
External_Internal		Factors in terms of internal or external effects (e.g., locus of control)
Social Supports		People that support one's health (e.g., friends, family, peers)
Stress		Factors related to experiencing or managing stress
Positive Attitudes		Factors related to positive attitudes or perceptions toward health/healthy behaviors
Comorbidities_Coexisting Conditions		Mentions of coexisting health conditions (e.g., diabetes, obesity)
Health Behaviors		Discussion of lifestyle behaviors: smoking, diet, physical activity
Community		Discussion of items at a community-level
	Community Characteristics_Barriers	Discussion of community characteristics/barriers (e.g., closing of mills/employment sources, etc.)
	Community Assets	Discussion of community assets (e.g., resources, facilities, supports)
	Environment	Discussion of community environmental factors (e.g., air quality, water quality)
Everyday Needs		Discussion of everyday life needs (e.g., work, childcare, etc.)
Mental Health		Discussion of mental health (e.g., stress, depression, anxiety, etc.)
Spatial Analysis Codes		
Household Income		Discussion of financial or monetary aspects
Food Environment		Discussion of the food environment (e.g., access, availability, affordability)
Exercise Environment		Discussion of the exercise environment (e.g., access, availability, affordability)
Healthcare Environment		Discussion of the healthcare environment (e.g., access, availability, affordability)
	Access to Care	Discussion of the access to healthcare in the community
	Quality of Care	Discussion of the quality of healthcare available
	Specialized Services	Discussion of specialized care (e.g., specialists, mental health services, etc.)
	Provider Characteristics	Discussion of provider characteristics (e.g., trust, communication, gender-concordance)
	Insurance Status	Discussion of having/not having insurance or being underinsured
Aging Population		Discussion of the aging population/older populations

Scoping Review Codes	
Cultural Practices	Discussion of regional or community-level cultural practices
Religiosity	Discussion of religion, faith, or spirituality in the community
Historical Trauma	Discussion of historical trauma/community history
Stigma	Discussion of any type of stigma related to health, gender, community, etc.
Policy	Discussion of the role of policy changes
Specialized Services	Discussion of specialized care (e.g., specialists, mental health services, etc.)
Community Assets	Discussion of community assets (e.g., resources, facilities, supports)
Caretaking Responsibilities	Discussion of the role as caretaker for family (e.g., children, elderly parents, etc.)
Family History	Discussion of one's family history (e.g., health history, generational effects)
Relationship History	Discussion of one's relationship history/interactions with partners/significant others
Power_Empowerment	Discussion of power or empowerment among women or as a community
Social Isolation	Discussion of social isolation in communities/among women
Health Literacy	Discussion of health literacy/ability to understand health information
Medical Knowledge	Discussion of medical knowledge
Medical History	Discussion of one's personal medical history
Appalachian Identify	Discussion of identifying or being a part of Appalachia
Employment Status	Discussion of having/not having a job or general community unemployment
Transportation	Discussion of access to transportation
Childcare	Discussion of access to childcare
Privacy	Discussion of the need for privacy/a lack of privacy
Distrust	Discussion of distrust of outsiders or of information
Apathy	Discussion of apathy toward health/healthy behaviors
Uncertainty	Discussion of uncertainty about health/healthy behaviors

Appendix O. Concept Mapping Full Cluster and Item List with Ratings

Appendix Table 4. Concept Mapping Full Cluster and Item List with Ratings

Item #	Cluster	Screening Importance	Lifestyle Importance	Feasibility to Change
1: Supportive People & Places				
82	Keeping up a regular exercise routine	**4.3**	**4.36**	**3.61**
10	Motivation/attitude toward healthy behaviors	**4.18**	**4.15**	3.51
46	Supportive family relationships	**4.04**	**4.15**	3.51
26	Gratitude/positive attitude toward health	**4.02**	**4.06**	**3.63**
65	Self-confidence/good self-image	3.93	4.04	**3.59**
69	Economical places to shop for food (e.g., Aldi, Costco, etc.)	3.93	3.74	3.18
92	Being able to manage stress, particularly during the pandemic	3.86	3.91	3.14
2	A good relationship so you can work at it together	3.8	3.85	3.35
61	Outdoor places for physical activities like walking, hiking, biking in rural areas	3.7	3.68	**3.7**
48	Concern for the well-being of others	3.63	3.66	3.55
20	Support by other women	3.58	3.42	3.47
18	Effect of your friends' and family's exercise and eating habits on your own (for better or worse)	3.54	3.45	3.29
33	Having a positive, open platform to express and discuss concerns and opinions	3.53	3.3	3.48
38	Buddy system for motivation	3.44	3.35	3.45
94	Local farms that offer good produce	3.42	3.42	3.5
8	Farmer's markets/CSAs to get fresh vegetables	3.39	3.32	3.53
1	Modern day conveniences available to women to make life easier	3.39	3.28	3.35
83	Sports/exercise spaces (e.g., tennis courts, basketball courts, bowling alleys)	3.34	3.3	3.29
68	Free parks with trails and outdoor exercise equipment	3.33	3.43	3.49
56	Availability of gyms	3.16	3.15	3.24
84	Community exercise programs at local parks	2.95	2.96	3.45
4	Community dinners at churches to provide healthy food	2.47	2.28	3.18

2: Knowledge & Understanding				
30	Education on symptoms of heart disease in women compared to men	**4.09**	**3.64**	**3.76**
24	Consistent information on the impact of heart disease in women	**3.93**	**3.64**	**3.71**
60	Health, wellness, and nutrition education on risks and benefits of behaviors	**3.82**	**3.66**	3.61
32	Open communication in communities at an early age of the importance of heart health	3.8	3.4	**3.75**
22	Feeling heart health issues won't happen to you until it's too late to make changes	3.68	3.34	3.37
74	Insurance companies offering gym memberships to elderly people	3.63	3.34	3.33
13	Thinking that if they don't do heavy physical labor that they are not in danger of having a heart attack	3.04	2.6	2.94
3: Obstacles to Healthcare				
42	Healthcare affordability	**4.65**	**4.28**	2.94
59	Good medical insurance	**4.58**	**4.35**	3.36
78	A doctor you trust	**4.57**	**4.36**	**3.71**
40	Going to annual doctor visits	**4.4**	**4.38**	**3.76**
77	Availability of women's health care services	4.3	3.87	3.41
34	Availability of specialist doctors in the community	4.23	4	3.35
16	Cost of medication, even with insurance coverage	4.19	4.09	2.96
54	Cost to maintain proper health screenings	4.13	4	3.18
43	Insurance changes repeatedly causing changes in doctors making it hard to get appointments/plan an overall health strategy	4.04	3.57	2.92
66	Seeing a dentist regularly to address tooth decay and gum disease	4.02	4.08	3.37
29	Medical care and specialists in nearby cities like Pittsburgh or Morgantown	3.98	3.79	**3.63**
23	Doctors not spending enough time with patients	3.95	3.73	3.37
27	Battling hospital networks make it difficult for residents to determine where you can go for care	3.93	3.45	3.18
39	Insurance requires pre-approval to see a heart specialist	3.84	3.42	3.02
51	Expanding insurance promotions/rewards for screenings	3.77	3.58	**3.57**
52	Distance to healthy activities and medical care	3.77	3.47	3.14
17	Difficulty in scheduling a doctor’s appointment	3.75	3.51	3.29
28	Resources to travel long distances to get care (e.g., reliable transportation, cost of gas)	3.68	3.29	2.98
19	Restrictive insurance causing the release of patients too early from hospitals	3.64	3.49	2.86
63	Free standing clinics/doctors' offices	3.42	3.23	2.98
80	Healthcare that is promoted and directed more towards men than women	3.21	3.19	3.27
9	Doctors telling/nagging to make better choices	3.02	2.89	3.18

4: Lifestyle				
37	Lack of exercise	**4.09**	**4.02**	**3.84**
25	Food and drink choices	**4**	**4.06**	**3.75**
85	Eating too much processed foods	**3.95**	**3.79**	**3.33**
62	Women take care of others before themselves/don't make their health a priority	**3.89**	3.7	2.94
3	Portion control	3.82	**3.92**	**3.53**
96	Exhaustion at the end of the workday makes prep of healthy meals into a chore	3.72	3.74	2.9
87	Childhood experiences with food and exercise affect adulthood	3.7	3.57	2.9
95	A sedentary, stay-at-home lifestyle, which is affected by COVID-19	3.35	3.23	3.32
75	Alcohol use	3.25	2.67	2.88
71	Effects of drug use/abuse (e.g., opiates)	3.19	2.74	3
14	Eating to fill the time during stay-at-home orders	3.11	2.94	3.29
12	Watching too much TV	3.05	2.72	3.04
88	Roads are not friendly to walkers or to bicycle riders	3	3.08	2.8
58	Fear to go to the gym even though it is open due to COVID-19	2.91	2.75	2.84
67	Too many electronics in the home	2.56	2.48	2.66
79	Availability of fast food restaurants	2.46	2.13	2.67
90	Arguments in the media/social media cause stress	2.65	2.58	2.47
5: Difficult to Control Factors				
55	Family history with heart health	**4.47**	**4.21**	2.76
44	Obesity	**4.11**	**3.88**	3.04
73	Genetics	**4.11**	**4.08**	2.57
36	Having multiple co-existing health issues (e.g., obesity, diabetes) may affect ability to afford treatment	**4.02**	3.77	3
45	Household income/finances	3.98	3.87	2.86
49	Mental health issues (e.g., anxiety, depression)	3.91	3.66	**3.33**
64	Diabetes	3.89	3.15	2.94
89	Chronic pain can cause you to not be able to exercise	3.81	**3.92**	2.88
21	Poverty	3.75	3.06	2.63
5	Smoking	3.64	2.92	2.86
35	An aging population	3.46	3.34	2.49
81	Water quality	3.4	3.6	**3.29**
15	Air quality	3.4	3.62	**3.1**
76	High unemployment	3.33	3.28	2.73
50	High-level of worry about breast cancer compared to heart problems	3.11	2.94	**3.1**
72	Asthma	3.02	2.64	2.43

6: Work, Family, & Life				
57	Ignoring the symptoms and delaying medical attention in order to care for/not worry their family	**4.07**	**3.89**	**3.51**
93	High cost of healthy food compared to unhealthy or fast food	**3.86**	**3.96**	**3.04**
53	Work schedules make life busy/cause a lack of free time	**3.77**	**3.62**	2.78
91	Weather like ice/snow affecting healthy behaviors (e.g., motivation to eat healthy, ability to exercise)	**3.27**	**3.23**	2.43
41	With COVID-19 mandates, it is difficult to get out of the home for more than essential needs	3.18	2.96	**2.98**
11	Working multiple jobs to support family makes fast food a more appealing option	3.16	2.81	2.78
70	Substandard housing affecting health	3.11	2.81	2.73
47	Programs and facilities that are closed now because of COVID-19	3.11	2.98	2.71
86	Small local markets closing	3.02	2.81	2.73
31	Weight after childbirth	2.89	2.62	**2.84**
7	Childcare needs limits time to exercise	2.79	2.58	2.6
6	Working in industrial settings	2.38	2.19	2.35

(Note: The bolded items have the highest ratings for the indicated rating scale within a given cluster.)

Bibliography

1. Appalachian Regional Commission. Health Care Costs and Access Disparities in Appalachia. In:2012.
2. PDA I, Cecil G. Sheps Center, Commission AR. Health Disparities in Appalachia. https://www.arc.gov/research/researchreportdetails.asp?REPORT_ID=138. Published 2017. Accessed September 22, 2017.
3. Appalachian Regional Commission. The Appalachian Region. https://www.arc.gov/appalachian_region/TheAppalachianRegion.asp. Published n.d. Accessed September 22, 2016.
4. Appalachian Regional Commission. Personal Income Rates, 2014. https://www.arc.gov/reports/custom_report.asp?REPORT_ID=63. Published 2014. Accessed September 22, 2016.
5. Appalachian Regional Commission. Poverty Rates, 2010-2014. https://www.arc.gov/reports/custom_report.asp?REPORT_ID=64. Published 2014. Accessed September 22, 2016.
6. U.S. Bureau of the Census. Poverty Thresholds for 2015 by Size of Family and Number of Related Children Under 18 years. In:2016.
7. Appalachian Regional Commission. Unemployment Rates, 2014. https://www.arc.gov/reports/custom_report.asp?REPORT_ID=23. Published 2014. Accessed September 22, 2016.
8. Appalachian Regional Commission. Education – High School and College Completion Rates, 2009–2013. https://www.arc.gov/reports/custom_report.asp?REPORT_ID=61. Published 2013. Accessed September 22, 2016.
9. Halverson JA. An Analysis of Disparities in Health Status and Access to Health Care in the Appalachian Region. In: Appalachian Regional Commission, ed2004.
10. Nahhas G, Daguise V, Ortaglia A, Merchant A. Determinants of major cardiovascular risk factors among participants of the South Carolina WISEWOMAN program, 2009-2012. *Preventing chronic disease.* 2014;11:E153.
11. Pearson TL. Cardiovascular risk in minority and underserved women in Appalachian Tennessee: a descriptive study. *Journal of the American Academy of Nurse Practitioners.* 2010;22(4):210-216.
12. US Centers for Disease Control and Prevention. Women and Heart Disease An Atlas of Racial and Ethnic Disparities in Mortality In: Research OfSEaH, ed. Second Edition ed 2000.
13. Singh GK, Kogan MD, Slifkin RT. Widening Disparities In Infant Mortality And Life Expectancy Between Appalachia And The Rest Of The United States, 1990-2013. *Health affairs (Project Hope).* 2017;36(8):1423-1432.

14. Thompson E, Fields S, Bors K. Appalachian Women and Heart Health: Current Prevention Strategies and Future Directions. *West Virginia Medical Journal.* 2013;109 (Rural Healthcare Disparities: Challenges and Solutions).

15. Pannu J, Poole S, Shah N, Shah NH. Assessing Screening Guidelines for Cardiovascular Disease Risk Factors using Routinely Collected Data. *Scientific reports.* 2017;7(1):6488.

16. LeFevre ML. Behavioral counseling to promote a healthful diet and physical activity for cardiovascular disease prevention in adults with cardiovascular risk factors: U.S. Preventive Services Task Force Recommendation Statement. *Annals of internal medicine.* 2014;161(8):587-593.

17. American Heart Association. Heart-Health Screenings. http://www.heart.org/HEARTORG/Conditions/Heart-Health-Screenings_UCM_428687_Article.jsp. Published 2016. Updated August 30, 2016. Accessed December 8, 2016.

18. Ahluwalia IB, Tessaro I, Greenlund KJ, Ford ES. Factors associated with control of hypertension, hypercholesterolemia, and diabetes among low-income women in West Virginia. *Journal of women's health (2002).* 2010;19(3):417-424.

19. O'Brien T, Talbot LA. Obesity Risk Factors for Women Living in the Appalachian Region: An Integrative Review. *Online Journal of Rural Nursing and Health Care.* 2011;11(1, Spring 2011):70-79.

20. Robbins CL, Keyserling TC, Pitts SB, et al. Screening low-income women of reproductive age for cardiovascular disease risk factors. *Journal of women's health (2002).* 2013;22(4):314-321.

21. Robbins CL, Keyserling TC, Jilcott Pitts S, et al. Outcomes of cardiovascular disease risk factor screening and referrals in a family planning clinic. *Journal of women's health (2002).* 2015;24(2):131-137.

22. Vaid I, Wigington C, Borbely D, Ferry P, Manheim D. WISEWOMAN: addressing the needs of women at high risk for cardiovascular disease. *Journal of women's health (2002).* 2011;20(7):977-982.

23. Rye JA, Rye SL, Tessaro I, Coffindaffer J. Perceived barriers to physical activity according to stage of change and body mass index in the west virginia wisewoman population. *Women's health issues : official publication of the Jacobs Institute of Women's Health.* 2009;19(2):126-134.

24. Oleson JJ, Breheny PJ, Pendergast JF, Ryan S, Litchfield R. Impact of travel distance on WISEWOMAN Intervention attendance for a rural population. *Preventive medicine.* 2008;47(5):565-569.

25. Mudd-Martin G, Biddle MJ, Chung ML, et al. Rural Appalachian perspectives on heart health: social ecological contexts. *American journal of health behavior.* 2014;38(1):134-143.

26. Scott S. Grannies, Mothers and Babies: An Examination of Traditional Southern Appalachian Midwifery. *Central Issues in Anthropology.* 1982(December 1982):17-30.

27. Masters HP. *A Study of the Southern Appalachian Granny-Woman Related to Childbirth Prevention Measures.*, East Tennessee State University; 2005.

28. Wiggington E. *Foxfire 2.* New York: Anchor Press; 1973.

29. Engel ME. The Appalachian "Granny": Testing the Boundaries of Female Power in Late-19th-Century Appalachian Georgia. *Appalachian Journal.* 2010;37(3/4):210-225.

30. Breckinridge M. *Wide Neighborhoods: A Story of the Frontier Nursing Service.* 2nd ed: University Press of Kentucky; 1981.

31. Bhatraju K. *Mud Creek Medicine: The Life of Eula Hall and the Fight for Appalachia.* First ed: Butler Books; 2013.

32. Snyder A, Thatcher E. From the trunk of a Volkswagen beetle: a mobile nursing clinic in Appalachia. *Family & community health.* 2014;37(3):239-247.

33. Paskett ED, Fisher JL, Lengerich EJ, et al. Disparities in underserved white populations: the case of cancer-related disparities in Appalachia. *The oncologist.* 2011;16(8):1072-1081.

34. Network ACC. Appalachia Community Cancer Network: Addressing the Cancer Burden in Appalachia. http://www.accnweb.com/#. Published 2006. Accessed March 28, 2017.

35. Royse D, Dignan M. The Appalchian Community Cancer Network: Issues and Challenges in Evaluation. *Research on Social Work Practice.* 2008;18(5).

36. Snell-Rood C, Staton-Tindall M, Victor G. Incarcerated women's relationship-based strategies to avoid drug use after community re-entry. *Women Health.* 2016;56(7):843-858.

37. Staton-Tindall M, Webster JM, Oser CB, Havens JR, Leukefeld CG. Drug use, hepatitis C, and service availability: perspectives of incarcerated rural women. *Social work in public health.* 2015;30(4):385-396.

38. Bailey BA, Daugherty RA. Intimate partner violence during pregnancy: incidence and associated health behaviors in a rural population. *Maternal and child health journal.* 2007;11(5):495-503.

39. Edwards KM, Greaney K, Palmer KM. Participants' Reactions to and Suggestions for Conducting Intimate Partner Violence Research: A Study of Rural Young Adults. *The Journal of rural health : official journal of the American Rural Health Association and the National Rural Health Care Association.* 2016;32(1):3-12.

40. Snell-Rood C, Feltner F, Schoenberg N. What Role Can Community Health Workers Play in Connecting Rural Women with Depression to the "De Facto" Mental Health Care System? *Community mental health journal.* 2018.

41. Snell-Rood C, Hauenstein E, Leukefeld C, Feltner F, Marcum A, Schoenberg N. Mental health treatment seeking patterns and preferences of Appalachian women with depression. *The American journal of orthopsychiatry.* 2017;87(3):233-241.

42. Ludke RL, Obermiller PJ. *Appalachian Health and Wellbeing.* 1st Edition ed: University Press of Kentucky; 2012.

43. Welch W. *Public Health in Appalachia: Essays from the Clinic and the Field.* 1st Edition ed: McFarland; 2014.

44. Studts CR, Tarasenko YN, Schoenberg NE, Shelton BJ, Hatcher-Keller J, Dignan MB. A community-based randomized trial of a faith-placed intervention to reduce cervical cancer burden in Appalachia. *Preventive medicine.* 2012;54(6):408-414.

45. Davis RE, Armstrong DK, Dignan M, Norling GR, Redmond J. Evaluation of educational materials on colorectal cancer screening in Appalachian Kentucky. *Preventing chronic disease.* 2006;3(2):A43.

46. Krok-Schoen JL, Oliveri JM, Young GS, Katz ML, Tatum CM, Paskett ED. Evaluating the stage of change model to a cervical cancer screening intervention among Ohio Appalachian women. *Women Health.* 2016;56(4):468-486.

47. Paskett ED, McLaughlin JM, Lehman AM, Katz ML, Tatum CM, Oliveri JM. Evaluating the efficacy of lay health advisors for increasing risk-appropriate Pap test screening: a randomized controlled trial among Ohio Appalachian women. *Cancer epidemiology, biomarkers & prevention : a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology.* 2011;20(5):835-843.

48. Curry WJ, Lengerich EJ, Kluhsman BC, et al. Academic detailing to increase colorectal cancer screening by primary care practices in Appalachian Pennsylvania. *BMC health services research.* 2011;11:112.

49. Gallant NR, Corbin M, Bencivenga MM, et al. Adaptation of an evidence-based intervention for Appalachian women: new STEPS (Strength Through Education, Physical fitness and Support) for breast health. *J Cancer Educ.* 2013;28(2):275-281.

50. Schoenberg NE, Kruger TM, Bardach S, Howell BM. Appalachian women's perspectives on breast and cervical cancer screening. *Rural and remote health.* 2013;13(3):2452.

51. Anderson RT, Yang TC, Matthews SA, et al. Breast cancer screening, area deprivation, and later-stage breast cancer in Appalachia: does geography matter? *Health services research.* 2014;49(2):546-567.

52. Singh J, Blaes A. *Shared Modifiable Risk Factors Between Cancer and CVD.* American College of Cardiology; April 26, 2017 2017.

53. Fleury J, Lee SM. The social ecological model and physical activity in African American women. *American journal of community psychology.* 2006;37(1-2):129-140.

54. Institute of Medicine Committee on Capitalizing on Social S, Behavioral Research to Improve the Public's H. In: Smedley BD, Syme SL, eds. *Promoting Health: Intervention Strategies from Social and Behavioral Research.* Washington (DC): National Academies Press (US); Copyright 2000 by the National Academy of Sciences. All rights reserved.; 2000.

55. National Heart L, and Blood Institute,. Atherosclerosis. https://www.nhlbi.nih.gov/health-topics/atherosclerosis. Published 2018. Accessed April 1, 2018.

56. Kannel WB, Wilson PW, D'Agostino RB, Cobb J. Sudden coronary death in women. *American heart journal.* 1998;136(2):205-212.

57. Low CA, Thurston RC, Matthews KA. Psychosocial factors in the development of heart disease in women: current research and future directions. *Psychosom Med.* 2010;72(9):842-854.

58. Shaw LJ, Bugiardini R, Merz CN. Women and ischemic heart disease: evolving knowledge. *Journal of the American College of Cardiology.* 2009;54(17):1561-1575.

59. McSweeney JC, Cody M, O'Sullivan P, Elberson K, Moser DK, Garvin BJ. Women's early warning symptoms of acute myocardial infarction. *Circulation.* 2003;108(21):2619-2623.

60. Vaccarino V, Parsons L, Peterson ED, Rogers WJ, Kiefe CI, Canto J. Sex differences in mortality after acute myocardial infarction: changes from 1994 to 2006. *Archives of internal medicine.* 2009;169(19):1767-1774.

61. Knox SS, Uvnas-Moberg K. Social isolation and cardiovascular disease: an atherosclerotic pathway? *Psychoneuroendocrinology.* 1998;23(8):877-890.

62. Mosca L, Benjamin EJ, Berra K, et al. Effectiveness-based guidelines for the prevention of cardiovascular disease in women--2011 update: a guideline from the american heart association. *Circulation.* 2011;123(11):1243-1262.

63. Charalampopoulos D, McLoughlin A, Elks CE, Ong KK. Age at menarche and risks of all-cause and cardiovascular death: a systematic review and meta-analysis. *American journal of epidemiology.* 2014;180(1):29-40.

64. Ahmed R, Dunford J, Mehran R, Robson S, Kunadian V. Pre-eclampsia and future cardiovascular risk among women: a review. *Journal of the American College of Cardiology.* 2014;63(18):1815-1822.

65. Oliver-Williams CT, Heydon EE, Smith GC, Wood AM. Miscarriage and future maternal cardiovascular disease: a systematic review and meta-analysis. *Heart (British Cardiac Society).* 2013;99(22):1636-1644.

66. Robbins CL, Hutchings Y, Dietz PM, Kuklina EV, Callaghan WM. History of preterm birth and subsequent cardiovascular disease: a systematic review. *Am J Obstet Gynecol.* 2014;210(4):285-297.

67. Palinski W, Napoli C. The fetal origins of atherosclerosis: maternal hypercholesterolemia, and cholesterol-lowering or antioxidant treatment during pregnancy influence in utero programming and postnatal susceptibility to atherogenesis. *FASEB journal : official publication of the Federation of American Societies for Experimental Biology.* 2002;16(11):1348-1360.

68. Daniels SR, Jacobson MS, McCrindle BW, Eckel RH, Sanner BM. American Heart Association Childhood Obesity Research Summit Report. *Circulation.* 2009;119(15):e489-517.

69. Bhatnagar A. Environmental Determinants of Cardiovascular Disease. *Circulation research.* 2017;121(2):162-180.

70. Mozaffarian D, Katan MB, Ascherio A, Stampfer MJ, Willett WC. Trans fatty acids and cardiovascular disease. *The New England journal of medicine.* 2006;354(15):1601-1613.

71. Booth FW, Lees SJ. Fundamental questions about genes, inactivity, and chronic diseases. *Physiological genomics.* 2007;28(2):146-157.

72. Ambrose JA, Barua RS. The pathophysiology of cigarette smoking and cardiovascular disease: an update. *Journal of the American College of Cardiology.* 2004;43(10):1731-1737.

73. Schultz WM, Kelli HM, Lisko JC, et al. Socioeconomic Status and Cardiovascular Outcomes: Challenges and Interventions. *Circulation.* 2018;137(20):2166-2178.

74. Kucharska-Newton AM, Harald K, Rosamond WD, Rose KM, Rea TD, Salomaa V. Socioeconomic indicators and the risk of acute coronary heart disease events: comparison of population-based data from the United States and Finland. *Annals of epidemiology.* 2011;21(8):572-579.

75. Shaw LJ, Merz CN, Bittner V, et al. Importance of socioeconomic status as a predictor of cardiovascular outcome and costs of care in women with suspected myocardial ischemia. Results from the National Institutes of Health, National Heart, Lung and Blood Institute-sponsored Women's Ischemia Syndrome Evaluation (WISE). *Journal of women's health (2002).* 2008;17(7):1081-1092.

76. Nguyen JK, Thurston RC. Association of Childhood Trauma Exposure with Inflammatory Biomarkers Among Midlife Women. *Journal of women's health (2002).* 2020.

77. El-Serag R, Thurston RC. Matters of the Heart and Mind: Interpersonal Violence and Cardiovascular Disease in Women. *Journal of the American Heart Association.* 2020;9(4):e015479.

78. Stewart AL, Barinas-Mitchell E, Matthews KA, et al. Social Role-Related Stress and Social Role-Related Reward as Related to Subsequent Subclinical Cardiovascular Disease in a Longitudinal Study of Midlife Women: The Study of Women's Health Across the Nation. *Psychosom Med.* 2019;81(9):821-832.

79. Wong ND, Pio J, Valencia R, Thakal G. Distribution of C-reactive protein and its relation to risk factors and coronary heart disease risk estimation in the National Health and Nutrition Examination Survey (NHANES) III. *Prev Cardiol.* 2001;4(3):109-114.

80. Ridker PM, Hennekens CH, Buring JE, Rifai N. C-reactive protein and other markers of inflammation in the prediction of cardiovascular disease in women. *The New England journal of medicine.* 2000;342(12):836-843.

81. Bairey Merz CN, Johnson BD, Sharaf BL, et al. Hypoestrogenemia of hypothalamic origin and coronary artery disease in premenopausal women: a report from the NHLBI-sponsored WISE study. *Journal of the American College of Cardiology.* 2003;41(3):413-419.

82. Wittstein IS, Thiemann DR, Lima JA, et al. Neurohumoral features of myocardial stunning due to sudden emotional stress. *The New England journal of medicine.* 2005;352(6):539-548.

83. Matthews KA, Chang YF, Sutton-Tyrrell K, Edmundowicz D, Bromberger JT. Recurrent major depression predicts progression of coronary calcification in healthy women: Study of Women's Health Across the Nation. *Psychosom Med.* 2010;72(8):742-747.

84. Denollet J, Maas K, Knottnerus A, Keyzer JJ, Pop VJ. Anxiety predicted premature all-cause and cardiovascular death in a 10-year follow-up of middle-aged women. *J Clin Epidemiol.* 2009;62(4):452-456.

85. Stewart JC, Janicki DL, Muldoon MF, Sutton-Tyrrell K, Kamarck TW. Negative emotions and 3-year progression of subclinical atherosclerosis. *Arch Gen Psychiatry.* 2007;64(2):225-233.

86. László KD, Janszky I, Ahnve S. Anger expression and prognosis after a coronary event in women. *Int J Cardiol.* 2010;140(1):60-65.

87. Gallo LC, Troxel WM, Kuller LH, Sutton-Tyrrell K, Edmundowicz D, Matthews KA. Marital status, marital quality, and atherosclerotic burden in postmenopausal women. *Psychosom Med.* 2003;65(6):952-962.

88. Janicki DL, Kamarck TW, Shiffman S, Sutton-Tyrrell K, Gwaltney CJ. Frequency of spousal interaction and 3-year progression of carotid artery intima medial thickness: the Pittsburgh Healthy Heart Project. *Psychosom Med.* 2005;67(6):889-896.

89. Zdravkovic S, Wienke A, Pedersen NL, Marenberg ME, Yashin AI, De Faire U. Heritability of death from coronary heart disease: a 36-year follow-up of 20 966 Swedish twins. *Journal of internal medicine.* 2002;252(3):247-254.

90. Tan J, Wang Y. Social Integration, Social Support, and All-Cause, Cardiovascular Disease and Cause-Specific Mortality: A Prospective Cohort Study. *Int J Environ Res Public Health.* 2019;16(9).

91. Freeborne N, Simmens SJ, Manson JE, et al. Perceived social support and the risk of cardiovascular disease and all-cause mortality in the Women's Health Initiative Observational Study. *Menopause.* 2019;26(7):698-707.

92. Kershaw KN, Brenes GA, Charles LE, et al. Associations of stressful life events and social strain with incident cardiovascular disease in the Women's Health Initiative. *Journal of the American Heart Association.* 2014;3(3):e000687.

93. Xia N, Li H. Loneliness, Social Isolation, and Cardiovascular Health. *Antioxidants & redox signaling.* 2018;28(9):837-851.

94. Valtorta NK, Kanaan M, Gilbody S, Ronzi S, Hanratty B. Loneliness and social isolation as risk factors for coronary heart disease and stroke: systematic review and meta-analysis of longitudinal observational studies. *Heart (British Cardiac Society).* 2016;102(13):1009-1016.

95. Cohen MC, Rohtla KM, Lavery CE, Muller JE, Mittleman MA. Meta-analysis of the morning excess of acute myocardial infarction and sudden cardiac death. *The American journal of cardiology.* 1997;79(11):1512-1516.

96. Spencer FA, Goldberg RJ, Becker RC, Gore JM. Seasonal distribution of acute myocardial infarction in the second National Registry of Myocardial Infarction. *Journal of the American College of Cardiology.* 1998;31(6):1226-1233.

97. de Mendoza S, Nucete H, Ineichen E, Salazar E, Zerpa A, Glueck CJ. Lipids and lipoproteins in subjects at 1,000 and 3,500 meter altitudes. *Archives of environmental health.* 1979;34(5):308-311.

98. Dadvand P, Bartoll X, Basagana X, et al. Green spaces and General Health: Roles of mental health status, social support, and physical activity. *Environment international.* 2016;91:161-167.

99. Bhatnagar A. Environmental cardiology: studying mechanistic links between pollution and heart disease. *Circulation research.* 2006;99(7):692-705.

100. Swinburn TK, Hammer MS, Neitzel RL. Valuing Quiet: An Economic Assessment of U.S. Environmental Noise as a Cardiovascular Health Hazard. *American journal of preventive medicine.* 2015;49(3):345-353.

101. Ford MM, Highfield LD. Exploring the Spatial Association between Social Deprivation and Cardiovascular Disease Mortality at the Neighborhood Level. *PloS one.* 2016;11(1):e0146085.

102. Diez-Roux AV, Nieto FJ, Muntaner C, et al. Neighborhood environments and coronary heart disease: a multilevel analysis. *American journal of epidemiology.* 1997;146(1):48-63.

103. Akwo EA, Kabagambe EK, Harrell FE, Jr., et al. Neighborhood Deprivation Predicts Heart Failure Risk in a Low-Income Population of Blacks and Whites in the Southeastern United States. *Circulation Cardiovascular quality and outcomes.* 2018;11(1):e004052.

104. Chaix B. Geographic life environments and coronary heart disease: a literature review, theoretical contributions, methodological updates, and a research agenda. *Annual review of public health.* 2009;30:81-105.

105. Comber AJ, Brunsdon C, Radburn R. A spatial analysis of variations in health access: linking geography, socio-economic status and access perceptions. *Int J Health Geogr.* 2011;10:44.

106. Spatz ES, Beckman AL, Wang Y, Desai NR, Krumholz HM. Geographic Variation in Trends and Disparities in Acute Myocardial Infarction Hospitalization and Mortality by Income Levels, 1999-2013. *JAMA cardiology.* 2016;1(3):255-265.

107. Mobley LR, Root ED, Finkelstein EA, Khavjou O, Farris RP, Will JC. Environment, obesity, and cardiovascular disease risk in low-income women. *American journal of preventive medicine.* 2006;30(4):327-332.

108. Sprung MR, Faulkner LMD, Evans MK, Zonderman AB, Waldstein SR. Neighborhood crime is differentially associated with cardiovascular risk factors as a function of race and sex. *J Public Health Res.* 2019;8(3):1643.

109. 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.

110. Barrientos-Gutierrez T, Moore KAB, Auchincloss AH, et al. Neighborhood Physical Environment and Changes in Body Mass Index: Results From the Multi-Ethnic Study of Atherosclerosis. *American journal of epidemiology.* 2017;186(11):1237-1245.

111. Giles-Corti B, Donovan RJ. The relative influence of individual, social and physical environment determinants of physical activity. *Social science & medicine (1982).* 2002;54(12):1793-1812.

112. Diez Roux AV, Evenson KR, McGinn AP, et al. Availability of recreational resources and physical activity in adults. *American journal of public health.* 2007;97(3):493-499.

113. Brownson RC, Baker EA, Housemann RA, Brennan LK, Bacak SJ. Environmental and policy determinants of physical activity in the United States. *American journal of public health.* 2001;91(12):1995-2003.

114. Giles-Corti B, Kelty SF, Zubrick SR, Villanueva KP. Encouraging walking for transport and physical activity in children and adolescents: how important is the built environment? *Sports Med.* 2009;39(12):995-1009.

115. Pont K, Ziviani J, Wadley D, Bennett S, Abbott R. Environmental correlates of children's active transportation: a systematic literature review. *Health & place.* 2009;15(3):827-840.

116. Frost SS, Goins RT, Hunter RH, et al. Effects of the built environment on physical activity of adults living in rural settings. *American journal of health promotion : AJHP.* 2010;24(4):267-283.

117. Sallis JF, Floyd MF, Rodríguez DA, Saelens BE. Role of built environments in physical activity, obesity, and cardiovascular disease. *Circulation.* 2012;125(5):729-737.

118. Morland K, Wing S, Diez Roux A. The contextual effect of the local food environment on residents' diets: the atherosclerosis risk in communities study. *American journal of public health.* 2002;92(11):1761-1767.

119. Seligman HK, Laraia BA, Kushel MB. Food insecurity is associated with chronic disease among low-income NHANES participants. *J Nutr.* 2010;140(2):304-310.

120. Vercammen KA, Moran AJ, McClain AC, Thorndike AN, Fulay AP, Rimm EB. Food Security and 10-Year Cardiovascular Disease Risk Among U.S. Adults. *American journal of preventive medicine.* 2019;56(5):689-697.

121. Crosby RA, Vanderpool R, Jones C. Associations of an abnormal Pap test result with attitudes and beliefs relevant to cervical cancer: a study of rural Appalachian women. *Cancer causes & control : CCC.* 2016;27(7):947-950.

122. Cohen EL, Gordon AS, Record R, Shaunfield S, Jones GM, Collins T. Using communication to manage uncertainty about cervical cancer screening guideline adherence among Appalachian women. *Journal of applied communication research : JACR.* 2016;44(1):22-39.

123. Mills LA, Head KJ, Vanderpool RC. HPV vaccination among young adult women: a perspective from Appalachian Kentucky. *Preventing chronic disease.* 2013;10:E17.

124. Head KJ, Cohen EL. Young women's perspectives on cervical cancer prevention in Appalachian Kentucky. *Qualitative health research.* 2012;22(4):476-487.

125. Schoenberg NE, Eddens K, Jonas A, et al. Colorectal cancer prevention: Perspectives of key players from social networks in a low-income rural US region. *International journal of qualitative studies on health and well-being.* 2016;11:30396.

126. Studts CR, Tarasenko YN, Schoenberg NE. Barriers to cervical cancer screening among middle-aged and older rural Appalachian women. *Journal of community health.* 2013;38(3):500-512.

127. Schoenberg NE, Howell BM, Fields N. Community strategies to address cancer disparities in Appalachian Kentucky. *Family & community health.* 2012;35(1):31-43.

128. Drew EM, Schoenberg NE. Deconstructing fatalism: ethnographic perspectives on women's decision making about cancer prevention and treatment. *Medical anthropology quarterly.* 2011;25(2):164-182.

129. Collins T, Stradtman LR, Vanderpool RC, Neace DR, Cooper KD. A Community-Academic Partnership to Increase Pap Testing in Appalachian Kentucky. *American journal of preventive medicine.* 2015;49(2):324-330.

130. Schoenberg NE, Studts CR, Hatcher-Keller J, Buelt E, Adams E. Patterns and determinants of breast and cervical cancer non-screening among Appalachian women. *Women Health.* 2013;53(6):552-571.

131. Vanderpool RC, Dressler EV, Stradtman LR, Crosby RA. Fatalistic beliefs and completion of the HPV vaccination series among a sample of young Appalachian Kentucky women. *The Journal of rural health : official journal of the American Rural Health Association and the National Rural Health Care Association.* 2015;31(2):199-205.

132. Documet PI, Green HH, Adams J, Weil LA, Stockdale J, Hyseni Y. Perspectives of African American, Amish, Appalachian And Latina women on breast and cervical cancer screening: implications for cultural competence. *Journal of health care for the poor and underserved.* 2008;19(1):56-74.

133. Allen KR, Roberto KA. Older women in Appalachia: experiences with gynecological cancer. *The Gerontologist.* 2014;54(6):1024-1034.

134. McAlearney AS, Oliveri JM, Post DM, et al. Trust and distrust among Appalachian women regarding cervical cancer screening: a qualitative study. *Patient Educ Couns.* 2012;86(1):120-126.

135. Schoenberg N, Baltisberger J, Bardach S, Dignan M. Perspectives on Pap test follow-up care among rural Appalachian women. *Women Health.* 2010;50(6):580-597.

136. Thompson E, Fields SA, Bors K. Appalachian women and heart health: current prevention strategies and future directions. *The West Virginia medical journal.* 2013;109(4):76-80.

137. Donohoe J, Marshall V, Tan X, Camacho FT, Anderson R, Balkrishnan R. Predicting Late-stage Breast Cancer Diagnosis and Receipt of Adjuvant Therapy: Applying Current Spatial Access to Care Methods in Appalachia. *Medical care.* 2015;53(11):980-988.

138. Pennsylvania Department of Health. HealthyWoman Program. http://www.health.pa.gov/My%20Health/Womens%20Health/HealthyWomen/Pages/Healthy%20Woman.aspx. Published 2017. Accessed June 30, 2017.

139. Pennsylvania Department of Human Services. Medicaid Expansion Report. In: Services H, ed2017.

140. Pensinger J, Modzelewski R. Stakeholder Leadership Team Report: NBCCEDP and Breast Working Group Update. Paper presented at: Pennsylvania Cancer Control, Prevention, and Research Advisory Board Meeting; June 22, 2017, 2017; Harrisburg, PA.

141. Appalachian Regional Commission. ARC History. https://www.arc.gov/about/ARCHistory.asp. Published n.d. Accessed September 22, 2016.

142. Behringer B, Friedell GH. Appalachia: where place matters in health. *Preventing chronic disease.* 2006;3(4):A113.

143. Centers for Disease Control and Prevention. All-Cause Annual Mortality Rates, Ages 15-64, by Region (1999-2015). In: Statistics NCfH, ed2017.

144. Denham SA. Does a Culture of Appalachia Truly Exist? *Journal of transcultural nursing : official journal of the Transcultural Nursing Society.* 2016;27(2):94-102.

145. Armstrong R. Affrilachian Poetry and the Evolution of a Regional Identity. *Transitions: Race, Culture, and the Dynamics of Change.* 2006;5:211.

146. Denham SA, Meyer MG, Toborg MA, Mande MJ. Providing health education to Appalachia populations. *Holistic nursing practice.* 2004;18(6):293-301.

147. Mareck DG. Federal and state initiatives to recruit physicians to rural areas. *The virtual mentor : VM.* 2011;13(5):304-309.

148. Vance ME. *Cervical Cancer, Knowledge, Beliefs and Behaviors in Appalachian Women*: Nursing, New Mexico State University; 2012.

149. Coyne CA, Demian-Popescu C, Friend D. Social and cultural factors influencing health in southern West Virginia: a qualitative study. *Preventing chronic disease.* 2006;3(4):A124.

150. Tripp-Reimer T, Kelley L, Small C. Appalachia. In: Giger J, Davidhizer R, eds. *Transcultural Nursing: Assessment and Intervention.* St. Louis, MO: Elsevier; 2008.

151. Borman K, Obermiller PJ. *From Moutain to Metropolis: Appalachian Migrants in American Cities.* Praeger; 1994.

152. Theobald P. Hillbilly Elegy: A Memoir of a Family and Culture in Crisis. *Journal of Research in Rural Education.* 2017;32(8):1-3.

153. Wallace ML, Ricco JA, Barrett B. Screening strategies for cardiovascular disease in asymptomatic adults. *Primary care.* 2014;41(2):371-397.

154. Labarthe D. *Epidemiology and Prevention of Cardiovascular Diseases: A Global Challenge.* Second ed: Jones & Bartlett Publishers; 2010.

155. American Heart Association. My Life Check - Life's Simple 7. http://www.heart.org/HEARTORG/Conditions/My-Life-Check---Lifes-Simple-7_UCM_471453_Article.jsp. Published 2017. Accessed April 19. 2018.

156. Folsom AR, Shah AM, Lutsey PL, et al. American Heart Association's Life's Simple 7: Avoiding Heart Failure and Preserving Cardiac Structure and Function. *The American journal of medicine.* 2015;128(9):970-976.e972.

157. Ma J, Stafford RS. Screening, treatment, and control of hypertension in US private physician offices, 2003-2004. *Hypertension (Dallas, Tex : 1979).* 2008;51(5):1275-1281.

158. Solberg LI, Kottke TE, Brekke ML. Variation in clinical preventive services. *Effective clinical practice : ECP.* 2001;4(3):121-126.

159. Rifas-Shiman SL, Forman JP, Lane K, Caspard H, Gillman MW. Diabetes and lipid screening among patients in primary care: a cohort study. *BMC health services research.* 2008;8:25.

160. Centers for Disease Control and Prevention. WISEWOMAN Overview. https://www.cdc.gov/wisewoman/about.htm. Published 2017. Accessed April 19, 2018.

161. Williams P, Elias T, Park Y, Yoder D, Monroe C. *Understanding Barriers to Lifestyle Change in Women Age 40-64.* Adagio Health Women's Health Symposium2018.

162. Park Y, Elias T. *Learning what works: Listening to WISEWOMAN participants.* University of Pittsburgh Health Disparities Poster Competition2018.

163. Wewers ME, Salsberry PJ, Ferketich AK, Ahijevych KL, Hood NE, Paskett ED. Risk factors for smoking in rural women. *Journal of women's health (2002).* 2012;21(5):548-556.

164. Slusher IL, Withrow-Fletcher C, Hauser-Whitaker M. Appalachian women: health beliefs, self-care, and basic conditioning factors. *Journal of cultural diversity.* 2010;17(3):84-89.

165. Leslie NS, Deiriggi P, Gross S, DuRant E, Smith C, Veshnesky JG. Knowledge, attitudes, and practices surrounding breast cancer screening in educated Appalachian women. *Oncology nursing forum.* 2003;30(4):659-667.

166. Bandura A. Human agency in social cognitive theory. *The American psychologist.* 1989;44(9):1175-1184.

167. Schoenberg NE, Peters JC, Drew EM. Unraveling the mysteries of timing: women's perceptions about time to treatment for cardiac symptoms. *Social science & medicine (1982).* 2003;56(2):271-284.

168. McAlearney AS, Song PH, Rhoda DA, et al. Ohio Appalachian women's perceptions of the cost of cervical cancer screening. *Cancer.* 2010;116(20):4727-4734.

169. Heath H, Cowley S. Developing a grounded theory approach: a comparison of Glaser and Strauss. *International journal of nursing studies.* 2004;41(2):141-150.

170. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative health research.* 2005;15(9):1277-1288.

171. Montez JK, Zajacova A, Hayward MD. Explaining Inequalities in Women's Mortality between U.S. States. *SSM Popul Health.* 2016;2:561-571.

172. Case A, Deaton A. *Mortality and Morbidity in the 21st Century.* 2017.

173. Meit M, Heffernan M, Tanenbaum E, Hoffman T. Appalachian Disease of Despair. In: Commission AR, ed2017.

174. Dunaway W. *Women, Work, and Family in the Antebellum Mountain South.* Cambridge University Press; 2008.

175. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology.* 2005;8(1):19-32.

176. Sucharew H, Macaluso M. Progress Notes: Methods for Research Evidence Synthesis: The Scoping Review Approach. *J Hosp Med.* 2019;14(7):416-418.

177. Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC medical research methodology.* 2018;18(1):143.

178. Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Info Libr J.* 2009;26(2):91-108.

179. Delgado López-Cózar E, Orduña-Malea E, Martín-Martín A. Google Scholar as a Data Source for Research Assessment. In: Glänzel W, Moed HF, Schmoch U, Thelwall M, eds. *Springer Handbook of Science and Technology Indicators.* Cham: Springer International Publishing; 2019:95-127.

180. Mark KP, Crosby RA, Vanderpool RC. Psychosocial Correlates of Ever Having a Pap Test and Abnormal Pap Results in a Sample of Rural Appalachian Women. *The Journal of rural health : official journal of the American Rural Health Association and the National Rural Health Care Association.* 2017.

181. Crosby RA, Hagensee ME, Vanderpool R, et al. Community-Based Screening for Cervical Cancer: A Feasibility Study of Rural Appalachian Women. *Sexually transmitted diseases.* 2015;42(11):607-611.

182. Kelly KM, Schoenberg N, Wilson TD, Atkins E, Dickinson S, Paskett E. Cervical cancer worry and screening among appalachian women. *The journal of primary prevention.* 2015;36(2):79-92.

183. Schoenberg NE, Hopenhayn C, Christian A, Knight EA, Rubio A. An in-depth and updated perspective on determinants of cervical cancer screening among central Appalachian women. *Women Health.* 2005;42(2):89-105.

184. Hutson SP, Dorgan KA, Duvall KL, Garrett LH. Human papillomavirus infection, vaccination, and cervical cancer communication: the protection dilemma faced by women in southern Appalachia. *Women Health.* 2011;51(8):795-810.

185. Amonkar MM, Madhavan S. Compliance rates and predictors of cancer screening recommendations among Appalachian women. *Journal of health care for the poor and underserved.* 2002;13(4):443-460.

186. Lyttle NL, Stadelman K. Assessing awareness and knowledge of breast and cervical cancer among Appalachian women. *Preventing chronic disease.* 2006;3(4):A125.

187. Yabroff KR, Lawrence WF, King JC, et al. Geographic disparities in cervical cancer mortality: what are the roles of risk factor prevalence, screening, and use of recommended treatment? *The Journal of rural health : official journal of the American Rural Health Association and the National Rural Health Care Association.* 2005;21(2):149-157.

188. Hall HI, Uhler RJ, Coughlin SS, Miller DS. Breast and cervical cancer screening among Appalachian women. *Cancer epidemiology, biomarkers & prevention : a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology.* 2002;11(1):137-142.

189. Hopenhayn C, Christian A, Christian WJ, Schoenberg NE. Human papillomavirus vaccine: knowledge and attitudes in two Appalachian Kentucky counties. *Cancer causes & control : CCC.* 2007;18(6):627-634.

190. Mills LA, Vanderpool RC, Crosby RA. Sexually related behaviors as predictors of HPV vaccination among young rural women. *Journal of women's health (2002).* 2011;20(12):1909-1915.

191. Vanderpool RC, Cohen E, Crosby RA, et al. "1-2-3 Pap" Intervention Improves HPV Vaccine Series Completion among Appalachian Women. *The Journal of communication.* 2013;63(1):95-115.

192. Katz ML, Zimmermann BJ, Moore D, Paskett ED, Reiter PL. Perspectives from health-care providers and women about completing human papillomavirus (HPV) self-testing at home. *Women Health.* 2017;57(10):1161-1177.

193. Head KJ, Vanderpool RC, Mills LA. Health care providers' perspectives on low HPV vaccine uptake and adherence in Appalachian Kentucky. *Public health nursing (Boston, Mass).* 2013;30(4):351-360.

194. Ruffin MTt, Hade EM, Gorsline MR, et al. Human papillomavirus vaccine knowledge and hypothetical acceptance among women in Appalachia Ohio. *Vaccine.* 2012;30(36):5349-5357.

195. Mitchell MD, Mannino DM, Steinke DT, Kryscio RJ, Bush HM, Crofford LJ. Association of smoking and chronic pain syndromes in Kentucky women. *The journal of pain : official journal of the American Pain Society.* 2011;12(8):892-899.

196. Chertok IR, Casey ML, Greenfield K. Approach to addressing prenatal smoking in West Virginia. *The West Virginia medical journal.* 2014;110(4):36-40.

197. Thomson TL, Krebs V, Nemeth JM, et al. Social Networks and Smoking in Rural Women: Intervention Implications. *American journal of health behavior.* 2016;40(4):405-415.

198. Nemeth JM, Bonomi AE, Lu B, Lomax RG, Wewers ME. Risk Factors for Smoking in Rural Women: The Role of Gender-Based Sexual and Intimate Partner Violence. *Journal of women's health (2002).* 2016;25(12):1282-1291.

199. Bailey BA. Effectiveness of a Pregnancy Smoking Intervention: The Tennessee Intervention for Pregnant Smokers Program. *Health education & behavior : the official publication of the Society for Public Health Education.* 2015;42(6):824-831.

200. Bailey BA. Factors predicting pregnancy smoking in Southern Appalachia. *American journal of health behavior.* 2006;30(4):413-421.

201. Cottrell L, Gibson M, Harris C, et al. Examining smoking and cessation during pregnancy among an Appalachian sample: a preliminary view. *Substance abuse treatment, prevention, and policy.* 2007;2:14.

202. Lam J, Lu B, Doogan N, et al. Depression, Smoking, and Ego-Centric Social Network Characteristics in Ohio Appalachian Women. *Rural mental health.* 2017;41(1):30-41.

203. Stubbs B, Hoots V, Clements A, Bailey B. Psychosocial well-being and efforts to quit smoking in pregnant women of South-Central Appalachia. *Addict Behav Rep.* 2019;9:100174.

204. Jesse DE, Wallace DC, Seaver W. A holistic approach to risk-screening in pregnancy with Appalachian women. *Journal of holistic nursing : official journal of the American Holistic Nurses' Association.* 2002;20(2):133-151.

205. Jesse DE, Reed PG. Effects of spirituality and psychosocial well-being on health risk behaviors in Appalachian pregnant women. *Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG.* 2004;33(6):739-747.

206. Bailey BA, McCook JG, Chaires C. Burden of elective early-term births in rural Appalachia. *Southern medical journal.* 2014;107(10):624-629.

207. Phillippi JC, Myers CR, Schorn MN. Facilitators of prenatal care access in rural Appalachia. *Women and birth : journal of the Australian College of Midwives.* 2014;27(4):e28-35.

208. Williams CM, Cprek S, Asaolu I, et al. Kentucky Health Access Nurturing Development Services Home Visiting Program Improves Maternal and Child Health. *Maternal and child health journal.* 2017;21(5):1166-1174.

209. Jesse DE. Prenatal psychosocial needs: differences between a TennCare group and a privately insured group in Appalachia. *Journal of health care for the poor and underserved.* 2003;14(4):535-549.

210. Jesse DE, Alligood MR. Holistic Obstetrical Problem Evaluation (HOPE): testing a theory to predict birth outcomes in a group of women from appalachia. *Health care for women international.* 2002;23(6-7):587-599.

211. Jesse DE, Seaver W, Wallace DC. Maternal psychosocial risks predict preterm birth in a group of women from Appalachia. *Midwifery.* 2003;19(3):191-202.

212. Bailey BA, Byrom AR. Factors predicting birth weight in a low-risk sample: the role of modifiable pregnancy health behaviors. *Maternal and child health journal.* 2007;11(2):173-179.

213. Phillippi JC, Myers CR. Reasons Women in Appalachia Decline CenteringPregnancy Care. *Journal of midwifery & women's health.* 2013;58(5):516-522.

214. McNeil DW, Hayes SE, Randall CL, et al. Depression and Rural Environment are Associated With Poor Oral Health Among Pregnant Women in Northern Appalachia. *Behavior modification.* 2016;40(1-2):325-340.

215. Shannon L, Nash S, Jackson A. Examining Intimate Partner Violence and Health Factors Among Rural Appalachian Pregnant Women. *Journal of interpersonal violence.* 2016;31(15):2622-2640.

216. Oza-Frank R, Conrey E, Bouchard J, Shellhaas C, Weber MB. Healthcare Experiences of Low-Income Women with Prior Gestational Diabetes. *Maternal and child health journal.* 2018;22(7):1059-1066.

217. O'Donnell J, Goldberg A, Lieberman E, Betancourt T. "I wouldn't even know where to start": unwanted pregnancy and abortion decision-making in Central Appalachia. *Reproductive health matters.* 2018;26(52):1513270.

218. Clements AD, Cyphers NA. Prenatal substance use: Religious women report lower use rates, but do they use less? *Journal of prevention & intervention in the community.* 2019:1-17.

219. Chopra I, Chopra A. Risk perception for diabetes in Appalachian women. *Women Health.* 2017;57(5):534-550.

220. Theeke LA, Mallow J, Gianni C, Legg K, Glass C. The Experience of Older Women Living with Loneliness and Chronic Conditions in Appalachia. *Rural mental health.* 2015;39(2):61-72.

221. Staton M, Strickland JC, Tillson M, Leukefeld C, Webster JM, Oser CB. Partner Relationships and Injection Sharing Practices among Rural Appalachian Women. *Women's health issues : official publication of the Jacobs Institute of Women's Health.* 2017;27(6):652-659.

222. Buer LM, Leukefeld CG, Havens JR. "I'm Stuck": Women's Navigations of Social Networks and Prescription Drug Misuse in Central Appalachia. *North American dialogue : newsletter of the Society for the Anthropology of North America.* 2016;19(2):70-84.

223. Appalachian Regional Commission. County Economic Status in Appalachia, FY 2020. https://www.arc.gov/research/MapsofAppalachia.asp?MAP_ID=149. Published 2019. Accessed December 18, 2019.

224. Schoenberg NE, Hatcher J, Dignan MB. Appalachian women's perceptions of their community's health threats. *The Journal of rural health : official journal of the American Rural Health Association and the National Rural Health Care Association.* 2008;24(1):75-83.

225. LeMasters T, Madhavan S, Atkins E, Vyas A, Remick S, Vona-Davis L. "Don't know" and accuracy of breast cancer risk perceptions among Appalachian women attending a mobile mammography program: implications for educational interventions and patient empowerment. *J Cancer Educ.* 2014;29(4):669-679.

226. Snell-Rood C, Merkel R, Schoenberg N. Negotiating the Interpretation of Depression Shared Among Kin. *Medical anthropology.* 2018.

227. Hayes PA. Home is where their health is: rethinking perspectives of informal and formal care by older rural Appalachian women who live alone. *Qualitative health research.* 2006;16(2):282-297.

228. Reiter PL, Wee AG, Lehman A, Paskett ED. Oral cancer screening and dental care use among women from Ohio Appalachia. *Rural and remote health.* 2012;12:2184.

229. Dorgan K, Huston S, Duvall K, Kinser A, Hall J. Connecting Place to Disease and Gender: Cohabitating Morbidities in Narratives of Women Cancer Survivors in Southern Central Appalachia. *Women's Studies in Communication.* 2014;37(3):292-312.

230. MacMaster SA. Perceptions of need, service use, and barriers to service access among female methamphetamine users in rural Appalachia. *Social work in public health.* 2013;28(2):109-118.

231. Walker JL, Holben DH, Kropf ML, Holcomb JP, Jr., Anderson H. Household food insecurity is inversely associated with social capital and health in females from special supplemental nutrition program for women, infants, and children households in Appalachian Ohio. *Journal of the American Dietetic Association.* 2007;107(11):1989-1993.

232. Golden SD, Earp JA. Social ecological approaches to individuals and their contexts: twenty years of health education & behavior health promotion interventions. *Health education & behavior : the official publication of the Society for Public Health Education.* 2012;39(3):364-372.

233. Hawe P. Lessons from complex interventions to improve health. *Annual review of public health.* 2015;36:307-323.

234. Rutter H, Savona N, Glonti K, et al. The need for a complex systems model of evidence for public health. *Lancet (London, England).* 2017;390(10112):2602-2604.

235. Palma A, Lounsbury D. Complexity: The Evolution Toward 21st-Century Science. In: El-Sayed A, Galea S, eds. *Systems Science and Population Health.* Oxford Scholarship Online2017.

236. Carey G, Malbon E, Carey N, Joyce A, Crammond B, Carey A. Systems science and systems thinking for public health: a systematic review of the field. *BMJ open.* 2015;5(12):e009002.

237. Peters DH. The application of systems thinking in health: why use systems thinking? *Health research policy and systems.* 2014;12:51.

238. Burke JG, Thompson JR, Mabry PL, Mair CF. Introduction to the Theme Issue on Dynamics of Health Behavior: Revisiting Systems Science for Population Health. *Health education & behavior : the official publication of the Society for Public Health Education.* 2020;47(2):185-190.

239. Vaughn LM, Jones JR, Booth E, Burke JG. Concept mapping methodology and community-engaged research: A perfect pairing. *Evaluation and program planning.* 2017;60:229-237.

240. Israel BA, Schulz AJ, Parker EA, Becker AB. Community-based participatory research: policy recommendations for promoting a partnership approach in health research. *Education for health (Abingdon, England).* 2001;14(2):182-197.

241. Minkler M, Wallerstein N. *Community-Based Participatory Research for Health: From Process to Outcomes.* John Wiley & Sons; 2011.

242. Vaughn L. Community-based participatory research: focus on children and adolescents. *Family & community health.* 2015;38(1):1-2.

243. Thompson JR, Burke JG. Increasing Community Participation in Public Health Research: Applications for Concept Mapping Methodology. *Progress in Community Health Partnerships: Research, Education, and Action.* 2020;14(2):243-250.

244. Creswell JW, Klassen AC, Plano Clark VL, Smith KC. Best practices for mixed methods research in the health sciences. *Bethesda (Maryland): National Institutes of Health.* 2011;2013:541-545.

245. Johnson RB, Onwuegbuzie AJ, Turner LA. Toward a definition of mixed methods research. *Journal of mixed methods research.* 2007;1(2):112-133.

246. Fetters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. *Health services research.* 2013;48(6 Pt 2):2134-2156.

247. Creamer EG. *An introduction to fully integrated mixed methods research.* sage publications; 2017.

248. Walker C, Baxter J. Method sequence and dominance in mixed methods research: A case study of the social acceptance of wind energy literature. *International Journal of Qualitative Methods.* 2019;18:1609406919834379.

249. Willis CD, Mitton C, Gordon J, Best A. System tools for system change. *BMJ quality & safety.* 2012;21(3):250-262.

250. Goldman KD, Schmalz KJ. "Accentuate the positive!": using an asset-mapping tool as part of a community-health needs assessment. *Health promotion practice.* 2005;6(2):125-128.

251. Burke JG, O'Campo P, Peak GL, Gielen AC, McDonnell KA, Trochim WM. An introduction to concept mapping as a participatory public health research method. *Qualitative health research.* 2005;15(10):1392-1410.

252. Thompson J, Burke J. Increasing Participation in Public Health Research: Applications for Concept Mapping. *Progress in Community Health Partnerships.* 2020;in press.

253. Creswell J, Klassen A, Clark VP, Smith KC. Best Practices for Mixed Methods Research in the Health Sciences. In: (OBSSR) OoBaSSR, ed2010:1-39.

254. Shay E, Combs T, Findley D, Kolosna C, Madeley M, Salvesen D. Identifying transportation disadvantage: Mixed-methods analysis combining GIS mapping with qualtitative data. *Transport Policy.* 2016;48:129-138.

255. Appalachian Regional Commission. Census Population Change, 2000–2010: Appalachian Pennsylvania. https://www.arc.gov/reports/region_report.asp?FIPS=42999&REPORT_ID=41. Published 2014. Accessed December 8, 2016.

256. Centers for Disease Control and Prevention. Interactive Atlas of Heart Disease and Stroke. https://nccd.cdc.gov/DHDSPAtlas/Default.aspx?state=PA. Published 2020. Accessed November 1, 2020.

257. United States Census Bureau. American Community Survey: Data Profiles (2011-2015 Data Profiles). https://www.census.gov/acs/www/data/data-tables-and-tools/data-profiles/2015/. Published 2020. Accessed November 2, 2020.

258. Ni H, Xu J. Recent Trends in Heart Failure-related Mortality: United States, 2000–2014. In: NCHS, ed. Vol No. 231. NCHS Data Brief2015:2-7.

259. Pennsylvania Health Statistics. Healthy People 2020 - County Statistics. In: Health PDo, ed2016.

260. Appalachian Regional Commission. Census Population Change, 2000-2010. https://www.arc.gov/reports/custom_report.asp?REPORT_ID=41. Published 2016. Accessed July 13, 2017, 2017.

261. Ezzell T, Lambert D, Ogle E, et al. Strategies for Economic Improvement in Appalachia's Distressed Counties. In: Prepared for the Appalachian Regional Commission, ed2012.

262. Roth GA, Dwyer-Lindgren L, Bertozzi-Villa A, et al. Trends and Patterns of Geographic Variation in Cardiovascular Mortality Among US Counties, 1980-2014. *Jama.* 2017;317(19):1976-1992.

263. United States Census Bureau. American FactFinder. https://factfinder.census.gov/faces/nav/jsf/pages/index.xhtml. Published 2017. Accessed November 11, 2017.

264. Robert Wood Johnson Foundation. Calculating Scores and Ranks. http://www.countyhealthrankings.org/ranking-methods/calculating-scores-and-ranks. Published 2017. Accessed July 13, 2017.

265. University of Pittsburgh Center for Urban and Social Research. Western Pennsylvania Regional Data Center. http://www.wprdc.org/. Published 2017. Accessed July 13, 2017.

266. Pennsylvania State University. Pennsylvania Cancer Atlas. https://www.geovista.psu.edu/grants/CDC/. Accessed July 13, 2017.

267. Pennsylvania State University. Pennsylvania Spatial Data Access: The Pennsylvania Geospatial Data Clearinghouse. http://www.pasda.psu.edu/. Accessed July 13, 2017.

268. Kane M, Trochin W. *Concept Mapping for Planning and Evaluation.* Thousand Oaks, CA: Sage Publications, Ltd.; 2007.

269. Concept Systems Incorporated. CS Global Max. http://www.conceptsystems.com/home. Accessed July 13, 2017.

270. Burke J, O'Campo P, Salmon C, Walker R. Pathways connecting neighborhood influences and mental well-being: socioeconomic position and gender differences. *Social science & medicine (1982).* 2009;68(7):1294-1304.

271. Burke JG, Albert SM. *Methods for Community Public Health Research: Integrated and Engaged Approaches.* Springer Publishing Company; 2014.

272. Burke JG, O'Campo P, Peak GL. Neighborhood influences and intimate partner violence: does geographic setting matter? *Journal of urban health : bulletin of the New York Academy of Medicine.* 2006;83(2):182-194.

273. Chopra I, Chopra A. Risk perception for diabetes in Appalachian women. *Women & health.* 2016:1-17.

274. Jilcott Pitts SB, Keyserling TC, Johnston LF, et al. Associations between neighborhood-level factors related to a healthful lifestyle and dietary intake, physical activity, and support for obesity prevention polices among rural adults. *Journal of community health.* 2015;40(2):276-284.

275. Della LJ. Exploring diabetes beliefs in at-risk Appalachia. *The Journal of rural health : official journal of the American Rural Health Association and the National Rural Health Care Association.* 2011;27(1):3-12.

276. Pedigo A, Aldrich T, Odoi A. Neighborhood disparities in stroke and myocardial infarction mortality: a GIS and spatial scan statistics approach. *BMC public health.* 2011;11:644.

277. Gustafson AA, Lewis S, Wilson C, Jilcott-Pitts S. Validation of food store environment secondary data source and the role of neighborhood deprivation in Appalachia, Kentucky. *BMC public health.* 2012;12:688.

278. Halverson JA, Barnett E, Casper M. Geographic disparities in heart disease and stroke mortality among black and white populations in the Appalachian region. *Ethnicity & disease.* 2002;12(4):S3-82-91.

279. The Center for Rural Pennsylvania. Rural Urban Definitions. http://www.rural.palegislature.us/demographics_rural_urban.html. Published 2017. Accessed September 8, 2017.

280. U.S. Department of Health & Human Services. Health Resources & Services Administration (HRSA) Data Warehouse. https://datawarehouse.hrsa.gov/. Published 2017. Accessed November 1, 2017.

281. ReferenceUSA. U.S. Businesses Database. http://resource.referenceusa.com/. Published 2019. Accessed December 18, 2019.

282. Centers for Disease Control and Prevention. Children's Food Environment State Indicator Report. In:2011.

283. United States Census Bureau. American FactFinder. https://factfinder.census.gov/faces/nav/jsf/pages/index.xhtml. Published 2019. Accessed December 18, 2019.

284. QGIS Development Team. QGIS Geographic Information System. http://qgis.osgeo.org. Published 2020. Accessed January 2020.

285. Anselin L, Ibnu S, Youngihn K. GeoDa: An Introduction to Spatial Data Analysis. In: *Geographical Analysis.* Vol 38.2006:5-22.

286. StataCorp. Stata Statistical Software: Release 14. In. College Station, TX: StataCorp LP.2015.

287. Scutchfield F. Root Causes of Appalachia's Deaths of Despair. *Journal of Appalachian Health.* 2019;1(2):1-6.

288. Vance ME. *Cervical Cancer Knowledge, Beliefs and Behaviors in Appalacian Women.* New Mexico State University; 2012.

289. Dave G, Frerichs L, Jones J, et al. Conceptualizing trust in community-academic research partnerships using concept mapping approach: A multi-CTSA study. *Evaluation and program planning.* 2017;66:70-78.

290. Frerichs L, Kim M, Dave G, et al. Stakeholder Perspectives on Creating and Maintaining Trust in Community-Academic Research Partnerships. *Health education & behavior : the official publication of the Society for Public Health Education.* 2017;44(1):182-191.

291. Lindstrom Johnson S, Burke JG, Gielen AC. Urban Students' Perceptions of the School Environment's Influence on School Violence. *Children & schools.* 2012;34(2):92-102.

292. O'Campo P, Salmon C, Burke J. Neighbourhoods and mental well-being: what are the pathways? *Health & place.* 2009;15(1):56-68.

293. Zoom Video Communications Inc. Zoom. https://zoom.us/. Published 2020. Accessed September 2020.

294. NVivo. NVivo 11: Run a Coding Comparison Query. http://help-nv11.qsrinternational.com/desktop/procedures/run_a_coding_comparison_query.htm. Published 2017. Accessed August 23, 2017.

295. Clayton C, Motley C, Sakakibara B. Enhancing Social Support Among People with Cardiovascular Disease: a Systematic Scoping Review. *Current cardiology reports.* 2019;21(10):123.

296. Luszczynska A, Schwarzer R. Multidimensional health locus of control: comments on the construct and its measurement. *Journal of health psychology.* 2005;10(5):633-642.

297. Hawk M, Coulter RWS, Egan JE, et al. Harm reduction principles for healthcare settings. *Harm Reduct J.* 2017;14(1):70.

298. Suero-Abreu GA, Barajas-Ochoa A, Perez-Peralta A, Rojas E, Berkowitz R. Assessment of the Effect of the Go Red for Women Campaign on Search Engine Queries for Cardiovascular Disease in Women. *Cardiol Res.* 2020;11(5):348-352.

299. Mosca L, Hammond G, Mochari-Greenberger H, Towfighi A, Albert MA. Fifteen-year trends in awareness of heart disease in women: results of a 2012 American Heart Association national survey. *Circulation.* 2013;127(11):1254-1263, e1251-1229.

300. Siokou C, Morgan R, Shiell A. Group model building: a participatory approach to understanding and acting on systems. *Public Health Res Pract.* 2014;25(1):e2511404.

301. Scott R. *Group model building: Using systems dynamics to achieve enduring agreement.* Springer; 2018.

302. Centers for Disease Control and Prevention. The Community Guide: Cardiovascular Disease Prevention. https://www.thecommunityguide.org/topic/cardiovascular-disease. Published 2021. Accessed March 1, 2021.

303. Matheson GO, Pacione C, Shultz RK, Klügl M. Leveraging human-centered design in chronic disease prevention. *American journal of preventive medicine.* 2015;48(4):472-479.

304. Schleimer E, Pearce J, Barnecut A, et al. A Precision Medicine Tool for Patients With Multiple Sclerosis (the Open MS BioScreen): Human-Centered Design and Development. *Journal of medical Internet research.* 2020;22(7):e15605.

305. Office of Disease Prevention and Health Promotion. Healthy People 2020: Disparities. https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities. Published 2017. Accessed May 30th, 2017.

306. National Heart L, and Blood Institute,. Research Priorities. https://www.nhlbi.nih.gov/about/documents/strategic-vision/research-priorities. Published 2017. Accessed September 25, 2017.