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Evaluating Socially Determined Health in Rural Appalachia:
Use of the Social Quality Theory

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

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

by
Paula Masters
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ABSTRACT

Evaluating Socially Determined Health in Rural Appalachia:

Use of the Social Quality Theory

by

Paula Masters

People living in rural America face unique social circumstances that can prevent them from reaching optimal health status. This fact holds especially true in the rural Appalachian region of the United States where income, education, living circumstances, and lack of resources create an environment that has some of the highest rates of morbidity and mortality in the country. While the rest of the country has seen improvement in many health behaviors and health outcomes, rural Appalachian communities remain unchanged and further behind other regions. In many cases, programming and policy have failed to create a culture of health in Appalachia. Social determinants of the area should be included in interventions and this practice is imperative to achieve effectiveness.

This study examined the social context and definitions of health in a rural, Appalachian community using the Social Quality Theory as a guiding framework. A community-based participatory research approach was adopted and implemented through the use of focus groups. The study generated many meaningful findings. It not only provided a new framework, but also provides an examination of how a rural, impoverished community lacks the social infrastructure to improve health. Current perceptions of health are limited to thoughts of disease or illness and overshadowed by negative social norms. There are few social resources currently available to improve health and a large presence of cultural impediments. Yet this “culture” also provides some advantages and assets that the community may leverage for change.

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CHAPTER 1

INTRODUCTION

America has experienced an increase in life expectancy over the last four decades. However, that increase has begun to lose momentum and for some populations, such as rural residents, higher rates of mortality exist compared to national rates. This is particularly true for those in remote, underserved areas such as the Appalachian region.

Many factors affect the health of communities and individuals. Despite annual health care spending projected to exceed \$3 trillion, health outcomes in America continue to lag behind other developed countries (Squires & Anderson, 2015). While overall spending in the United States on social services and health care is comparable to other Western nations, the United States disproportionately spends more on health care and less on social services (Bradley & Taylor, 2013). While it is widely known that proper health care is important to good health, research shows that it is not the strongest determinant. Health behaviors such as poor diet and smoking are important determinants of premature death and growing recognition show social, economic, and environmental factors shape population's opportunities and barriers for health (McGinnis & Foege, 1993; Schroeder, 2007). Such social determinants have significant impact on health outcomes. They include elements such as access to healthcare, socioeconomic status, employment, education and social support networks (Marmot, Friel, Bell, Houweling, & Taylor, 2008). Review of approximately fifty studies found that social determinants of health accounted for over a third of total deaths in the United States in a given year (Galea, Tracy, Hoggat, DiMaggio, & Karpati, 2011). Therefore, efforts to address social determinants to achieve greater health equity are imperative.

Healthy People 2020 states that “health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their race, religion, gender, socioeconomic security, geographic location or other characteristics historically linked to discrimination or exclusion” (Healthy People, 2017, paragraph 1). The Department of Health and Human Services (DHHS) define health disparity as “differences in health outcomes that are closely linked with social, economic, and environmental disadvantage” (Healthy People: Disparities, 2017, paragraph 6). Both organizational definitions acknowledge that health disparity is rooted in social determinants, those circumstances in which a person lives. A growing number of initiatives focusing on the social determinants of health have emerged, calling for improved, evidenced-based approaches in research and programming, specifically targeting those communities experiencing the greatest disparities.

For example, the Robert Wood Johnson Foundation (RWJF) launched an initiative in 2015 to focus attention on social determinants of health: Culture of Health. It is a framework containing four action areas; Making Health a Shared Value, Fostering Cross-Sector Collaboration to Improve Well-Being, Creating Healthier, More Equitable Communities, and Strengthening Integration of Health Services and Systems (RWJF, 2017). Making health a shared value in communities is foundational to building a culture of health and progress toward improved health equity. Thus it is notably the first action in the framework (Chandra et al., 2016). Chandra and colleagues assert that “achievement of this shared understanding of health as a cultural value will be enhanced through action-specific drivers: mindset and expectations, sense of community, and civic engagement” (2016, p. 1959). This assertion was built from the examination of literature and stakeholder engagement. Researchers at RWJF believe that while this group’s notion is respectable, there are other approaches examining drivers to culturally determined health

including broader understanding of the social determinants. Therefore, RWJF has sought innovative measures for Culture of Health to complement completed work such as those by Chandra et al. (2016) and others, creating an exceptional opportunity.

Research Purpose

The purpose of this study was to build from the growing research into social determinants and culture of health and the funding opportunity presented through the RWJF Culture of Health initiative, to pilot a new approach. Upon completion of an extensive literature review and guided by observation of the unique health challenges faced in rural Appalachian communities, a new theory to elaborate on socially determined health was used. The Social Quality Theory, founded in Europe, is a theoretical framework to evaluate the association of social determinants of health and culture of health. The following chapters detail how rural, Appalachian residents define health, connect those definitions to social determinants for poor health, and tests the Social Quality Theory as a framework to describe the contributors. The specific aims are presented below.

Specific Aims

Aim 1: Evaluate the current definition and perceptions of health in this sample of rural Appalachian residents through use of focus groups; additionally, to identify the scale and scope of social contributors to poor health.

Aim 2: Test the Social Quality Theory and its components as a framework to describe social determinants of health through thematic analysis of findings from the focus groups.

Hypotheses

Hypothesis 1: Rural, Appalachian communities define neither health nor perceptions of health using social determinants.

Hypothesis 2: Use of the Social Quality Theory will offer new information to describe the current culture of health and social determinants for the pilot community.

CHAPTER 2

LITERATURE REVIEW

Rural Health Disparities

Rural areas and rural residents are very different from their urban counterparts; particularly when considering health and its determinants. Overall, rural Americans suffer from higher prevalence of chronic disease, increased chronic disease mortality, and higher rates of suicide and substance abuse than non-rural residents (Rural and Urban Chartbook, 2014). In addition, the number of households living in poverty is higher in rural America. According to the 2016 American Community Survey, 16.9 percent of people living in non-metropolitan areas of the country were living below the federal poverty level, compared to 13.6 percent of people living in metropolitan areas (United States Department of Agriculture, 2017). In America, rural residents tend to be poorer with a per capita income of \$7,417 less than their urban counterparts according to the National Rural Health Association (NHRA) (2013). Nearly 24% of rural children live in poverty, compared to 21% of urban children (United States Department of Agriculture, 2017) and are less likely to have employer-based health insurance and/or covered by Medicaid (O'Hare, 2009). Lack of access to care, as an example, highlights the evident disparity when you evaluate the capacity and number of quality health care services in rural areas. Rural American communities represent 65% of Health Professional Shortage Areas, but only 10% of physicians practice in rural areas (NRHA, 2013). The American Academy of Family Physicians found that family physicians account for about 15% of the outpatient physician workforce, yet rural family physicians perform 42% of visits in their rural service area (AAFP, 2014). The academy also states that if the family physician, which are primary providers in rural areas, were

extracted from the 1,548 rural counties that are not Primary Care Health Personnel Shortage Areas (PCHPSA), 68% of those counties would become PCHPSAs (AAFP, 2014).

Access to care is by far the most widely cited social determinant across the nation. However, it is merely one of many social and behavioral determinants behind the disparity experienced by rural communities, all which play a crucial role in health outcomes. Healthy People 2020 includes a number of other social determinants for focus. They include access to educational and economic opportunities, availability of resources to obtain and maintain daily needs such as food and housing, quality education and job training, community resources and support, transportation, social support, residential segregation, literacy, concentrated poverty, access to emerging technologies, and culture (Healthy People, 2017). Healthy People 2020 selected many objectives to address social determinants, and categorized them into five main areas: 1) economic stability, 2) education, 3) health and health care, 4) neighborhood and built environment, and 5) social and community context. The overarching goal of that work is to “create social and physical environments that promote good health” (Healthy People, 2017, paragraph 1). However, in a national survey completed by rural stakeholders, asked to rank the objectives set forth by Healthy People 2020, only 21.3% listed “social determinants of health” as a top ten priority, making it the 19th highest priority for rural communities (Bolin et al., 2015). Respondents also identified important sub-objectives related to social determinants for rural areas. They are poverty/income, education, race/ethnicity, healthy lifestyle, housing and employment (Bolin et al., 2015). The shortage of health services and providers and the burden of disease in rural areas, creates a complex environment in which to address social determinants of health. There is an urgent need for a systematic approach to assist these rural communities in their efforts.

Appalachia

Appalachian Disparities

The Appalachian region of the United States contains 420 counties and some of the most beautiful natural resources and landscapes in the world (Figure 1). It is home to approximately 25 million people. The population density varies, with some metropolitan counties comprised of more than 1 million residents and many rural counties with below 10,000 residents. Only 40% of the region's counties have population concentrations at or above the national average, most due in part to geography consisting of mountainous terrain. The landscape creates complexities for residents in which to work, live and play. The area's people are often connected by culture and family and embrace the isolation the mountains provide, yet suffer by the same. The Appalachian people experience alarming disparities, especially in the rural areas, facing some of the highest levels of poverty, disease, and death when compared to national averages (Murray, Kulkarni, & Ezzati, 2005). The geography and intrinsic characteristics found in Appalachia could be cited as the cause for poor health. However, the social determinants are also potential drivers for poor health outcomes. For example, Smith, Humphreys and Wilson found that while the people in rural Appalachia do engage in less healthy behaviors than in urban areas, the social determinants of income, education, unemployment, and environment play a much larger role than do individual behaviors (2008).

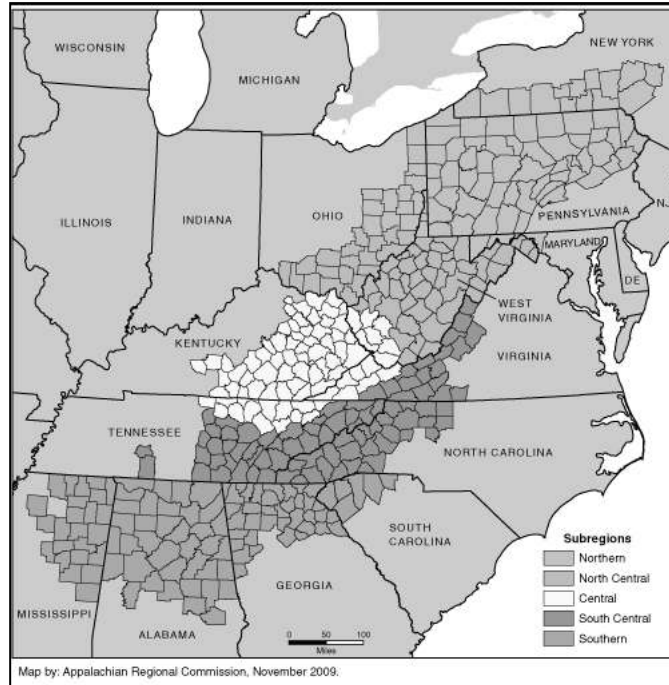


Figure 1. Appalachian region. Figure created by author based on Appalachian Regional Commission website map

The region falls below national norms because of generations of poverty, limited economic growth, poor education and few, diverse economic resources (Chenoweth & Galliher, 2004). Appalachians have an average per capita market income 75% lower than their United States counterparts, with some rural areas as low as 51% of their counterparts at the national level (ARC, 2016). More than a quarter of the nation’s lowest 15% of counties ranked on household income are found in the Appalachian region. Some communities/counties have poverty levels of almost 23% compared to the US average of 15%. While those with a bachelor’s degree or higher in the United States averages 28.8%, there is a state in Appalachia with only 18%. The region has been consistently ranked among the lowest in educational obtainment and highest in high school dropout rates of national regions for decades (Ali & McWhirter, 2006). While these numbers show the disparities of health and economics in the region, they do not speak to the culture and values that are possibly underpinning the disparity.

Appalachian Social Context

There have been a number of studies that have attempted to better understand the people of Appalachia and their health perceptions and beliefs, though they are a bit dated. Tang and Russ make note in their work that evaluation of previous studies conducted in Appalachian still hold true as they believe the culture relatively unchanged (2007). DeMarris (1998), along with Seals and Harmon (1995), state that the Appalachian culture poses difficulties for residents to set and obtain goals. They state that inter-generational poverty, economic exploitation and inadequate education disadvantage the people and interrupt achievement and success. Tang and Russ (2007) also suggest that many Appalachians seek value through meeting family needs from within the family structure, often including extended family, in some instances encompassing four generations. This loyalty, sense of localism, and identification with the geography and place encourages residents to stay close to “home” (Duncan, 2001) and replaces individualistic motivation with family need when seeking success (Sugar, 2002).

Rosswurm and colleagues assessed the influence of the Appalachian culture on illness experiences (1996). Over 200 patients hospitalized in southern Appalachia that shared similar demographic and socioeconomic factors were evaluated. They found that the predominant cultural health beliefs included an inability to prevent illness, an orientation toward merely coping with its consequences, heavy influence of religious faith in illness recovery, and the importance of extended family (Rosswurm, 1996). Their findings illustrated a need for culturally appropriate care and innovative education in reducing health risks in Appalachia. They also speak of the fatalistic views encompassing all other cultural health beliefs in Appalachia and refers to fatalism as a passive acceptance of illness (Rosswurm, 1996). This adoption of fatalism was also observed in 1993 by Lemon, Newfield, and Dobbins (1993) who found Appalachians to

have a perceived lack of control between person and nature/science and do not expect positive outcomes from personal effort, yet use fatalism as a self-protective mechanism. Vance, Basta, Bute and Denham (2012) and Coyne and colleagues found similar perceptions in their studies of Appalachian populations. The populations showed tendencies of fatalism, aversion to seeking help due to lack of trust of “non-Appalachians”, and connection to “take care of their” own (Vance et al., 2012; Coyne, Demian-Popescu, & Friend, 2006). The majority of work on values and beliefs regarding health behaviors has been disease- or treatment-specific (Deskins et al., 2006; Krummel, Humphries & Tessaro, 2002; Tessaro, Smith & Rye, 2005). These individualistic approaches have not accounted for the social context or how the social determinants could work to create a culture of health.

Culture of Health Initiative

In 2014, the Robert Wood Johnson Foundation (RWJF) launched a new health initiative called Culture of Health. This new initiative was driven by the United States spending 2.7 trillion dollars a year on healthcare, yet remaining less healthy than many other countries (Lavizzo-Mourey, 2015). Culture of Health means shifting values and actions of the American population where health becomes the default of the people, rather than as a way to not become ill. Culture of Health seeks to reframe the conversation toward creating a culture around health instead of singularly focused on individual behavioral change and intervention. By making health the cultural norm, a new paradigm could be created where all have the chance to lead healthy lives (Mockenhaupt & Woodrum, 2015). The four areas comprising the action framework for the Culture of Health Initiative are listed below and provided in Figure 2.

1. Making Health a Shared Value, measured by indicators such as the percentage of people who strongly agree that health is influenced by their peers and their communities and the percentage who indicate they have adequate social support from family and friends.
2. Fostering Cross-Sector Collaboration to Improve Well-Being, the number of local health departments that collaborate with community organizations and employers who promote better health in the workplace.
3. Creating Healthier, More Equitable Communities, such as the number of grocery stores, farmers' markets, and safe sidewalks in communities; the ratio of children attending preschool; and the affordability of housing.
4. Strengthening Integration of Health Services and Systems, gauged by measures such as the percentage of people served by a comprehensive public health system and the percentage of physicians sharing electronic data with other clinicians, health systems and patients (RWJF, 2017).

The first action item, Making Health a Shared Value, provides a great fit for research and greater attention, with special focus on rural, underserved populations, as those residents tend to suffer from poorer health status (Rural-Urban Chartbook, 2014). This area of action “focuses on engaging communities, providers, and advocates in understanding social and economic determinants of health” (RWJF, 2017, p. 17). It encourages everyone to view health as a priority and cannot be accomplished through individual interventions. It adopts the lens of community, groups and social structure. Dr. Alonzo Plough, VP of Research-Evaluation-Learning and Chief Science Officer at RWJF, states “the conceptual base for this action dimension rests on research and practice evidence in social network theory, community resilience, well-being science, and asset based community development” (Plough, 2015, p. S151). He goes on to further highlight

the intention is to achieve a place where “health is a shared value.....to which individuals feel a sense of interdependence with each other” (Plough, 2015, p. S151).



Figure 2. Culture of health action framework. Figure created by author based on Robert Wood Johnson Foundation’s Culture of Health Action Framework (2017)

There is a lack of current empirical evidence on how to address social norms. The current thinking of traditional focus areas for funding remains in disease specific research, such as with the National Institutes of Health. Finally, the organization’s perspectives are that it is seemingly much easier to monetize traditional mechanisms than launch a system re-conceptualization that encompasses the complexity needed for social change (Mockenhaupt & Woodrum, 2015). This need for evidence and openness to innovative research is a large area of opportunity to employ other means of evaluation to address social context of underserved areas.

Definition of Health

The tracking of health outcomes and measurement of health behaviors of populations has been completed through a number of different methodologies by a diverse group of sectors, including urban, rural or disadvantaged populations. How populations define health is not well known. Even when health status is known to be poor, investigating what health “means”, how it is defined, and factors antecedent to those beliefs are less explored than clinical or biological antecedents. This is especially true as sociocultural factors have such great impact on health, including the developmental significance culture has on beliefs and perceptions of the people in that culture. In order to better assist populations and adopt effective practices to move toward improved health, understanding how populations define their health and what contributes to that definition is essential. This is becoming more of a priority as the social determinants of health are receiving increased attention and gaining prominence in research, medical and community practices. Confirming if, and illuminating how, communities associate social factors to definitions of health may help researchers, practitioners, community leaders and other interested parties tailor and target efforts. Sociocultural factors must be in the forefront of how health improvement work is planned, implemented, and evaluated.

A systematic literature review conducted by Gessert et al. (2015) looked at the body of work into how rural populations define health (Gessert et al., 2015). The criteria for inclusion were if the literature was published in English, reported on original research and findings or commentary to rural definition of health, published in the last 40 years, and based on work conducted in rural United States, Canada, or Australia. Two researchers were assigned each article and blinded to the other’s review. If dissenting reviews occurred, a third blind review was performed. There were 125 published articles identified and 34 included findings relevant to the

rural definition of health (Gessert et al., 2015). There was a broad range of how good health was characterized, but most commonly it was the ability to work, reciprocate in social relationships and maintain independence. The review largely confirmed many general characteristics of rural views of health and documented large methodological limitations in quality and quantity. The authors call for a need to gain a better understanding of the health beliefs in rural populations and suggests that rural residents hold a distinct view on how to define health. They also encourage more rigorous studies to be conducted to confirm their findings and further the work (Gessert et al., 2015).

Articles from the Gessert (2015) review that were found to possess relevance for this study were further evaluated. The inclusion criteria for this evaluation were if the article was 1) research, not commentary 2) the population was in the United States, and 3) in an Appalachian or Southeastern state. Of the 34 articles eligible from Gessert's work, 10 articles were selected. Other articles from the literature review were also included based on the above criteria and if they included examination of health perceptions/beliefs/attitudes, defining health or health needs, or explored cultural or social factors of health. An additional six articles were found. Below, in Table 1, is a summary of all articles, followed by further discussion on relevant findings across and within studies.

Table 1.

Articles containing rural relevance/population

Author/Focus	Study Design	Study Population	Findings
Arcury, 2001/Focus: health maintenance and meaning of health	3-year ethnographic study, qualitative research, 145 interviews in 2 rural counties	North Carolina	-Residents identified 7 significant health maintenance domains: eating right, drinking water, taking exercise, staying busy, being with people, trusting in God and participating in church, and taking care of yourself.
Arcury, 2005/Focus: Complementary and Alternative Medicine (CAM)	3-year ethnographic study, qualitative research, 145 interviews in 2 rural counties	North Carolina	-CAM therapies are widely used by are limited to folk and home remedies and vitamin and mineral supplements. The CAM therapies were integrated into their health behaviors and beliefs.
Coyne, 2006/Focus: Social and cultural factors influencing health	Qualitative research, focus groups, 10 groups, 61 participants	West Virginia	-Seeking help from a medical institution was regarded as a last resort and religious beliefs in faith and God were important when sick or in need of healing.
Davis, 1991/Focus: Health beliefs and practices of rural elders	Qualitative research, interviews, 31 interviews	Rural Alabama	-Subjects relied on how they felt to determine themselves as healthy or not healthy.

Table 1 continued

Della, 2010/Focus: diabetes beliefs in at-risk	Intercept interviews at public locale, 168 completed questionnaires	Appalachian Kentucky	-Participants associated family history and weight with diabetes, however they did not internalize these as personal risk factors.
Deskins, 2006/Focus: Preventive care, cholesterol screening	Qualitative research, individual interviews and focus groups, 142 participants	West Virginia	-Identification of barriers to participation in cholesterol screening included lack of knowledge, concern about the outcomes and of needles, and cultural beliefs. Beliefs included resistance to a preventative approach, to new people and ideas, using denial as a coping strategy and fatalistic view toward health.
Goins, 2011/Focus: Lay meanings of health among older adults	Qualitative research, focus groups and brief surveys, 101 participants	West Virginia	-Described clean living as a key to health and endorsed a conventional Christian way of life. Participants assigned high value to health as it enabled them to be active and fulfill social roles.
Griffith, 2011/Focus: self-rated health	Quantitative research, survey, 1,576 completed survey	Appalachia	-Respondents reported being healthy, yet between 57% and 66% had at least 2 disease conditions or poor health behaviors.

Table 1 continued

Harju, 2006/Focus: attitudes related to seeking medical care	Telephone survey of urban and rural residents, 586 rural and 433 urban participants	North Carolina	-Fear of hospitals was associated with effective compliance and mistrust of doctors for low adherence in rural residents.
Hutson, 2007/Focus: cancer disparities and perspectives on the cancer experience	Qualitative research, focus groups, 22 participants	Appalachia	-Four major themes emerged and are seemingly unique or contain unique factors to Appalachians: cancer storytelling, cancer collectivism, healthcare challenges, and cancer expectations.
Krummel, 2002/Focus: cardiovascular health in rural women	Qualitative research, focus groups, 34 participants	West Virginia	-Participants were unaware of their risk and common themes included overriding influence of family preferences and cultural food pattern on choices and lack of support for adoption of healthy diet.
Pheley, 2002/Focus: food security and perceptions of health status	Quantitative research, survey, 1,006 completed	Appalachian Ohio	-Economic and social factors were correlated with food insecurity and poor health status.

Table 1 continued

Slusher, 2010/Focus: Health beliefs and self-care in women	Mixed methods, interviews, 129 participants	Appalachia	-Participants provided a highly functional definition of health including ability to get out of bed, energy level, participate in activity, care for family and provide service to others. Health was associated with feeling good, belief in God, feeling no pain and no need for a doctor.
Tessaro, 2005/Focus: Diabetes knowledge and perceptions	Qualitative research, focus groups, 101 participants	West Virginia	-Lack of knowledge of diabetes and low risk perceptions exist. Social interactions were found to be negatively affected by diabetes and cultural and economic barriers to early detection occur.
Vance, 2012/Focus: identification of health needs	Mixed methods, focus groups, interviews, modified BRFFS, 32 focus group, 8 interviews, and 399 survey participants	Ohio	-Health of participants was influenced by rural Appalachian culture, geography and access to health care, and lack of access/knowledge about preventive health behaviors.
Walker, 1994/Focus: cancer perceptions and beliefs	Multi-phase project, telephone surveys, focus groups, 282 participants	West Virginia	-46% agreed there is nothing they can do to prevent cancer, 64% would not change habits to avoid cancer and 38% agreed they would rather not know if they have cancer.

Salient Themes

Upon evaluation across articles, two important themes emerged related to findings and discussion elements. First, was the direct and indirect reference to “culture” whether linked to health status or forming the definition of health. Culture was mentioned in all but one of the articles (Pheley, 2002) as a direct contributor to poor health or definition of health or indirect through reference to perceptions and beliefs. These common cultural factors included 1) faith in God or some foundation in religion, 2) fear/mistrust in providers, healthcare systems, screenings, outcomes and competency levels, and 3) confidence in or lack of knowledge of preventative clinical measures. These cultural factors are both unique across the articles, but also intersect with many of the social factors that were described. For example, in the two articles by Arcury et al., both include instances of participants exhibiting cultural influences such as cross sections of religious influences on personal/self-care and how one perceives and defines health (Arcury, Quadnt, & Bell, 2001; Arcury, Bell, Vitolins & Quadnt, 2005). Arcury even states the “concept of health seamlessly integrates physical, mental, spiritual and social aspects of health, reflecting how health is embedded in the everyday experience of these elders” (Arcury et al., 2001, p. 1541). Goins et al. also confirms the multifaceted nature of themes stating “according to participants, health cannot be compartmentalized but includes elements of physical, behavioral, psychological and spiritual well-being” and “value-based definitions of health are dependent on what an individual’s culture deems valuable” (Goins, Spencer & Williams, 2010, p. 17). Culture largely framed health in the studies and is of great importance when evaluating the health status of a population. As Drew stated, “culture is the medium through which a person’s beliefs, standards, and norms for health and illness behaviors are structured, learned, shared practiced and judged” (Drew, 2008, p. 118).

The second salient theme is that of socioeconomic impacts on defining health and perceptions and behaviors. Shared themes were 1) fulfillment of social roles, responsibilities and expectations, 2) participation in activities and groups, and 3) economic security. Socioeconomic factors not only affect how one defines health but also greatly influence health behaviors, preventative and personal care, health service access, and understanding of health related information (Tessaro, Smith & Rye, 2005). Even when there is a present desire to make positive changes and engage in healthier behaviors, social and economic factors impede that change and serve as barriers (Vance, Basta, Bute & Denham, 2012). A good example was found by Arcury et al. (2001) where “staying busy and being with people” were stand-alone themes that emerged from analysis, but also “social integration” was found as a cross-cutting theme. These social factors were found to be positively associated with physical and mental health and were linked to other established themes (Arcury et al., 2001). Interestingly, Coyne et al. (2006) found that one social factor influencing health in the study population was “sense of place” including place attachment, place identity and place dependence. These created a social construct that could house either healthy or unhealthy beliefs or perceptions (Coyne, Demian-Popescu, & Friend, 2006). An example of economic security was in the poor economic factors being directly correlated with food insecurity in Pheley’s study. Those participants with low income and/or unemployed were much more likely to experience food insecurity (Pheley, 2002). One of the most common social groups referenced throughout most articles was that of the family unit. Participation in family activities and the ability to take care of family was identified as one of the greatest factors defining health and health status. Slusher et al. found that being “able to take care of family and home” was how participants stated they promote their individual health and practice self-care (Slusher, Withrow-Fletcher & Hauser-Whitaker, 2010).

Cultural and socioeconomic factors greatly impact how rural populations define health. A large majority of articles called for more robust studies further examining these factors to form a more comprehensive picture and provide increased understanding. This is of great importance for disadvantaged areas such as Appalachia, as many such communities experience greater health needs, riskier health behaviors, less health services, and lack of knowledge and access to health education and prevention services. Health is a subjective, multi-dimensional concept deeply rooted in everyday experiences.

Theoretical frameworks for measuring sociocultural factors

For a long time, social scientists and social epidemiologists have focused extensive energy on representing social circumstances in a scientific manner by using reliable data structured with rational underlying logic or theory. A number of theories and approaches have been adopted to evaluate health for populations that include sociocultural factors such as social capital, community assets, quality of life, and other similar concepts. However, they lack the ability to measure both the individual and community simultaneously and, thereafter, provide leverage points that may be used to guide health improvement. The Social Quality Theory (SQT) was developed to accomplish measurement of sociocultural factors at the ‘social’ or group level and contain constructs that identify areas of interest that may be used for collective or individual intervention. The next section details SQT and explores other theoretical models compared against SQT.

Social Quality Theory

History. SQT is a theoretical and conceptual framework that aims to overcome the gap between sectors and single-pronged approaches. It provides a comprehensive, holistic framework for understanding social problems and possibilities for social change. In 1997 the European

Foundation on Social Quality (EFSQ) began a public debate on social quality. The focus was on creating a comprehensive theory with methodological instruments to understand and compare daily life in all parts of Europe (Vander Maesen & Walker, 2005). The Foundation consisted of representatives of universities from fourteen countries: Belgium, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Netherlands, Portugal, Slovenia, Spain, Sweden, United Kingdom, and two international Non-governmental organizations (NGO)-partners: the International Council on Social Welfare (ICSW) and the European Anti-Poverty Network (EAPN). The Foundation engaged more than a hundred scientists and policy makers in the project. At that time, there was an overabundance of individualized quality of life measures that neglected the social constructs of communities (Walker, 2009). Research and evaluation was either at the individual level or community level, but were treated as mutually exclusive. Construction of SQT and its indicators was completed in 2005, representing a forty-two month process (Van der Maesen & Walker, 2005). The group formulated a working definition of social quality; “the extent to which citizens are able to participate in the social and economic lives of their communities under conditions which enhance their wellbeing and individual potential” (Beck, Van der Maesen, Thomése & Walker, 2001, p. 3). They asserted that social quality connects societal experiences that concern the welfare of the individual on one side and the quality of individuals as social beings on the other. It is a complex approach underlining interactions between the simple and multifaceted perspectives, as well as those between formal societal structures and the informal communities (Nectoux & Thomese, 1999). SQT addresses the imbalance of societal focus on measuring wellbeing, happiness and quality of life as individuals and shifts to measuring groups, communities and other social relationships. In this approach, “social is not juxtaposed from individual, instead they are both part of and packaged in

the same phenomenon” (Bhaskar, 2008, p. 2; Ward, Meyer, Verity, Gill & Luong, 2011). SQT is not dismissive of individual based theories and approaches, but finds that their use and effectiveness is best for clinical settings and one-on-one solutions, as they are not suited for population level efforts. These approaches can speak to the needs of individuals and their circumstances, but cannot explain why certain communities are worse than others, nor guide community-level interventions (Van der Massen & Walker, 2005).

Formation of measures and indicators. SQT was created with empirical application as a goal. Yet, as with all theories, certain assumptions are present. Four conditional factors of social quality were distinguished, and measures of these conditional factors were explored by creation of indicators in each (Beck et al., 2001). They are social cohesion, social empowerment, social inclusion, and socioeconomic empowerment. Elaboration of the understanding of the conditional factors was accomplished through both deductive and inductive forms of reasoning by input from scientists in the previously mentioned countries. The input allowed for consensus of the definitions of the factors in relation to how “social” is defined by the creators of the theory (Van der Maesen, Walker & Keizer, 2005). The theory states that self-realization of individuals and the formation of collective identities influence each other, establishing a constitutive interdependency. This interdependency happens in the context of two basic pulls, depicted by the horizontal and vertical axis in Figure 3 (Habermas, 1989; Lockwood, 1999). However, SQT does not treat the relationship as opposing poles, rather this axis is an emphasis of the interaction between unequal players; people and systems (Van der Maesen & Walker, 2005). On the left the interaction is concerned with the relationship between individuals and the world of systems, while on the right the relationship is between people and societal entities such as communities. Between the poles there is simultaneous mutuality and reciprocity (Beck et al., 2001). The

vertical axis crosses the horizontal with those elements occurring in societal development and biographical development creating the life course spectrum as proposed by Heinz (Weymen & Heinz, 1996). Heinz contends that modern society causes the life course to force people into flexible responses of self-reflexive decision making and risk taking, and they no longer follow a predetermined pattern (Weyman & Heinz, 1996). In other words, life course is dependent on the realities of place and relationships.

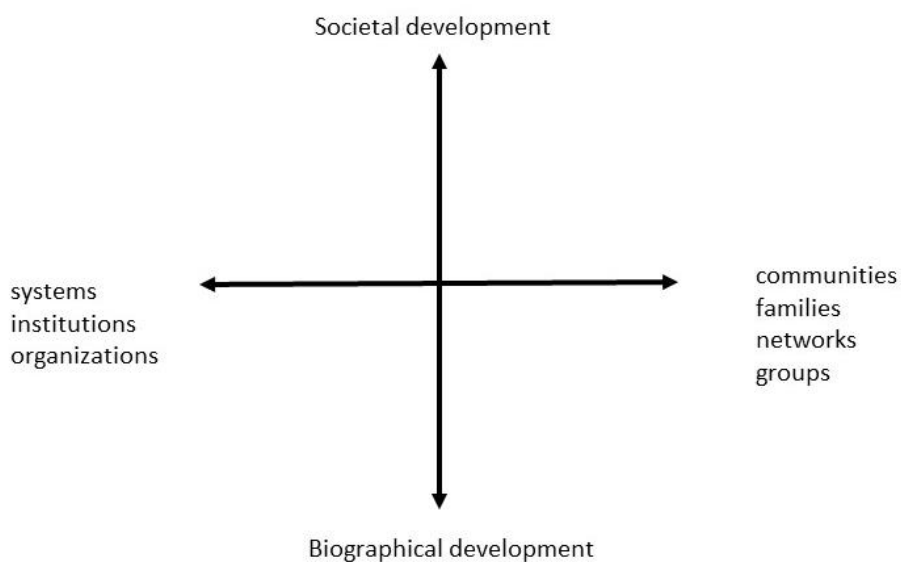


Figure 3. Context for constitutive interdependency. Figure created by author based on Social Quality: From theory to Indicators, Figure 3.2 (2012).

According to SQT, the social world is the interaction between self-realization of the individual as a social being and the construction of collective identities occurring in the context of the relationships presented in Figure 3. The theory refers to this as the structure of the “social”. There are four conditions that determine the opportunity for these social relations to grow: 1) people must possess the capability to interact (social empowerment); 2) the structural context must be accessible to them (social inclusion); 3) people must have access to the essential resources that facilitate interaction (socio-economic security); and 4) the necessary collective

accepted values and norms enabling community building (social cohesion) (Beck et al., 2001). These conditions are rooted in the definition presented earlier of social quality and reinforce the capacity of individuals contributing to society and the outcomes influencing conditions for their self-realization. The addition of conditional factors to social quality may be seen in Figure 4 below. An iterative process involving the network of countries evaluating the conditions and applying their situational knowledge yielded the following definitions outlining essential pieces of each factor:

- Socio-economic security is the extent to which people have resources over time.
- Social cohesion is the extent to which social relations, based on identities, values and norms, are shared.
- Social inclusion is the extent to which people have access to and are integrated into the different institutions and social relations that constitute everyday life.
- Social empowerment is the extent to which the personal capabilities of individual people and their ability to act are enhanced by social relations (Van der Maesen & Walker, 2012).

The four conditional factors are not independent of one another nor are they four pieces equally distributed. The emphasis is on their position in the quadrangle and interactivity between locations. Other elements of each quadrangle also play a role in modifying interactions, and all components are relational (Van der Maesen & Walker, 2012).

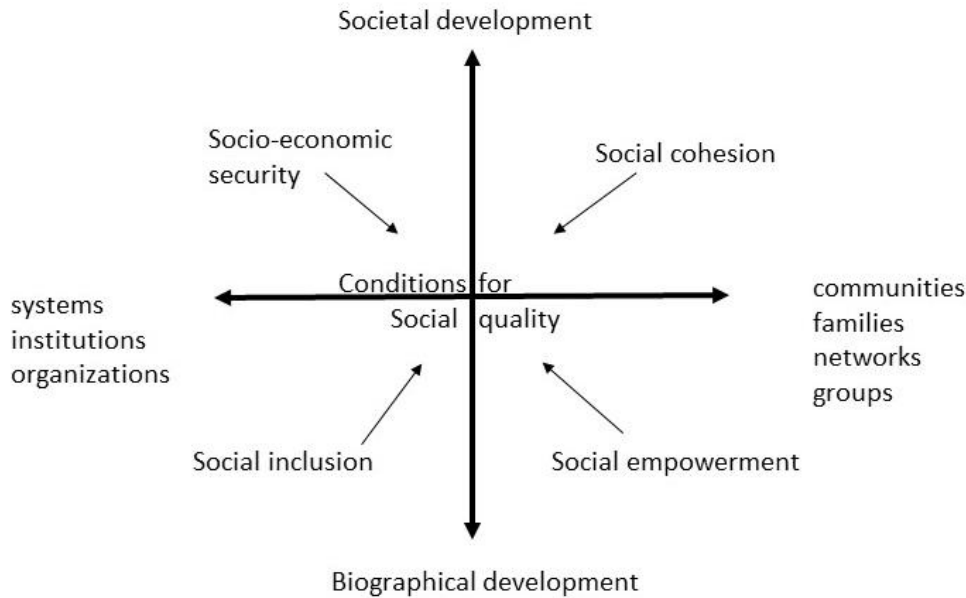


Figure 4. The quadrangle of the conditioning factors for social quality. Figure created by author based on Social Quality: From theory to Indicators, Figure 3.4 (2012).

Once the conditional factors were defined, the next step was to develop indicators, or measurement tools, for each. The Foundation wanted to create a robust set of indicators and substantially increase the understanding of the four conditions. This was operationalized by creation of each factor and related domains, formation of sub-domains, and indicators for each sub-domain. Consensus for all indicators was gained by the entire network through processes including relationship to the core of social quality, representation of the sub-domain, and link to the main domain (conditional factors). Table 2 below displays the domains for each conditional factor. Table 3 displays *social cohesion*, as a sample, its domains, sub-domains and the agreed upon indicators for measurement, while the remaining three domains, sub-domains and corresponding indicators may be found in Appendices A, B, and C (Berman & Phillips, 2004; Herrmann, 2003; Keizer & Van der Maesen, 2003; Van der Maesen & Walker, 2005; Walker & Wigfield, 2003). Upon completion of sub-domains and indicators, the definition of SQT was amended to state that “social quality is the extent to which people are able to participate in social

relationships under conditions which enhance their well-being, capacities and potential.” While this is a seemingly small change, it is extremely important to note the substitution of social and economic life’ for ‘social relationships’ and the addition of ‘capacity’. This change emphasizes the dynamic nature of social quality and how individual’s participation in their own development and shaping of their own circumstances also cultivates societal development and has the potential for positive outcomes (Van der Maesen & Walker, 2012).

Table 2.
SQT Conditional factors and domains

<u>Socio-economic Security</u>	<u>Social Cohesion</u>
Financial resources	Trust
Housing and the environment	Other integrative norms and values
Health and care	Social Networks
Work	Identity
Education	
<u>Social Inclusion</u>	<u>Social Empowerment</u>
Citizenship rights	Knowledge base
Labor market	Labor market
Services (public and private)	Openness and Supportiveness of Institutions
Social Networks	Personal Relations

Adapted from Van der Maesen & Walker (2005).

Table 3.
Indicators of Social Cohesion

Domain	Sub-domain	Indicators
Trust	Generalized trust	Extent to which ‘most people can be trusted’.
	Specific trust	Trust in: government; elected representatives; political parties; armed forces; legal system; the media; trade unions, police; religious institutions; civil service; economic transactions. Number of cases being referred to European Court of law. Importance of: family; friends; leisure; politics; respecting parents; parents’ duty to children.

Table 3 continued

Other integrative norms and values	Altruism	Volunteering: number of hours per week. Blood donation.
	Tolerance	Views on immigration, pluralism and multiculturalism. Tolerance of other people's self-identity, beliefs, behavior and lifestyle preferences
	Social contract	Willingness to pay more taxes if you were sure that it would improve the situation of the poor. Intergenerational: willingness to pay 1 percent more taxes in order to improve the situation of elderly people in your country. Willingness to actually do something practical for the people in your community/ neighborhood, such as: picking up litter, doing some shopping for elderly/disabled/sick people in your neighborhood, assisting neighbors/community members with filling out (fax/municipal/etc.) forms, cleaning the street/porch/doorway. Division of household tasks between men and women: Do you have an understanding with your husband/spouse about the division of household tasks, raising of the children, and gaining household income?
Social Networks	Networks	Membership (active or inactive) of political, voluntary, charitable organizations or sport clubs. Support received from family, neighbors and friends
Identity	National Identity/Regional/Community/Local	Sense of national pride. Identification with national symbols and Regional symbols. Sense of regional/community/local identity.
	Interpersonal identity	Sense of belonging to family and kinship network.

Adapted from Berman & Phillips (2004).

Social Quality Theory was widely disseminated for application upon completion the framework and measurement tools (indicators). Representatives from each of the fourteen

countries went back to their respective areas and formulated teams to apply SQT and measure social quality. Each customized the approach to ensure appropriate fit to their populations and systems, leading to rich diversity of variations that brought about policy implications within and between countries. The theory's scope also expanded to Asia, particularly China, where scholarly work continued to increase. It is also crossing into the health field as the theory's alignment with the social determinants of health is receiving attention (Meyer, Luong, Tsourtow, & Ward; Van der Maesen & Walker, 2012). However, SQT has yet to be adopted in the United States.

SQT for measuring social determinants of health. Though SQT was developed outside of the health sector, it has potential to impact to the social drivers of health. In terms of public health policy, there are obvious potential applications of SQT for reduction of health inequalities. The social determinants of health are known to lead to equal or greater influence on poor health than those of biological determinants. Therefore, the possibility of SQT serving as a catalyst for change in socially influenced ill health is ripe for exploration. Dr. Paul Ward, an Australian public health researcher with a background in sociology, has conducted extensive research into SQT and its applicability to public health. Ward puts forth SQT as a potential mechanism for knowledge transfer between practice and research by providing a framework to understand public health problems in concert with engagement of policy (Ward, 2006). He states that SQT “can make sense of theory, policy and practice, thus facilitating dialogue between members of the respective camps” (Ward, 2006, p. 2). Ward and colleagues assert that the core of SQT is the importance of reciprocity between social structures and individual subjects and the cultural conditions of interaction changes the conditions, whether positively or negatively. He concludes that public health presents opportunities for SQT to 1) improve social conditions that stimulate

health, 2) prevent conditions that threaten health, and 3) neutralize existing conditions that cause ill health (Ward, 2006).

In a study conducted in 2011, Ward and his team operationalized SQT to not only measure social quality in Australia, but its linkage to social determinants of health in the population. The work was born out of the belief that most research tools available only allow for focus on a singular social determinant of health such as social capital or social inclusion. However, SQT facilitates a more complete understanding of those determinants (Ward et al., 2011). Data were collected using a national random postal survey of 1,044 residents. The original SQT indicators were developed into a questionnaire consisting of fifty questions organized into the four conditional factors. The tool was tested for both validity and reliability, including collaboration from Berman, Herrmann, Keizer and Walker, the SQT indicator designers (Berman & Phillips, 2004; Herrmann, 2003; Keizer & Van der Maesen, 2003; Walker et al., 2003). A copy of the questionnaire, letter of information, letter of introduction and stamped return envelope was sent to 5000 households in all eight Australian states (Ward et al., 2011).

Analysis consisted of descriptive statistics for all areas of social quality. Bivariate logistic regression was then undertaken to evaluate simple association between sociodemographic factors and indicators of social quality. Those yielding significance were then included in multivariate logistic regression analyses. For the regression models, the four questions identified in 2004 by EFSQ were used as dependent variables (Ferris, 2004). However, the complete questionnaire contained many indicators that have been shown as proxies of social quality (Meyer et al., 2010). Two additional variables were created; Socio-Economic Indicator for Areas, which provides a score for the level of socio-economic deprivation of an area and Accessibility and Remoteness

Indicator for Areas, which provides a score for the distance to major service centers. These were identified as important for potential impact on social quality. Along with these variables, age, sex, employment status and income were chosen as covariates (Ward et al., 2011).

Lower social quality was found among disadvantaged individuals, who scored significantly lower in all four domains; socioeconomic security, social cohesion, social empowerment and social inclusion. Retired respondents were found to have the lowest levels of socio-economic security and women had lower social inclusion than men, with special mention of experienced discrimination. The authors suggest that the findings confirm the utility of SQT as it provided the ability to examine more than one area of social life and moved beyond partial understandings of social problems (2011). Using the SQT in this study allowed for the empirical examination of social factors, which provided more appropriate targets for policy and action. The social quality approach reveals how the social is conceived and how social and health are interrelated and formulated. This approach has future implications as repeated measures would create a means to evaluate the outcomes of policy and programming interventions (Ward et al., 2011).

SQT versus Quality of Life and Social Capital

Social scientists have attempted to fit ranges of social phenomena into unified analytical frameworks to meet research needs for decades, especially with respect to connecting to health outcomes. SQT, as described, has been proven as a tool for measuring social quality and social determinants of health, however many other theories and approaches also exist. There is a large body of work on the utility of Quality of Life (QOL) and Social Capital (SC) as guiding theories and measures for work in social determinants of health. However, proponents of SQT and

skeptics of QOL and SC believe neither provides a comprehensive picture of the social factors or have the applicability of measurement at the community level.

Quality of Life was an approach first proposed by Lawton who defined it as behavioral competence (1983). Most of the early research was conducted in the United States and focused on satisfaction, happiness and well-being. Many in the health sector adapted the QOL, but did so with empirical interest in individual perspectives of quality (Van der Maesen & Walker, 2012). When comparing QOL and SQT, the overarching difference is the respective unit of operation; QOL is individual oriented and explores how well individuals live in society (Veenhoven, 1996) or an individual's total well-being including emotional, physical and social aspects of the individual's life (Lin, 2013). However, SQT, as explained in detail, is society-oriented. Quality of Life measures indicators such as income, educational level, housing situation, and social factors such as leisure/recreation time, social well-being, and social belonging to gauge overall quality of life (Kane, 2003; Gregory, Johnston, Pratt, Watts & Whatmore, 2009). Yet using those to describe overall conditions of society is a potentially questionable practice as those are isolated, individual realities that cannot be confirmed for a community. Social quality is the accumulation of life qualities of individuals, which includes interaction between self-realization of individuals and formation of collective identities (Beck et al., 2001). Social quality analysis focuses attention to the contextual analysis of the social system beyond the indicators for QOL (Lin, 2013). There is a level of overlap between QOL and SQT such as indicators related to socioeconomic security. This provides an opportunity to use the theories complementarily. Both can support social development toward enhanced life satisfaction and policy development toward societal improvement. Quality of Life can reveal problems of housing, income, education and can encourage policy actions to be taken on these demands. Simultaneously, SQT allows for the

examination of key social issues for improvement to guide central tasks for the policies being developed (Lin, 2011). When considering social determinants of health and culture of health, QOL does not serve the purpose of constructing the comprehensive picture of the social reality of the groups of interest, as it ignores crucial social factors.

Social Capital (SC) is the other most widely used approach and is very popular in the United States especially in the health and social sectors. It has existed for a long time, but has gained momentum over the last decade as researchers are looking to better understand community and the life course. Most often, SC measures include data on personal relationships, social network support, civic engagement, and trust and cooperative norms (OECD, 2017). Beck et al suggest that SC is similar to popular European approaches of the “idea of social protection and social cohesion as productive factors for economic relations” (2001). When evaluating SQT and SC, it is like comparing unequal parts. Social Capital includes just one element of measures in SQT within the domain of social cohesion. The themes of trust, values and norms within SC are all social cohesion concepts (World Bank, 2000). Measuring SC is a valid approach, however it does not accomplish the scope of assessment of SQT. Social Quality Theory simply contains an increased number of metrics that provide additional, essential information when evaluating social determinants of health and culture (Ward, 2006).

CHAPTER 3

METHODS

Study Design

This study received grant funding from Blue Cross Blue Shield Foundation of Tennessee and the Niswonger Foundation in the amount of \$30,000. The grant team consisted of four East Tennessee State University faculty/staff members: Paula Masters, Assistant Dean of Student Services-College of Public Health, Ginny Kidwell, Executive Director-Tennessee Institute of Public Health, Dr. Kate Beatty, Assistant Professor- College of Public Health, Department of Health Services Management and Policy and Dr. Megan Quinn, Assistant Professor- College of Public Health, Department of Biostatistics and Epidemiology. The Institutional Review Board (IRB) at the university approved this study in February 2017. This chapter outlines the study framework, sampling plan, methodology and data analysis. The study employs the use of qualitative methods, utilizing focus groups as the primary data collection method.

Setting

Central Appalachia was chosen as it experiences higher levels of mortality and morbidity in many areas when compared to its northern and southern counterparts (NORC, 2017). The study location, Hancock County, Tennessee, was one of the many rural, distressed counties in Central Appalachia. Hancock County is one of the unhealthiest counties in Tennessee, the Appalachian region and the country. People of Hancock experience more than twice the years of potential life lost compared to the United States, a rate almost 40% higher than the TN average (County Health Rankings, 2016). The county has an adult smoking rate of 26%, only 3% of community members have access to physical activity, and the county suffers from an extremely high injury death rate (County Health Rankings, 2016). These disparities are exacerbated by only

one physician serving the entire county of 6,572 people (County Health Rankings, 2016). The people of Hancock have a per capita income half that of the United States and 40% less than others in Appalachia (Appalachian Regional Commission, 2016). Hancock's unemployment rate is 10% compared to Tennessee's 5.8% and poverty rate for children is 44%, well above the state's 24%. Hancock has a low high school graduation rate of 83% and 43% of residents who have "some college" (County Health Rankings, 2016). While these statistics are alarming and unacceptable, this county is not unique with respect to the economic, health and educational hardships in rural Appalachia (Appalachian Regional Commission, 2016).

Guiding Model and Measures

Theoretical Framework. While Appalachia may be characterized by poverty and hardship, a better understanding of the social/cultural context is needed to identify ways to improve outcomes and create a culture of health. While there is agreement on the importance of the social determinants of health and a call for efforts to tackle the disparities these determinants create, there has been a lack of evidence-based models with which to work. Improvements have been made over the past few decades in the research of social determinants of health, yet most of the work is outside of the United States, is strongly focused on empirical research methods and lacks adoption of guiding theories (Richter, 2010). The Social Quality Theory, the rationale for which was detailed previously, was adopted as the guiding framework.

Data Collection Design. Data collection was conducted within a cross-sectional, qualitative, focus group design over a twelve-month period. This design was chosen as it is the most widely used in qualitative and mixed methods research (Creswell, 2014; Draper & Swift, 2010) and was the most appropriate to test the utility of the Social Quality Theory.

Community Based Participatory Research. Community-based participatory research (CBPR) uses interdisciplinary mixed and multi-method research designs to produce outcomes that are meaningful to communities. Lucero et al. finds that CBPR is gaining recognition in its utility to address some of the challenges posed by more standard research designs (Lucero et al., 2016). The challenges that CBPR can address are ensuring external validity, translating to local communities, improving research integrity, and demonstrating both individual and community benefit. This allows for acceptable rigor, but also allows for increased community applicability (Lucero et al., 2016). CBPR builds on principles of participatory models such as respect for diversity, community strengths, cultural identities, co-learning, and power-sharing (Israel et al., 2013). It incorporates community cultural values and means of knowledge that are critical for reducing health disparities and improving quality of life (Lucero et al., 2016). Typically, researchers use in-depth literature reviews to guide the development of the research problem they address. However, within CBPR this process is also guided by initial discussions within the study population (community) to focus the research.

The community, Hancock County, was consulted during the entire process from initial project development to selection of tools and questions. Special attention was paid to participation burden and fatigue was maintained throughout the process. By adopting CBPR as a guiding framework for the study, the project was aligned with the locations and topics for the population and cultural relevance. Use of CBPR in this situation allowed for cultural concepts to be honored, an enhancement of community-university trust, and a rich opportunity for multidirectional learning. During preliminary discussion with the study community, the concept of mistrust and organizational bullying was referenced often and presented a potential obstacle for the project. These same concerns have been identified in the literature when working in other

areas of Appalachia (Coyne et al., 2006; Slusher, 2010; Vance et al., 2012). CBPR helped to reduce those fears and reassure the communities of the sincerity and commitment to the people and their well-being.

Focus Groups

Focus groups were used for data collection and conducted throughout Hancock County between July-November 2017. Both focus groups (Coyne et al., 2006; Deskins et al., 2006; Goins et al., 2011; Hutson, 2007; Krummel et al., 2002; Tessaro et al., 2005; Vance et al., 2012; and Walker, 1994) and key informant interviews (Arcury et al., 2005; Davis, 1991; Della, 2010; Slusher et al., 2010; and Vance et al., 2012) were used in the studies previously mentioned, however due to time and funding constraints, key informant interviews were outside the scope of this study. Planned data collection sites were 1) Mulberry Gap School, 2) Seal Mathis School, 3) Hancock County Arts, 4) Flat Gap School, and 5) River Place. Figure 5 is a map representing locations of those of the sites, indicated with a circle and corresponding number. The selection of sites was guided by the intention to obtain geographical representation. While Hancock County has a small population, its terrain makes travel difficult. All locations were highly accessible, easily accommodating a group session with adequate space and parking. However, after working with the sites, not all were available or still active, therefore alternate arrangements were made. Sites 3 and 5 were used along with four additional sites identified by community participants; Hancock County Elementary School, Hancock County Health Department, Treadway Fire Hall and a personal residence. These sites are indicated with a triangle in Figure 5.

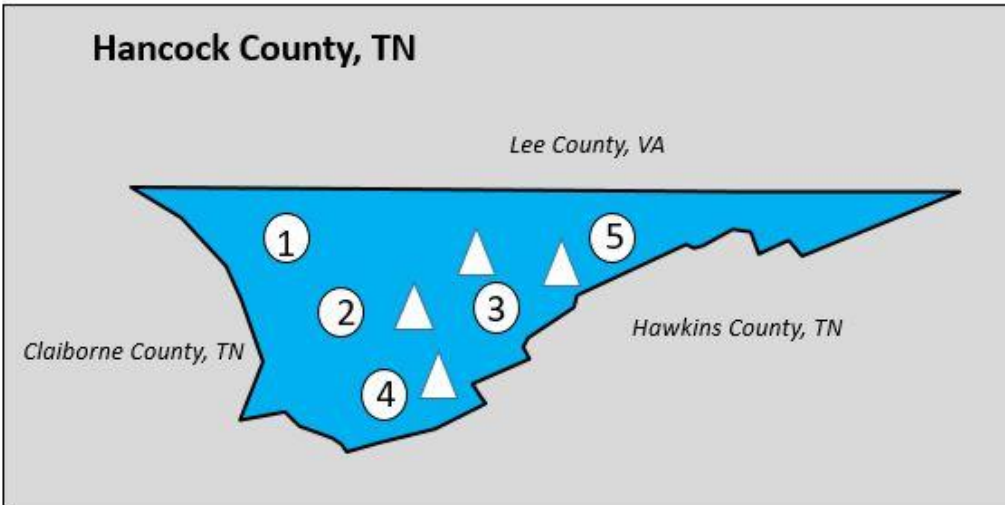


Figure 5. Focus Group Location Map.

Initially, five focus groups were planned with 6-8 participants in each group. Six to eight participants is the suggested number for a manageable focus group (Creswell, 2014). The goal was saturation of concepts from respondents. Saturation occurs when no new themes, insights or properties are found (Charmaz, 2006; Creswell, 2014). Though saturation was reached, an additional focus group was added in an attempt to gain more participants and demographic representation of the community, attempting to achieve closer demographic representation as seen in Hancock County residential profiles (see Table 4). A total of six groups were completed hosting a total of 35 participants. Descriptive statistics for the focus groups are provided in the results section.

A moderator’s guide was developed and used by all group facilitator(s) to ensure consistency between groups. The guide (Appendix D) included introductory narrative, topical descriptions, confidentiality language, study questions, and probes. Each group session lasted between 43:33 and 85:58 minutes. All sessions were recorded and transcribed by BabbleType© for analysis. One moderator conducted all sessions, there was one official note taker present at each session, and those notes were used for additional analysis (Appendix E). Those notes

included descriptions of the location/site, communication patterns of the group, observer perceptions and thoughts, and other information the note taker believed provided a comprehensive picture of the session. A debriefing session was also conducted after each focus group to review preliminary findings and express observations.

Sampling Plan

Convenience sampling was used. Common areas throughout the county were identified and confirmed through collaboration with community members. Recruitment materials were placed in those locations with the intent of attracting those visiting to participate in the group. Recruited participants were encouraged to tell others about the study. There were 18 different physical locations where recruitment materials were placed ranging from the single grocery store in the county to gas stations to the community health center. Social media was also used as a “common area” for recruitment. The study hoped to attract residents representing the population demographics presented in Table 4 with regard to sex, age, income, education level and employment status. The sampling frame were all Hancock County residents above the age of eighteen, 5,178 persons or 78.8% of the population (FTDD, 2017).

Table 4.
Hancock County Demographics

Demographic Variable	Measure
Population	6,577
% females	50.5
Median Age	44
% Unemployment	10
Median Household Income	\$26,898
% High School graduate or higher	73.3
% Bachelor's degree or higher	10.6

US Census, 2016 and County Health Rankings (2016).

Recruitment Strategies

Recruitment of participants for the focus groups used both printed and electronic approaches. Appendix F includes the invitation flier that was posted in common and/or shared community spaces. As mentioned, 18 sites were identified and included to post materials: examples are 1) Greene's IGA-the single supermarket in the town of Sneedville, a site includes a community bulletin board as patrons enter the building; 2) Hancock County Arts-community arts center and the only official extracurricular activity site for youth; 3) Senior Center-devoted to housing activities for those 55 and older; 4) Courthouse building; 5) Clinch River Market-convenience store with an area for music for the public; 6) River Place-market and restaurant supplying patrons with both local foods and goods; and 7) Last Chance Market-convenience store located at the foot of Clinch Mountain. A space in the Sneedville Shopper, the county's only newspaper, was also secured to post the recruitment flier. This paper has wide circulation in the county and is the main local informational source for many residents.

Electronic recruitment via social media was used as well. Hancock County operates a county Facebook page, Overhome Happenings, where members post information on community programs, upcoming events, celebration of accomplishments of residents and organizations, and birth and death announcements. The page is restricted to only those who currently or have resided in Hancock County. It receives high levels of traffic and posts. There are currently 3,799 active members to the group. The page contains both relevant and up-to-date information and is administered by a community champion and life-long resident. Recruitment language was posted to Overhome Happenings before each focus group, with reminders posted twenty-four hours before group start time.

Solicitation of participation also occurred through email and phone calls to identified residents. Appendix G provides the email/phone language used to invite participants. Invitations were sent at least two weeks prior to the selected date with one follow up call occurring 48 hours before meeting. Confirmation of participants were compiled and tracked and reminder calls were made two days before the date of each focus group.

Measures

As outlined, SQT has a number of indicators that have been used to measure social quality and linked to gauging social factors that determine health (Ward et al., 2011). The study sought to elaborate on Ward's work (2011) leveraging qualitative data collection using not only SQT measures, but also measures for defining health in populations, and further exploration into sociocultural factors. Generally, measures included how people in rural Appalachia define health, how the population interprets the social determinants of health (guided by SQT) and perceptions measuring the present culture of health. The data collection tool consisted of semi-structured questions within the overarching themes referenced above and detailed below (Appendix D: Moderator's Guide).

Rural definition of health. Using knowledge gained upon review of the body of literature for rural definitions of health offered by those in rural areas, with special attention to those studies conducted with Appalachian populations, three questions were selected for measuring the current definition of health. The questions, and corresponding probes, were constructed by combining previously validated questions (Arcury et al., 2005; Coyne et al., 2006; Davis, 1991; Goins et al., 2011; Slusher et al., 2010; Tessaro et al., 2005; Vance et al., 2012). Though previous studies included more questions directly related to defining health, the focus of those studies was primarily to define health and did not contain the other elements

evaluating links to social determinants. The questions and probes were: 1) *What does health mean to you? Probe-What contributes to that?;* 2) *What does health mean to Hancock County? Probes-Community, Businesses, Families, Faith, How is health incorporated into daily living?;* and 3) *How does health affect quality of life? Probes-Physical Health, Mental Health, Emotional Health.* These represent the first section of the moderator's guide.

Social determinants. The construction of questions to evaluate the population's interpretation of the social determinants of health used the SQT domains as guides (social cohesion, social empowerment, social inclusion and socioeconomic security) and those overarching proxy questions established by Meyers et al. (2010). All sub-domains and indicators were contained within the four primary SQT domains. The most commonly referenced social determinants of health; education, economic status, and physical environment; were also included (Heiman & Artiga, 2015). It was believed that through combining both direct and indirect questions of social factors, richer conversation would occur. There were six questions in this section. This was the largest section, as it represented the overall goal of the study. The questions and probes were: 1) *What do you think contributes to the health of Hancock?;* 2) *How do social factors such as social networks and groups, personal relationships, social services, contribute to health? Probes-What resources are available for health?, How are they accessed?, What social structures and/or networks around health exist?, How do those function?, How is health made a part of daily conversation, activities and life?, How are residents provided support toward health?;* 3) *How does education contribute to health?;* 4) *What about economic status such as income or other financial resources, how does that affect health?;* 5) *How does the environment contribute to health?;* and 6) *What are other contributors to health in Hancock?*

Culture of health. Staying within the RWJF Culture of Health framework, questions for the final section of the moderator's guide were selected. The intent was to simply ask focus group participants directly about the current culture and perceptions providing an opportunity to freely discuss their identified cultural guides and supports instead of assuming factors of cultural foundations. There were three questions in the culture of health section: 1) *How does the current culture support health?*; 2) *What do you think the overall perception of health is in Hancock? Probe-What drives that perception?;* and 3) *What barriers or challenges exist?*

Participant demographics. Previous studies collected demographic information from focus group and interview participants. This approach was adopted and seen as essential as it provided a more comprehensive view of the study population, and allowed for another factor of culture and identity to be explored (Coyne et al., 2006). Participant demographics were captured through a simple anonymous survey that each participant completed after the focus group commenced and placed in a box to protect confidentiality. There were no identifying questions, however to ensure confidentiality the forms were not reviewed until all information was compiled at the end of the data collection period. The demographic questions and categorical answer options were taken from supporting literature and the United States Census Survey (US Census, 2017). However, there was an additional measure unique to the study population, which was the inclusion of Melungeon as an identity option. Melungeons are a group of racially diverse people originating in the mountains of northeast Tennessee, specifically Hancock County, and are present throughout this area and southwest Virginia and eastern Kentucky (Yates & Hirschman, 2010). Upon observation of the study population, this is a potential piece of identity that must be included as there is a sense of pride in 'being' Melungeon among some of the

residents. All information was compiled and entered into Microsoft Excel for simple descriptive statistics. The demographic participant form may be found in Appendix H.

Researcher's Role

The role of the researcher in qualitative research is one that should be communicated to all involved. That communication should include information on personal values, assumptions, experiences and biases. Disclosure of the primary researcher is provided below.

“I come to this project with preconceived notions of what the data will unveil.

These notions are grounded in growing up until age eighteen in the study site and among the participants. Though I relocated to pursue college, I still continue to spend time in the county and with the residents. I am the child of a rural physician and nurse. I watched as they struggled to meet the high demand of disease and ailment of the community with little to no resources. I also experienced the loss of any health care infrastructure with the closure of the only hospital within 45 minutes and growth of despair throughout the community as many other jobs faced the same fate as healthcare. I watched my community decline with decreasing population and economic growth and adoption of unhealthy or dangerous behaviors. These experiences guided me to my career path in public health and now to this study. I have worked in public health with the charge of health promotion and disease prevention for Northeast Tennessee for fourteen years.

Due to these previous experiences and my career discipline, I bring certain biases to the study. Although every effort and mitigation measure was taken to ensure objectivity, this bias may shape the way I see and understand the data and interpret the findings. I began this study with the view that there is complexity involved in how one defines health and it is difficult to articulate connections between the social determinants

of health. I believe this is especially challenging when there are cultural impediments present that do not allow for a clear picture of the relationships to be made. I also have a deep passion and commitment to the study population as they are still and will always be part of my roots and family”.

Data Analysis

Thematic Analysis

All focus groups were recorded and transcribed verbatim by BabbleType©. Consent was secured before participation in the group and informed consent language adhered to ETSU IRB rules and regulations. The transcripts were then entered into Microsoft Excel for content analysis and assignment of themes. Thematic analysis, assignment of codes to phrases, sentences or paragraphs that are connected to a specific content/theme (Decuir-Gunby, Marshall & McClulloch, 2011) were both data-driven and theory driven, and allowed for continual iteration. Theory driven codes relied on SQT domains, subdomains and indicators (Table 3 and Appendices A, B and C). A codebook to assist analysis and increase reliability was constructed for use. It included codes, definitions and examples found in the data (Decuir-Gunby et al., 2011) and is found in Appendix I. Codebooks are “essential to analyzing qualitative research because they provide a formalized operationalization of the codes” (Fereday & Muir-Cochrane, 2006, p. 4). Figure 6 provides a visual depiction of the process used during code development.

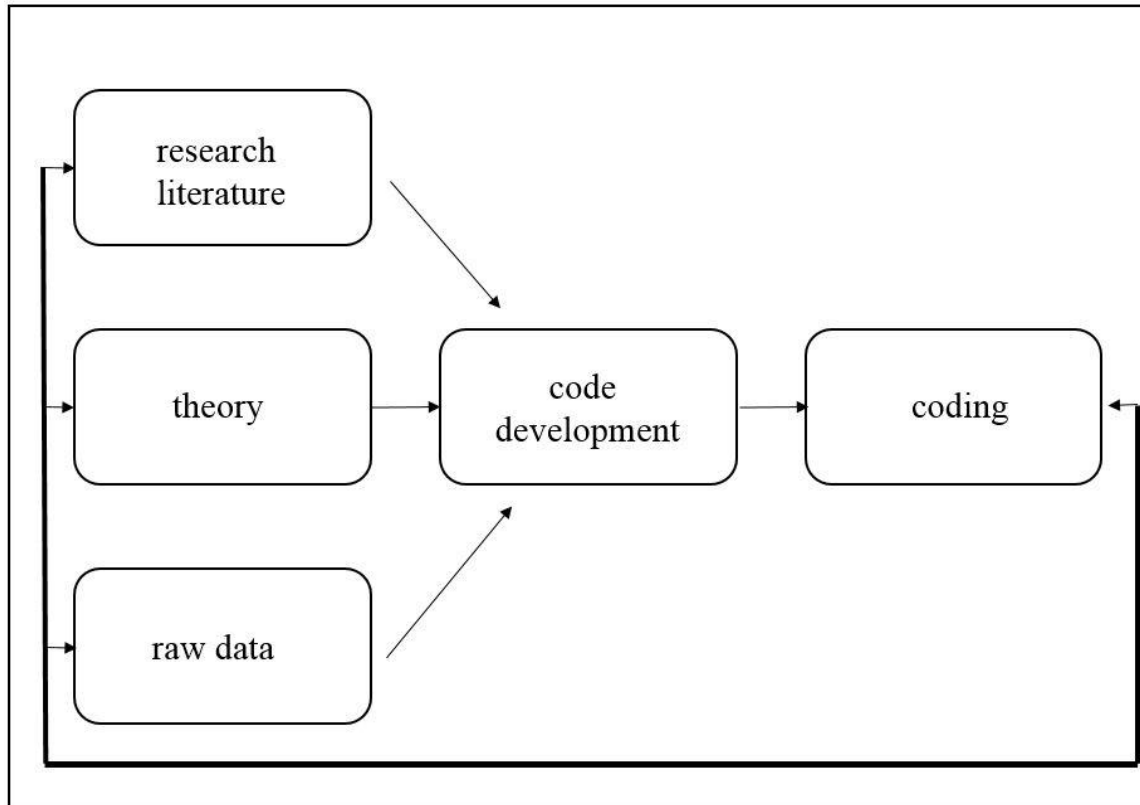


Figure 6. Circular process of coding. Figure created by author based on Decuir-Gunby et al. (2011).

Reliability and Validity Strategies

The study included multiple strategies to ensure comprehensive and rigorous priority through its entirety. It is a misconception that qualitative research compromises its level of reliability and validity (Cresswell, 2014). It merely employs different measures than that of quantitative research. The following section outlines the steps taken to ensure both reliability and validity.

Creswell (2014) proposes adoption of multiple approaches to validity. He encourages the use of as many approaches as possible to better ensure the trustworthiness, authenticity and credibility of the data (Creswell & Miller, 2000). Creswell and other leading experts have identified eight primary strategies for validity to be incorporated by the researcher. They are 1) triangulation of multiples sources of data, 2) member checking -taking the findings back for

comment from the participants, 3) rich, thick description to convey findings, 4) clarify the bias the researcher brings to the study, 5) presentation of negative or discrepant information, 6) spending prolonged time in the field/site, 7) peer debriefing, and 8) use of an external auditor (Creswell, 2014). It was not the goal to use all eight, but as many as possible and most appropriate to the study. Below are the chosen validity strategies and their application for the study.

Validity Strategies

1. Triangulation of data---all focus groups were recorded and transcribed. There was also a primary note taker at each group. One person was required to complete field notes with reflection from each session attended. These three diverse pieces of data were triangulated for each session, compiled for evaluation across sessions, and were used in the thematic analysis. There was one focus group where notes were not taken due to lack of staff.
2. Member checking---a preliminary report of themes and findings were taken back to some participants for determination of accuracy. Comments provided in the findings during this process were used in analysis and included in relevant results.
3. Use of rich, thick description---all results and reports include very descriptive language of the sites/settings to allow the audience to better understand the perspectives of the themes and participants and lean toward an atmosphere of shared experiences. This was accomplished through inclusion of a setting description in field notes (Appendix E).
4. Clarification of bias---each project staff constructed a narrative disclosing how their backgrounds or pre-conceived ideology may have affected their interpretations of the

findings. Narratives are included in Appendix J and discussed under the heading *cultural bias* in the limitations section.

5. Presentation of negative information---allowance of communication of counter or contradictory evidence of a theme are included in results. The results and discussion sections of the study include both supportive and non-supportive findings from thematic analysis.
6. Spending a prolonged amount of time in the site---a large amount of time had already been spent in the field location, which led to the interest in the research. Additionally, ten visits by at least two members of the study staff were completed to gain better observation and understanding.

The reliability in qualitative research ensures that the approaches and procedures are consistent across different researchers and projects (Gibbs, Kealy, Willis, Green, Welch & Daly, 2007). There are a number of reliability measures suggested by Gibbs et al. (2007), including; 1) check transcripts for obvious mistakes, 2) ensuring there is not variability or shifting in the codes, 3) coordination of communication among coders, and 4) intercoder agreement. Each of these were accomplished and detailed below.

Reliability Strategies

1. Check transcripts for obvious mistakes---all transcripts were immediately reviewed upon receipt. There were no obvious mistakes found outside of incorrect names of person(s) and places, which were not important to analysis, therefore required no action.
2. Ensuring no variability or shifting in codes---all members with the responsibility of coding were provided training on the process, thorough instruction on the codebook, and consistent reinforcement of codes and their definitions and application.

3. Coordination of communication among coders---regular meetings of the coders took place during the data collection and analysis phases of the project; bi-weekly communication.
4. Intercoder agreement---codes developed independently of one another on the same transcript were crosschecked to determine the level of consistency with a threshold target of 90% agreement (Creswell, 2014). All were above the target, ranging from 91-94%.

Pilot Group. Another chosen strategy to ensure reliability and validity of the study was through use of a pilot group to evaluate both the focus group implementation design and the proposed questions. A group of descriptively similar community members was identified in Greene County, Tennessee. Greene County is a rural, Appalachian area in Northeast Tennessee as well and experiences similar social, economic, education and health outcomes as Hancock County. Recruitment of participants, focus group implementation and proposed questions for the pilot were completed as described in the methods section. The pilot focus group was conducted in March 2017. There were no findings from the pilot that required any action or correction.

CHAPTER 4

RESULTS

The results are organized into three sections. The first section consists of the descriptive statistics including demographics of the participant population. The second and third sections present the results of the study by each research aim and hypothesis. The investigator assessed each focus group individually as well as in aggregate for global and cross-cutting themes.

Descriptive Statistics

Demographic information was collected from each participant (n=35) during each of the focus group sessions. Demographic information for each focus group is not provided to maintain anonymity. Figures 7-12 highlight variables that were of most interest to the investigator, consistent with the purpose of the study. The majority of participants were female (n=26, 74%), married (n=28, 80%), white (n=35, 100%), and non-Hispanic (n=27, 77%; no answer=8, 23%). Lack of racial and ethnic diversity was expected as Hancock County has a 97.1% white, non-Hispanic population (US Census, 2016).

The study included residents not representing demographic variables of the “average” Hancock County resident (Table 4) such as higher level of income, education and employment. While efforts were made to recruit a representative sample such as adding focus groups locations and numbers, additional locations for posting, and direct phone calls and emails, the data suggest that those with lower incomes, education and unemployed were less likely to participate.

Age category options were 18-19, 20-29, 30-39, 40-49, 50-59, 60-69, 70-79, and 80+. There were no participants under 30 years of age and none 80 years or older. Most participants fell between 30-39 (29%) and 40-49 (26%), mirroring the Hancock median age of 44 (US Census, 2016). Attempts were made to recruit participants between 18-29 years of age. Reasons

provided by community members for lack of engagement by these age categories included high levels of substance abuse in this age group, no network connecting this age group and lack of interest in activities in the community.

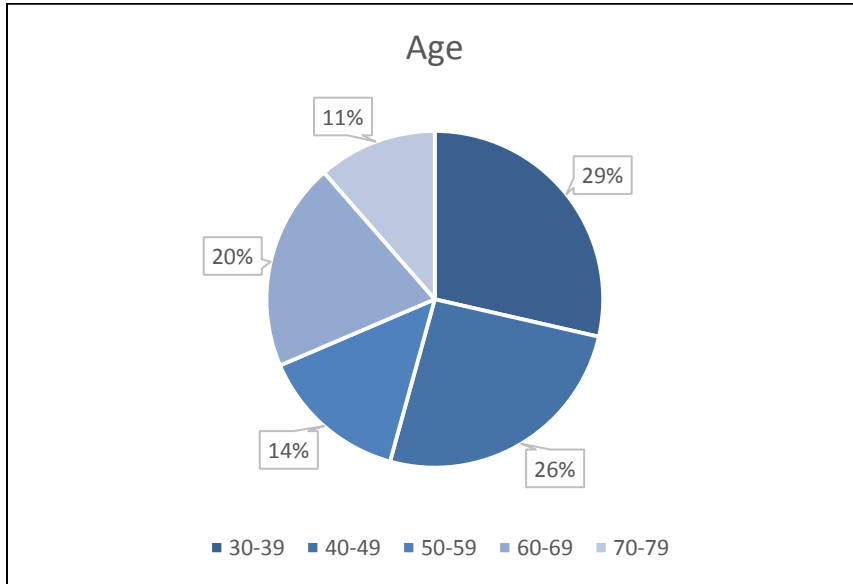


Figure 7. Participant Age for Focus Group Participants, Hancock County, TN

Level of education was a factor of interest as it is a primary social determinant of health. Participants were asked to mark their highest level of education. As shown, the majority of participants had a College degree or Master’s degree, much different from Census information for Hancock County where only 10.6% have a Bachelor’s degree or higher (2016). Therefore, this group is not representative of educational status for the average resident. Interestingly, and discussed in detail in sections two and three, relevance of educational attainment to health status was extremely low.

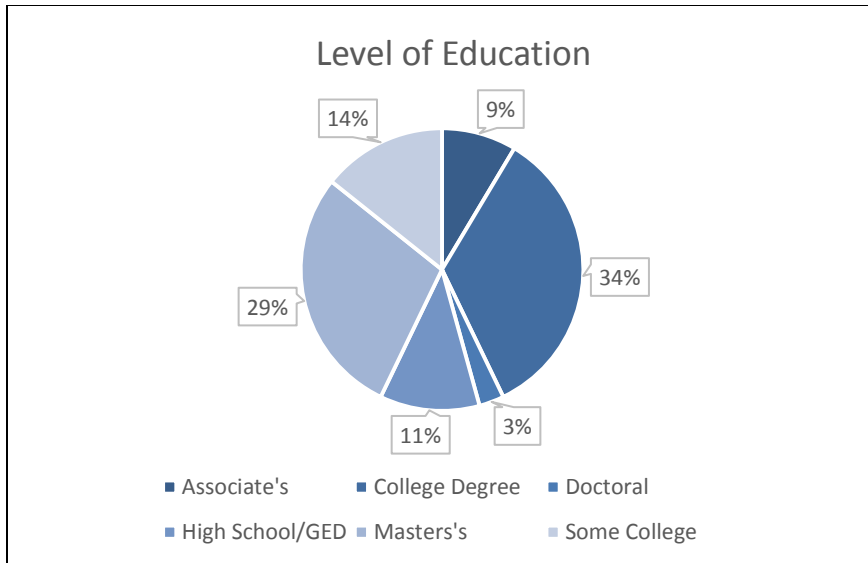


Figure 8. Participant Educational Obtainment for Focus Group Participants, Hancock County, TN

Another social determinant of interest is that of employment status, as unemployment and poverty are often interwoven and due to Hancock County experiencing high levels of unemployment, 10% (County Health Rankings, 2016). The participant unemployment rate was lower than that of the population at large in the community, representing only 3%. Most participants were employed (71%) and there were a large number of retirees in the sample (23%). Efforts to reach out to unemployed persons were made through contact with the Department of Human Services in the county, who agreed to post the announcement in their office.

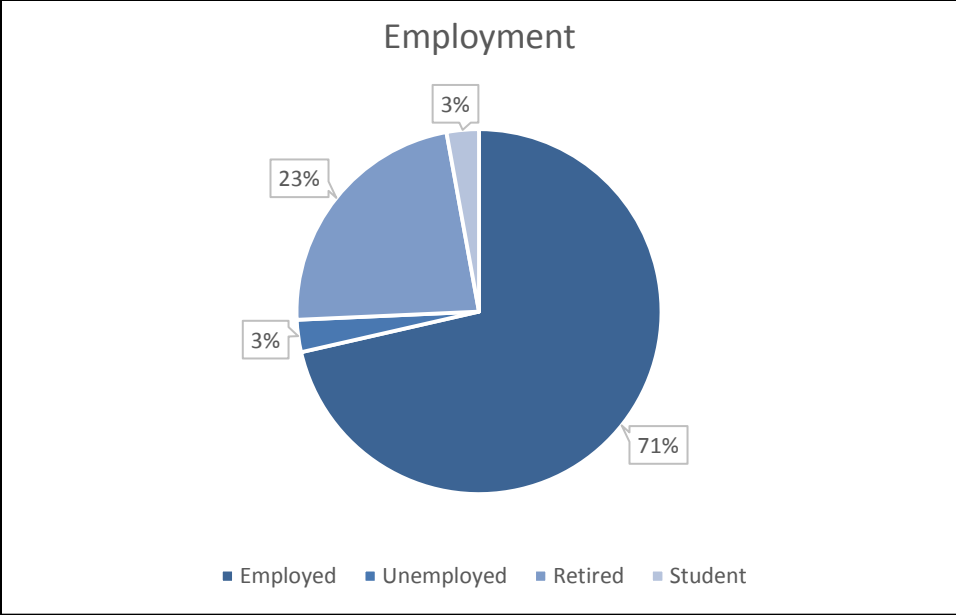


Figure 9. Participant Employment Status for Focus Group Participants, Hancock County, TN

Median household income in Hancock County is \$26, 898 (US Census, 2016). Yet, 60% of participants had incomes of \$50,000 or more and 20% between \$40,000-49,000.

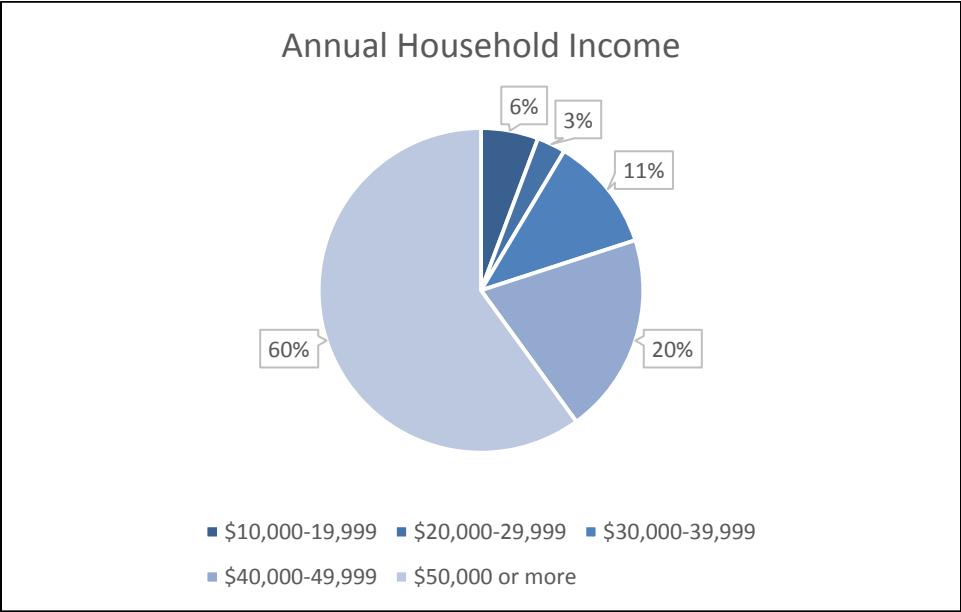


Figure 10. Participant Annual Household Income for Focus Group Participants, Hancock County, TN

Previous studies included a simple question of self –rated health with answers allowing participants to choose excellent, very good, good, fair and poor (Arcury et al., 2005; Coyne et al.,

2006; Davis, 1991; Goins et al., 2011; Slusher et al., 2010; Tessaro et al., 2005; and Vance et al., 2012). Participants overall were found to be in good (49%) or very good (31%) health. No participant reported poor health, while 6% did report being of fair health. This is lower than the County Health Rankings finding of 24% of fair or poor health in the county (2016). However, this measure uses the Behavioral Risk Factor Surveillance System which uses county estimates for counties with limited or no data due, therefore caution should be taken for use in evaluating Hancock County.

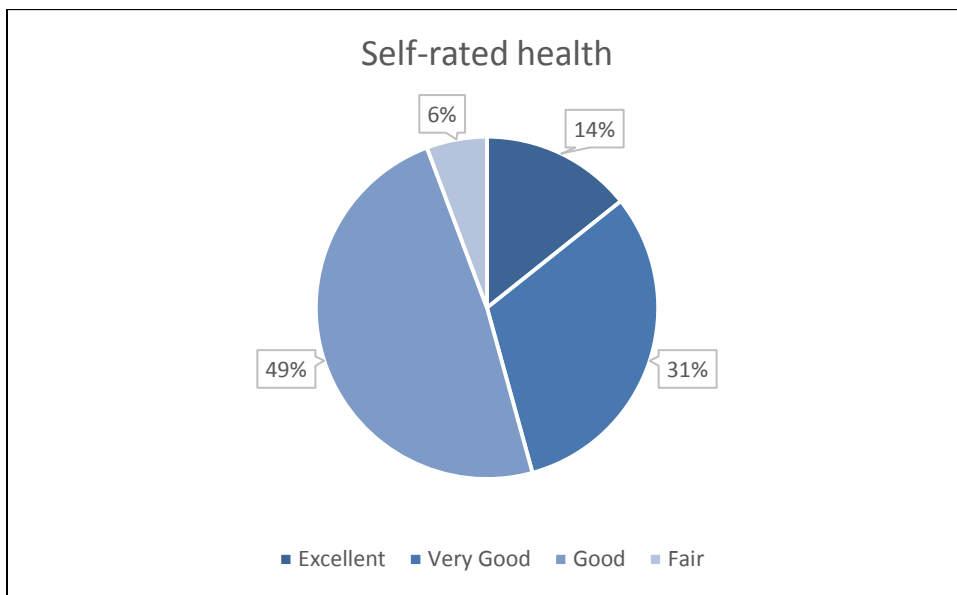


Figure 11. Self-rated Health for Focus Group Participants, Hancock County, TN

One of the areas of interest from by previous studies (Coyne et al., 2006) was the cultural measurement of identity to those factors relevant to the community. Those chosen were Appalachian, rural, and Melungeon (described previously). Participants were asked to answer yes or no to whether they identify as the options or they could choose not to answer. A large majority of participants (n=31) identified as rural and many identified as Appalachian (n=24). Also, 24 participants identified as both Appalachian and rural. For the identity of Melungeon, included by community feedback, the majority of participants did not identify (n=16) or choose

not to answer (n=14). Only five participants identified with that group, suggesting that most participants did not identify with that ethnic/cultural category.

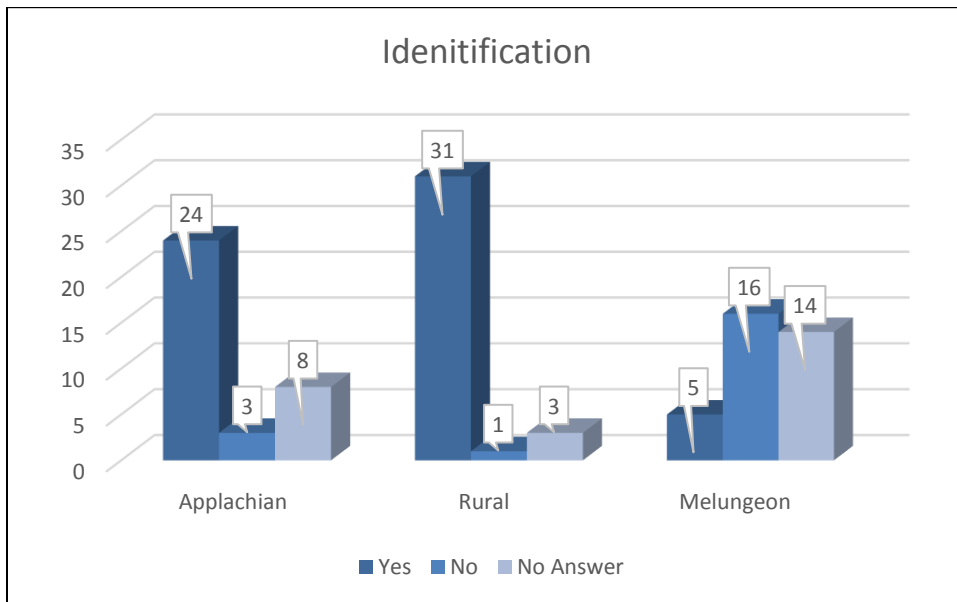


Figure 12. Participant Identification for Focus Groups, Hancock County, TN

Aims

Aim 1: Evaluate the current definition and perceptions of health in this sample of rural Appalachian residents through use of focus groups. Additionally, to identify the scale and scope of social contributors to poor health.

The first step in analysis was to assign each transcribed response a code based on those derived by the researcher, using data- and theory-driven approaches. Coders also had the option of double coding when appropriate. There were seven global themes that arose: definition of health, culture, social cohesion, social empowerment, social inclusion, socioeconomic empowerment and cross-cutting. There were also thirty sub-themes and those are listed in Table 5 below.

Table 5.
Global and Sub-Themes

Global Themes	Sub-themes
Definition of Health	Physical
	Mental
	Comprehensive/Holistic
	Independence
	Survivalistic
Culture	Social Norm-Positive
	Social Norm-Negative
	Fatalism
	Spiritual/Faith
	Integrative Norms-Altruism
	Integrative Norms-Tolerance
Social Cohesion	Integrative Norms-Social Contract
	Social Network
	Identity-Local/Regional/Community
	Identity-Interpersonal
Social Inclusion	Services
	Social Networks
	Financial Resources-Income
	Insufficiency
	Financial Resources-Income
Socioeconomic Security	Insecurity
	Housing and Environment
	Health and Care
	Work
	Education
	Knowledge Base
	Labor Market
Social Empowerment	Openness and Supportiveness of
	Institutions
	Public Space
	Personal Relationships
Cross-Cutting Themes	Assets
	Challenges and Barriers

When evaluating definitions and perceptions of health, participants were asked to describe what health means to them, what health means to Hancock, and how health affects quality of life. There were 194 references to definition of health. Most participants cited their definition of health as a sense of physical well-being or ability to function. This was the case in 105 instances (54%). Examples include “to be active, take care of others,” “be able to

function...quality living, not quantity,” and “able to navigate, whether its work, family or contribute to society.” Though the main focus was on the physical nature of health, participants also spoke to health being more than the body, including mental and emotional health or more of a holistic definition, responding 89 times (46%) in this manner. The primary focus was on physical wellness. Overall wellness was only mentioned if mental and emotional health were at healthy levels. Examples were “good health means everything,” “good health is state of mind,” “positive mental health is positive health,” and “feeling good, emotionally.”

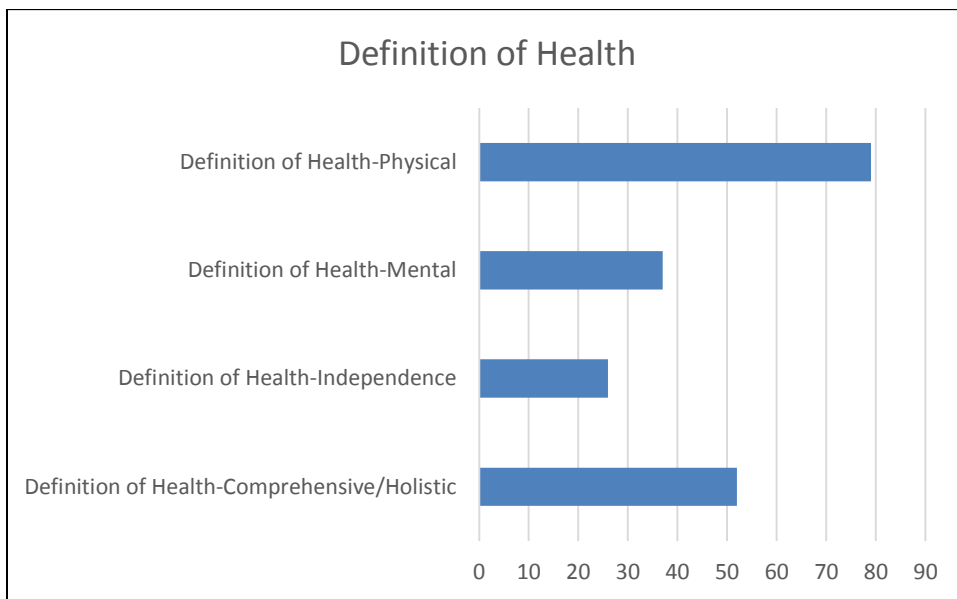


Figure 13. Definition of Health

Participants spoke to cultural factors when responding what health meant to Hancock such as “it doesn’t mean anything,” “it is not cared about” or “why even try.” This type of negative social norm was a common theme across focus groups and occurred during all sections of questioning. Negative social norms also were seen in responses such as “healthy or being fit is not normal here and people will think you are vain if you focus on yourself,” “you are supposed to take care of your family, not yourself,” “health is not even a thought that crosses our minds,”

“don’t be too good, don’t shine too bright” and “we are set in our ways and it ain’t healthy.” This occurred 203 times and is the highest frequency theme (Figure 14).

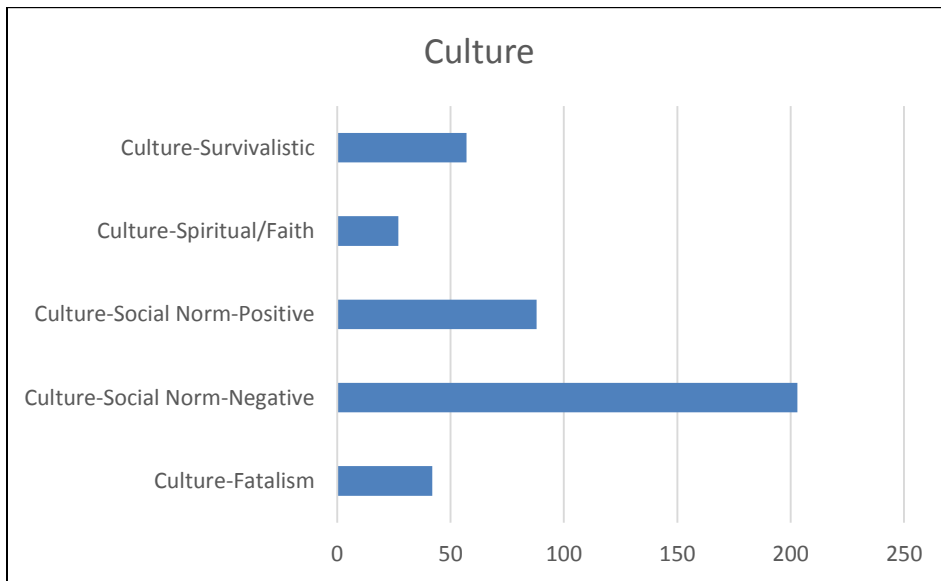


Figure 14. Culture

Other cultural themes emerged when discussing community perceptions of health and quality of life. Fatalism appeared 42 times through responses such as “don’t think about it till something bad happens,” “what’s the point” or “it’s not up to us.” They felt strongly that residents were merely “getting by” and did not place importance on health as evidenced by 57 responses around the community being survivalistic. While the ability to survive was also seen as a positive cultural element, the focus on merely surviving was believed to take away from focusing on being healthy. This was communicated in ways such as “you got bad knees, you climb up on that roof anyway,” “I’ve got to get by this month,” and “everyone is just in survival mode here.”

There were also cultural factors that surfaced that were positive. The participants were very proud of being survivalists and being able to accomplish great things when collectively empowered. They also have a shared love of the land and feel extremely tied to it and what it means to their families, community and spirituality. Participants saw positive elements when

they look at their community and referenced the same with comments like “we take care of one another,” “the land is why we stay,” “the benefits far outweigh the negative,” and “it’s a slower pace here, we love it.” These positive social norms were cited 88 times.

Participants mentioned faith in the land and in God, many times connecting good health and spiritual well-being. They stated that church is one of the few social networks in the community and their “faith” and/or prayer is how they often handle poor health or illness. This was seen through “your faith is key,” “pray for me/them, I’m/they’re sick,” or “I pray over my food and ask God to sanctify it.” The culture of spirituality/faith appeared 27 times.

The third section of questions was directly aimed at ascertaining the current culture of health. However, cultural elements began developing very early in all focus groups. Questions in this section included how does the current culture support health, what is the overall perception of health in Hancock and challenges and barriers. As mentioned, there is a lack of focus on health or existing health supports. Figure 14 shows the cultural factors that emerged, showing that though there is presence of positive cultural factors, nonetheless the current culture is monopolized by negative factors creating an unfavorable, unhealthy environment.

While discussing culture of health, and during the course of conversation across groups, assets, challenges and barriers were mentioned as cross-cutting themes (Figure 15). Participants referenced programs for children such as sports, schools and school programs, and school clinics, as those areas that provided healthy avenues. However, they also pointed out that those are limited as not all children have the financial means to participate in sports and there is an overall lack of interest in accessing healthcare, even in school. There was an obvious lack of assets for adults, as only a substance abuse treatment or grief group and kayaking the Clinch River were revealed. There were other assets mentioned, such as the land, peace and quiet in the county, and

the increased focus on improving the health and lives of children. Quotes supporting assets included “we love the land, and it is part of us,” “there are increasing programs for children,” and “we have got to focus on the next generation” and occurred 93 times.

Challenges and barriers were cited 180 times. Participants spoke to isolation, stubbornness, substance abuse, lack of transportation, and reliance on government assistance as large areas of concern. Respondents felt these barriers make achieving health seemingly impossible or for efforts to be sustainable.

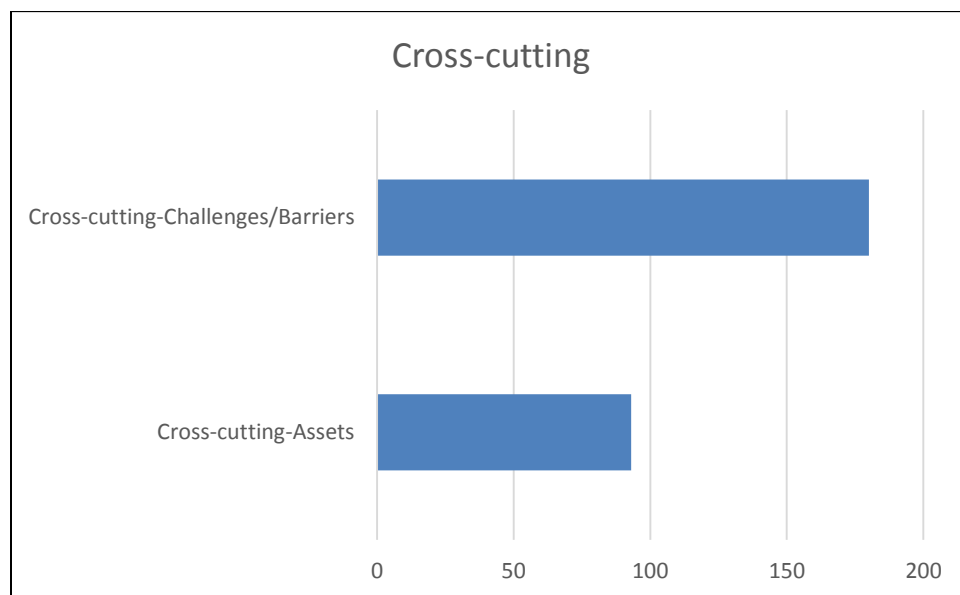


Figure 15. Cross-cutting themes

Aim 2: Test the Social Quality Theory and its components as a framework to describe social determinants of health through thematic analysis of findings from the focus groups.

The focus groups contained questions directed toward learning if participants connected social contributors to health and tested the Social Quality Theory as a framework. Analysis allowed for both theory driven and data driven coding. Questions focused on what participants thought contributed to health in Hancock, how social factors such as social networks, personal relationships, and social services contribute to health, and how education, income/financial

resources, and the environment contribute to health. While discussion involving culture and cross-cutting themes occurred during this section, it was as a secondary code.

Social cohesion, the extent to which social relations, based on identities, values and norms are shared, was the global theme that appeared the most, occurring 203 times. Sub-themes included trust, social network, tolerance, social contract, altruism, identity-local/regional/community, and identity-interpersonal. Figure 18 contains these themes.

The largest sub-theme under social cohesion dealt with identity. Participants held a sense of pride in the community and a connection to their shared heritage. They spoke to connectedness to rural living and farm life, sense of family, reliance on one another as a necessity, closeness to a fault, heritage and history, and pride in “their” culture. Responses supporting this included; “we’re a small community that supports each other when something bad happens,” “we take care of one another like family,” “we grew it, we ate it, and did it together,” and “its been like this for generations, family to family.” There are, however, areas of social cohesion that create barriers to adoption of healthy behaviors or creating a culture of health. Participants, especially women, suffer from an integrative norm of negative social contract where they are required to take care of others and neglect themselves and their own health and care. This was depicted with examples such as “we feel guilty if we’re not taking care of everyone,” “I should be serving instead of taking care of myself” and “then somebody else is taking care of your kids.” There were also many mentions of a lack of social network opportunities through examples of “there are no groups” or “we have to go 45 minutes just to be part of something healthy.” Table 6 outlines the theme of Social Cohesion, its sub-themes, definitions of each and corresponding quotes.

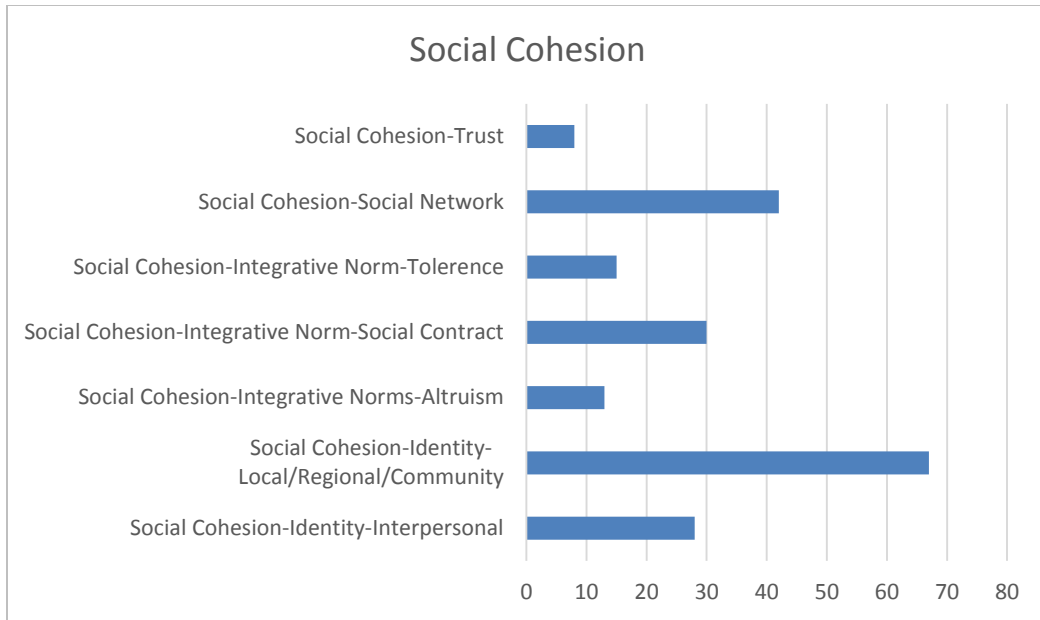


Figure 16. Social Cohesion

Table 6.
Social Cohesion Theme Summary

Sub-theme	Definition	Examples
Integrative Norms-Altruism	Volunteering, civic participation, donations	"the school has a backpack program", "Shepherd's Corner hands out food boxes", "The Mission provides clothes and hygiene items"
Integrative Norms-Tolerance	Tolerance of other's beliefs, behaviors, and lifestyle preferences	"its how you are raised", "they can't help it", "they don't know any different"
Integrative Norms-Social Contract	Paying more to support others, willingness to do something practical for the people in the community, understanding of division of tasks between men/women-spouse	"feeling bad for leaving after being away at work all day", "we feel guilty if we're not taking care of everyone", "I should be serving instead of taking care of myself", "we, women, feel guilty if we don't have supper ready and everybody is taken care of", "then somebody else is taking care of your kids"

Table 6 continued

Social Network	Membership of any organization or club	"small community that supports each other when something bad happens", "church and social supports", "there are no groups", "we have to go 45 minutes just to be part of something healthy"
Identity-Local/Regional/Community	Sense of pride, sense of community identity, identification with community/regional symbols	"this is a small community, we are not like bigger places and see healthier people", "we take care of one another, like family", "small community that supports each other when something bad happens", "we grew it, we ate it, and did it together", "we come together, we just need to do it for health"
Identity-Interpersonal	Sense of belonging to family and kinship network	"take care of each other", "its been like this for generations, family to family"

Social Empowerment, the degree to which personal capabilities of individuals and their ability to act are enhanced by social relations, was found to be very low, not only in terms of frequencies of theme and sub themes, but also in the presence of participant’s feelings of empowerment. There is little by way of public involvement in decision making or shared knowledge. This was cited 51 times (see Figure 17). Participants felt that there was insufficient monetary support or facility provision for group activities and events. They also spoke of the lack of support for social interactions either through lack of planning, implementation or interest. They did state an interest in improving this for children and there is more of an infrastructure for youth than for adults. Participants provided responses such as “we have three pharmacies, why,” “Rite-Aid is leaving and no one knew about it,” “the park is sketchy and has needles

everywhere,” and “there is nothing to get involved in.” A summary of the theme is found in Table 7.

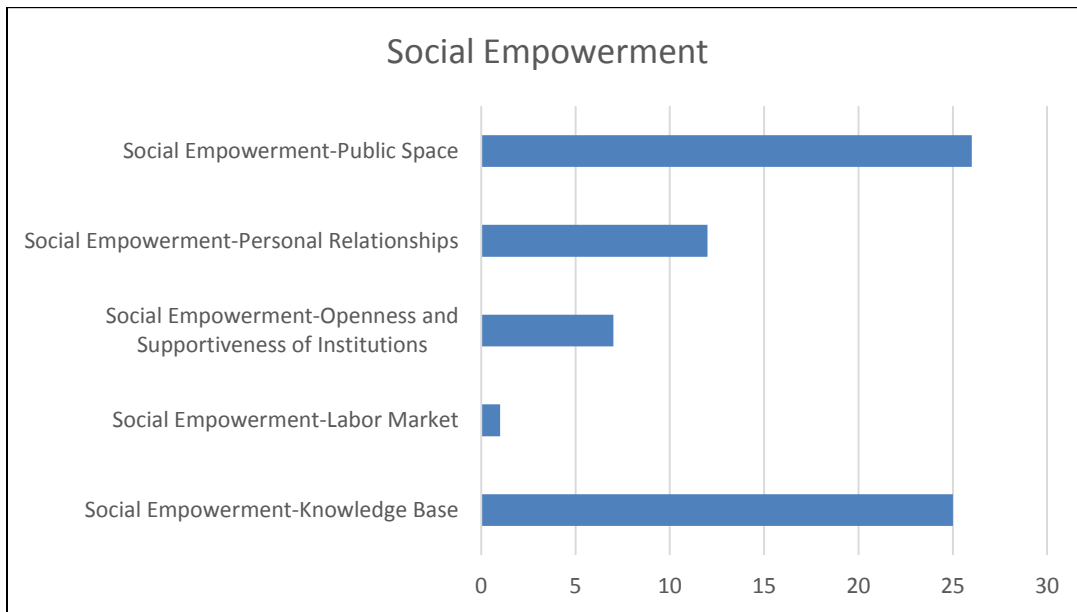


Figure 17. Social Empowerment

Table 7.
Social Empowerment Theme Summary

Sub-theme	Definition	Examples
Knowledge Base	Extent to which mobility is knowledge based	"clinic has provided education to the children, they can take it home"
Labor Market	Provision of skill or trade based training, work-life balance supports	"there is a new industry coming"
Openness and Supportiveness of Institutions	Existence of public involvement in economic decisions, organizations with work councils or unions	"the Rite-Aid is leaving and no one knew about it", "we have three pharmacies, why"
Public Space	Monetary and facility support for cultural groups and events	"The Mission", "churches do some things", "the senior center has tried some recipes and things", "the park is sketchy and has needles everywhere"
Personal Relationships	Provision of services supporting physical and social independence, support services for social interaction	"teach the kids better things", "there is nothing to get involved in"

Social Inclusion, the amount to which people have access to and are integrated into the different institutions and social relations that constitute everyday life, was very low in the groups (Figure 18), with little available by way of services or networks. There were 84 mentions of services. The majority of mentions (78%) referencing lack of services. Participants mentioned the overall absence of any social network or support system in the community, especially for adults. There are channels through churches and the school, however these are concentrated on treatment or illness such as addiction, diabetes, or grief. Children have insufficient opportunities to participate in healthy activities, which are limited to sports. Yet, these are not an option for those with limited income. Examples of inadequate social inclusion (Table 8) are “you know certain families and so you go ahead and give them extra,” “if you don’t have a car, you can’t go to town and that is where what little is going on happens,” “there isn’t anything,” “The Mission helps people who are addicted” and “there is a grief group.”

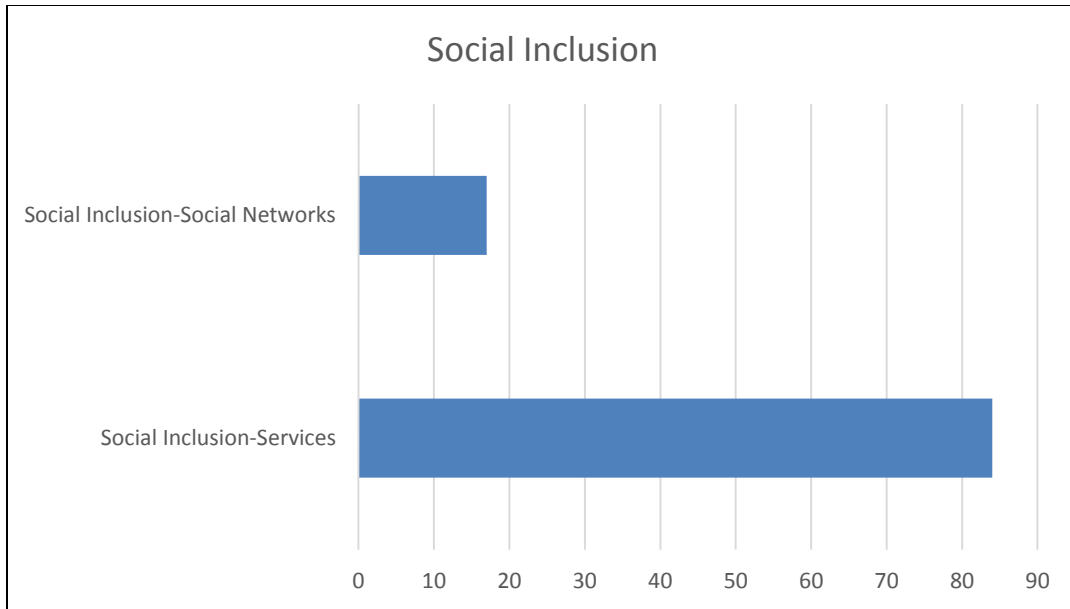


Figure 18. Social Inclusion

Table 8.
Social Inclusion Theme Summary

Sub-theme	Definition	Examples
Services	Number/proportion using health services, Number of civic/cultural facilities	"you know certain families and so you go ahead and give them extra"
Social Networks	Regular contact with neighbors, friends, family Negative-feeling lonely/isolated	"there is a grief group", "The Mission helps people who are addicted", "kids can go to the Jubilee center", "if you don't have a car, you can't get into town, and that is where what little is going on happens"

Socioeconomic Security, the extent to which people have resources over time, was a significant source of concern due to the insufficiency and insecurity of financial resources referenced during the groups. Participants cited lack of monetary, educational, employment and service support 199 times (Figure 19). They believe this to be the root of the majority of ill health and lack of advancement of the community. Respondents painted a very grim picture and did not feel there is a way to combat this deep-seeded issue. They are aware that it is

intergenerational and feel impotent in actualizing any solutions. Examples were “these kids have one set of clothes, if that, don’t have a way to bathe or eat,” “kids go home and a lot of times take care of the parents,” “people can’t afford childcare even if it were available,” “these kids only get the food at school,” “their parents didn’t continue school so why,” and “just can’t afford it, live paycheck to paycheck, if they work.” Summarization of the theme is below in Table 9.

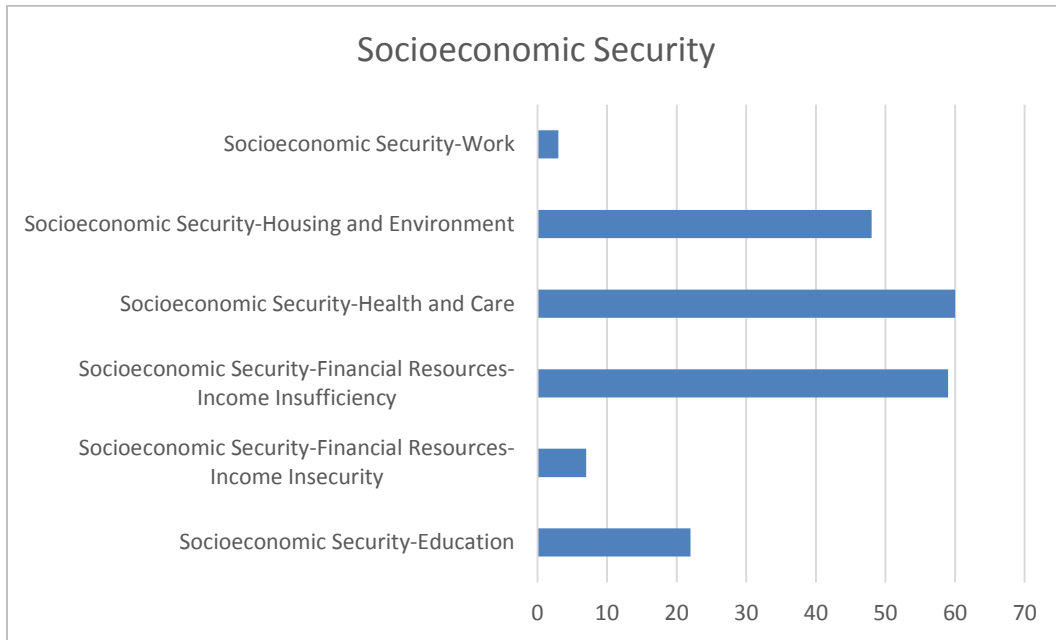


Figure 19. Socioeconomic Security

Table 9.
Socioeconomic Security Theme Summary

Sub-theme	Definition	Example
Financial Resources-Income Insufficiency	Lack of money for health, clothing, food, housing	"people can't afford childcare even it were available", "a lot of kids don't have the money for sports", "these kids only get the food at school", "they go home to nothing and a lot of times take care of the parents"
Financial Resources-Income Insecurity	Identified in poverty or receiving federal assistance	"there are so many on gov assistance and know nothing else", "these kids have one set of clothes, if that, don't have a way to bathe or eat", "just can't afford it, live pay check to pay check, if they work"

Table 9 continued

Housing and Environment	Living in houses without basic amenities, living in households situated in high pollution areas, high crime	"kids go home to a house without water or a way to heat food"
Health and Care	Insured, adequate clinical providers, adequate time for emergency and specialty care	"there are clinics, in the school too", "the kids have the clinic", "there is no childcare here. If your family isn't stepping up to help, you can't do it"
Work	Employed versus unemployed	"so many don't work", "many don't want a job cause its easier not to"
Education	Graduation rates, degree obtainment	"their parents didn't continue school so why"

Hypotheses

Hypothesis 1: Rural, Appalachian communities do not define health nor perceptions of health using social determinants.

As detailed in previous sections, participants did not reference the social determinants of health when describing definitions and perceptions. They spoke primarily to health as physical wellbeing or ability to function. When asked directly about contributors of health, there was an evident lack of connection to education and social networks or relationships. Education was only mentioned as the identification of needing health or nutrition education. Educational attainment and health was mentioned by one member and briefly discussed. Participants did connect financial resources such as income as a strong contributor to health, stating that those in poverty or limited income, simply did not have sufficient monetary resources to purchase healthy foods or participate in healthy behaviors.

Respondents continuously depicted the extreme lack of any social network, especially for adults and stated there are no social relationships or groups for health. They indirectly connected

this as a contributor to health, yet with little attention to the void created for emotional and mental wellbeing. When discussing the environment and health, they brought attention to the positive factors such as clean mountain air, mountains to use for physical activity and a clean river. However, there was no mention of built environment, residential segregation or concentrated poverty, all of which exist in the county. References were made to environmental limitations of geographical isolation from other populations and treacherous roads increasing the likelihood of injury.

Hypothesis 2: Use of the Social Quality Theory will assist in describing the current culture of health and social determinants for the pilot community.

Use of SQT and its domains proved a suitable framework to describe the current culture of health, evaluate participant's connections to social determinants of health, and isolate cultural assets that the community may use to improve health. Participant's responses were categorized using SQT themes a combined 574 times. Participants frequently identified the social contribution of poverty or limited financial resources for unhealthy behaviors or how this creates environments and a home life that prevent healthy lifestyles, especially for children. They also mentioned the lack of employed residents or available workforce either due to addiction, reliance on government assistance, or with no interest in working. Participants feel disempowered and believe that there are no social networks or services, whether formal or informal, that they may access. This is complicated by the low level of social inclusion found in the county. However, there is a sense of social cohesion with special attention to those factors that contain shared identity. The theory's framework assisted in organizing the cultural factors as well, as they occurred both inside SQT themes and outside creating a global theme of culture. The domains and subdomains of SQT allowed for sociocultural elements to be discussed more

comprehensively with attention to those relevant indicators pertaining to social determinants and the shared value of health.

CHAPTER 5

DISCUSSION

The study examined how residents in a rural, Appalachian county define health and the extent to which the definition contained the social determinants and culture of health. It also tested the use of the Social Quality Theory to assist in describing those social determinants to highlight areas for intervention and programming. Previous studies have found the importance of including cultural factors when evaluating rural definitions of health, and encouraged the use of such approaches (Coyne et al., 2006). The emphasis on rural health disparities in the United States and the initiative presented by the Robert Wood Johnson Foundation created an opportunity to test new mechanisms in this research area.

Summary of Findings

The study population primarily defined health as physical well-being or ability to care for one's self. There is a high level of sense of survival, merely getting by, that contributes to the definition and perceptions of health. This aligns with the findings presented by Gessert et al. (2015). The result is the diminishment of any form of self-care or preventative behavior. Cross-cutting themes showed many barriers and challenges, yet there are many assets to leverage and focus attention such as schools, a strong sense of pride and survival, motivation to help children, and love of the land and community. Figure 20 summarizes thematic findings in a word cloud where size of the word is based on frequency of the theme.



Figure 20. Thematic Word Cloud

Social Quality Theory

The Social Quality Theory served as a meaningful framework to describe and organize participant responses in a systematic way to highlight areas for intervention, improvement, and create a new culture of health. To best summarize the findings with regard to SQT, each domain and the large majority of sub-domains, emerged as theory-driven themes. There were positive and negative references. Socioeconomic Security was cited 199 times with no positive mentions throughout any of its sub-themes. There was a large amount of dialogue on the high rates of poverty, lack of financial resources, employment opportunities, and poor housing. However, Social Inclusion was cited 101 times with a mixture of positive and negative discussion. Positive remarks, though few, centered around services available in the community, while negative mentions spoke to inadequate services and lack of social networks. Social Empowerment was another theme that contained no positive mentions and was cited only 71 times. The highest

frequency theme was Social Cohesion, presenting with both negative and positive comments. It was cited overall 203 times. Negative references (51 of 203 comments) centered on poor social networks, lack of trust, and negative social norms. It did contain many instances of positive exchange including positive identity, both interpersonal and local/regional/community and altruism (152 references). Figure 21 revisits the quadrangle of conditional factors, themes, for social quality. Overlaid are the results from thematic analysis, with green circles indicating positive mentions and red negative mentions. The size of the circles indicates frequency of citations for each. The location of the circles show the distance from the center quadrangle where conditions of social quality may occur.

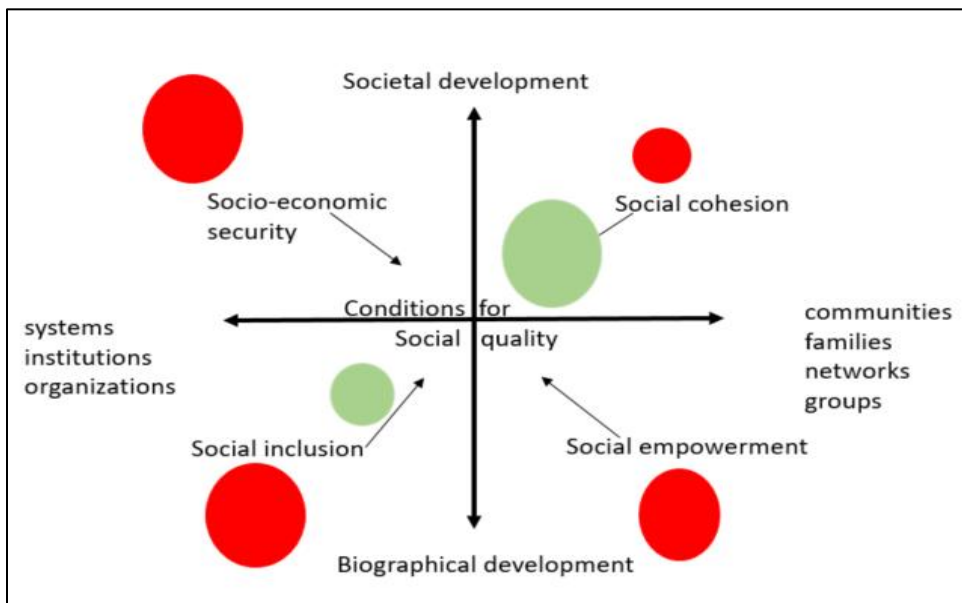


Figure 21. SQT quadrangle of conditional factors with study results

Socioeconomic Security; limited income, lack of education, amount receiving governmental assistance, poor housing, and limited care options played a significant role in discussion. Participants often mentioned the inability to afford health services or healthy options and those who may possess the financial security, cannot as there are no options inside the

county. Of those involved in physical activity or wellness programs, the large majority drive 45 minutes outside the county to access. This is extremely costly and time consuming.

Regarding Social Empowerment, participants alluded to these factors the least, with special attention to deficiencies in shared knowledge, provision of training supports, existence of public involvement, and offerings of facility support and social interaction. There was an overall sense of “simply nothing to become involved in” or currently no groups or activities organized to tackle this issue. There was a strong sense of disempowerment among participants as they believe there is purely no capacity for social interaction or networking in the county and that there is a lack of political will and knowledge of how to improve health.

Social Inclusion was an area of high concern as residents continuously pointed to the inadequate number of services available for the community with regard to health and social services. The conversation centered on the absence of formal offerings such as healthy food options, gyms, childcare, parks and recreation facilities, and health education. There was also discussion devoted to shortage of professionals to assist with mental health and addiction. It became evident that participants felt there was no assistance, services or personnel that could provide this type of help.

The area that provided the most abundant source of information for social improvement was Social Cohesion. While there were areas of concern such as social contracting, lack of social networks, and issues with trust, there were many opportunities that materialized. Participants expressed a strong desire for the creation of social networks. While they did not connect social networks necessarily to health improvement overall, they did translate poor mental health to lack of networks, personal interaction and isolation. They also exhibit a solid cohesiveness through areas of shared identity. This was seen in responses pertaining to family focus, living off the

land, and taking care of one another, especially during tragedy or illness. Participants felt one of their greatest strengths, and something they rely heavily upon, is pride in the collective nature of the community and how everyone is included in this “family”.

Cultural factors that appeared added both areas of concern and areas of opportunity. There was a frequent mention of negative social norms that supported and promoted adverse and unhealthy behaviors, such as health not being valued, lack of interest and motivation, and healthy viewed as foreign or non-desirable, even in some cases serving as a source of contention. However, there were also positive social norms and references by the participants to faith in God and one another. Culture, while serving as a global theme, also was interwoven through many SQT themes and sub-themes. Participants spoke to culture, in general, as something that creates pride in the community and serves as a link from person to person. Yet, they also are aware that some of their “culture” prevents them from being healthy and generates obstacles to improve health.

Study Population

As previously outlined, study participants were not a demographic representative group for the county population. Participants held higher levels of education, higher annual income, were employed, and in good health. Table 10 provides a comparison of county and study population demographics. Though this group was not representative, they were engaged community stakeholders that provided meaningful conversation. They spoke to assets in the community and referenced a need for change, especially for youth. This group acknowledged that they face many barriers, but have a desire to begin tackling them collectively. They simply lack the social infrastructure and resources to start. These participants could serve as agents of change given the tools necessary to address the identified barriers and leverage assets.

Table 10.
County and study demographic comparison

Demographic Variables	Hancock County	Study Population
% Self-rated fair/poor health	24	6
Median Age	44	54.2% between 30-49
% Unemployment	10	2.8
Median Household Income	\$26,898	60% \$50,000 or more
% High School graduate or higher	73.3	100
% Bachelor's degree or higher	10.6	65.7

Study Limitations

Selection Bias

Although the study reached the goal of saturation during focus groups, an additional group was added to increase the number of participants and to attempt to better represent the demographic characteristics of the “average” Hancock County resident. A total of thirty-five participants were part of the study, however the study suffered from selection bias, yielding participants with higher incomes, higher education levels that were more likely to be employed. Key informant interviews of those residents exhibiting demographics more representative of the study population would have helped to correct this issue. However, it was outside the scope of the funding for this project.

The investigator encountered issues recruiting. This issue is one that has been experienced by others conducting research in remote, rural areas (Coyne et al., 2006; Deskins et al., 2006; Goins et al., 2011; Vance et al., 2012). Additional times were added to conduct focus groups, yet participants still did not attend. Working with the community, the investigator identified persons and/or groups to invite. This approach helped to add thirteen participants that would have not participated otherwise. In addition, a community-based, substance abuse group

was identified and showed interest in participating. However, due to meeting location change and change of leadership internally, the group wanted to delay participation to further into 2018.

Social Desirability

Because responses were collected in a group setting, responses may have underestimated negative elements and overestimated positive ones leading to socially desirable answers.

Although, participants were assured all information was confidential and could not be tracked to any individual response and questions were phrased in a manner to show acceptability of non-socially desirable answers, some members may have hesitated to communicate issues they believed to be “bad” or challenges for the community. This was evidenced by responses during one group that included a county government official, where challenges that had been listed in other groups received less attention.

Generalizability

Due to the small numbers included in the study and inclusion of a single county, findings should not be used to describe other demographically similar populations. However, further quantitative analysis of the Social Quality Theory and inclusion of additional communities utilizing the methodology presented here, will help alleviate this limitation.

Cultural Bias

While all team members identified their biases before the study commenced, there is still the possibility of the presence of cultural bias. Measures such as personal narratives, field notes and one, single group moderator were implemented to decrease this bias. Yet removal of 100% cultural bias is impossible.

Recommendations and Future Research

The study serves as a pilot to assess the current culture of health and connection to social determinants in an impoverished rural county. It also tests a new theory, Social Quality Theory, to evaluate those social determinants and better understand the culture of health in rural, distressed, and/or Appalachian communities. Future studies may examine other rural, distressed communities outside of Appalachia and may expand to test SQT in other communities. The theory also requires testing using quantitative methods presented by Ward et al. (2011). The investigator plans to further test the theory utilizing quantitative approaches within the pilot county and has received interest from the community to do so. Funding to accomplish this work is currently being sought with one agency already secured.

The results of the study indicate the utility of the SQT theory to describe current cultures of health and the connections to social determinants. In order to enhance this work, further training on its utility in the public health discipline is needed. Special attention to application using qualitative and quantitative methods would be beneficial. This study provides a new approach for evaluating socially determined health in rural/distressed areas in the US, and may also be useful in urban or more resourced areas. Previous use of the theory in other countries suggest utility across various demographically diverse populations (Walker, 2009; Ward et al., 2011).

Recently the NORC Walsh Center for Rural Health Analysis conducted a formative research project, *Exploring Strategies to Improve Health and Equity in Rural Communities*, with over 400 stakeholders to better understand strengths and assets in rural areas across the United States (2018). This study occurred concurrently with the study presented here. The Walsh Center found that rural communities have many strengths and rich cultures that are often overlooked

when developing strategies to improve health and equity, and while rural communities suffer from disproportionate amounts of death and illness, it is these strengths and cultures that are essential to improve health (2018). Results from the study were similar to those presented here and help to support the focus on the sociocultural factors when working to improve rural health, areas where the disparities and inequity is all too often created by social determinants of health. The NORC Walsh study concludes that 1) programs, policies, and practices should align with local culture and history, 2) culture and history shape core community values, serve as important local assets, and influence how other community assets can be leveraged, 3) leveraging culture and history requires a participatory approach to addressing local needs, and 4) cooperation, social cohesion, and “community spirit” are commonly described assets across rural communities (NORC, 2018). These key findings mirror those put forth by this work and are submitted with the belief in potential success in creating a culture of health in rural/distressed areas to improve the lives of those residing in those communities.

Contribution to Public Health

This study adds to the growing body of literature on rural health definitions and perceptions, but more importantly puts forth a new approach to evaluate the current culture of health in rural and/or distressed areas. Though further testing of the Social Quality Theory is required, it still provides a locally relevant model for evaluating the current culture of health. The methods used here can be guide for using the theory in rural, distressed areas. The findings provide useful implementation elements for those communities who already have identified the need to focus attention and efforts on the social determinants of health, assuming they also collect similar data.

Currently RWJF encourages the creation of a shared value of health in communities, yet seeks ways to measure the current culture to leverage ways to create that very important shared value. The Foundation could adopt the use of SQT detailed here to explore the shared value of health, the connection to social determinants, and utilize the cultural findings and implementation methods for customization of use in rural, distressed and/or Appalachian communities.

Conclusion

This study provides communities and researchers a framework for using a new theory to evaluate current cultures of health and explore connections to social determinants. The study is an example for public health practice and academic professionals to borrow theories from other disciplines to navigate the expanding landscape of socially determined health. Results from the study can be used to identify areas of focus for resources and time be allocated for intervention and programming.

The methods used can easily be replicated in other communities, providing easy implementation for evaluating socially determined health with culturally appropriate approaches. Overall, this study provides information on the use of the Social Quality Theory in the United States and its value to communities focusing on how best to address social determinants of health, with special attention to those who lack the resources to fully address the issue.

The study generated many meaningful findings. It not only provided a new framework, but also provides an examination of how a rural, impoverished community lacks the social infrastructure to improve health. Current perceptions of health are limited to thoughts of disease or illness and overshadowed by negative social norms. There are few social resources currently available to improve health and a large presence of cultural impediments. Yet this “culture” also

provides some advantages and assets that the community may leverage for change. It is those cultural assets that should power social improvement, leading to increased capacity of healthy networks, and ultimately creating a culture of health.

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APPENDICES

Appendix A

Indicators of Social Inclusion (Walker et al., 2003)

Domains	Sub-domains	Indicators
Citizenship rights	Constitutional/ political and rights	Proportion of residents with citizenship.
		Proportion having right to vote in local elections proportion exercising it.
	Social right	Proportion with right to a public pension (i.e., a pension organised or regulated by the government).
		Women's pay as a proportion of men's.
Civil rights	Proportion with right to free legal advice.	
	Proportion experiencing discrimination.	
Economic and political networks	Proportion of ethnic minority groups elected or appointed to parliament, boards of private companies and foundations.	
	Proportion of women elected or appointed to parliament, boards of private companies and foundations.	
Labour market	Access to paid employment.	Long-term unemployment (12+ months). Involuntary part-time or temporary employment
Services	Health services	Proportions with entitlement to and using public primary health care.
	Housing	Proportion homeless, sleeping rough. Average waiting time for social housing.
	Education	School participation rates and higher education participation rates.
	Social care	Proportion of people in need receiving care services. Average waiting time for care services (including child care).
	Financial services	Proportion denied credit differentiated by income groups. Access to financial assistance/advice in case of need.
	Transport	Proportion of population who has access to public transport system. Density of public transport system and road density.
	Civic/cultural services	Number of public sport facilities per 10,000 inhabitants. Number of public and private civic & cultural facilities (e.g., cinema, theatre, concerts) per 10,000 inhabitants.
Social networks	Neighbourhood participation	Proportion in regular contact with neighbours.
	Friendships	Proportion in regular contact with friends.
	Family life	Proportion feeling lonely/isolated. Duration of contact with relatives (cohabiting and non-cohabiting). Informal (non-monetary) assistance received by different types of family.

Appendix B

Indicators of Socioeconomic Security (Keizer et al., 2003)

Domains	Sub-domains	Indicators
Financial resources	Income sufficiency	Part of household income spent on health, clothing, food and housing (in the lower and median household incomes).
	Income security	How certain biographical events affect the risk of poverty on household level. Proportion of total population living in households receiving entitlement transfers (means-tested, cash and in-kind transfers) that allow them to live above EU poverty level.
Housing and environment	Housing security	Proportion of people who have certainty of keeping their home. Proportion of hidden families (i.e., several families within the same household).
	Housing conditions	Number of square meters per household member Proportion of population living in houses with lack of functioning basic amenities (water, sanitation and energy).
	Environmental conditions (social and natural)	People affected by criminal offences per 10,000 inhabitants Proportion living in households that are situated in neighbourhoods with above average pollution rate (water, air and noise).
Health and care	Security of health provisions	Proportion of people covered by compulsory/voluntary health insurance (including qualitative exploration of what is and what is not covered by insurance system).
	Health services	Number of medical doctors per 10,000 inhabitants. Average distance to hospital, measure in minutes, not in metres. Average response time of medical ambulance.
	Care services	Average number of hours spent on care differentiated by paid and unpaid.
Work	Employment security	Length of notice before employer can change terms and conditions of labour relation/contract. Length of notice before termination of labour contract. Proportion employed workforce with temporary, non permanent, job contract. Proportion of workforce that is illegal.
	Working conditions	Number of employees that reduced work time because of interruption (parental leave, medical assistance of relative, palliative leave) as a proportion of the employees who are entitled to these kinds of work time reductions. Number of accidents (fatal/non-fatal) at work per 100,000 employed persons (if possible: per sector) Number of hours a full-time employee typically works a week (actual working week).
Education	Security of education	Proportion of pupils leaving education without finishing compulsory education (early school leavers).
	Quality of education	Study fees as proportion of national mean net wage. Proportion of students who, within a year of leaving school with or without certificate, are able to find employment.

Appendix C

Indicators of Social Empowerment (Herrmann, 2003)

Domains	Sub-domains	Indicators
Knowledge base	Application of knowledge	Extent to which social mobility is knowledge-based (formal qualifications).
	Availability of information	Per cent of population literate and numerate. Availability of free media. Access to the Internet.
	User friendliness of information	Provision of information in multiple languages on social services. Availability of free advocacy, advice and guidance centres.
Labour market	Control over employment contract	Percent of labour force that is member of a trades union (differentiated to public and private employees). Percent of labour force covered by a collective agreement (differentiated by public and private employees).
	Prospects of job mobility	Percent of employed labour force receiving work-based training. Percent of labour force availing of publicly provided training (not only skills based). (Please outline costs of such training if any.) Percent of labour force participating in any 'back to work scheme'
	Reconciliation of work and family life (work/life balance)	Percent of organisations operating work life balance policies. Percent of employed labour force actually making use of work/life balance measures (see indicator above).
Openness and supportiveness of institutions	Openness and supportiveness of political system	Existence of processes of consultation and direct democracy (e.g., referenda).
	Openness of economic system	Number of instances of public involvement in major economic decision making (e.g., public hearings about company relocation, inward investment and plant closure).
	Openness of organisations	Percent of organisations/institutions with work councils.
Public space	Support for collective action	Percent of the national and local public budget that is reserved for voluntary, not-for-profit citizenship initiatives. Marches and demonstrations banned in the past 12 months as proportion of total marched and demonstrations (held and banned).
	Cultural enrichment	Proportion of local and national budget allocated to all cultural activities. Number of self-organised cultural groups and events. Proportion of people experiencing different forms of personal enrichment on a regular basis.

Domains	Sub-domains	Indicators
Personal relationships	Provision of services supporting physical and social independence	Percentage of national and local budgets devoted to disabled people (physically and mentally).
	Personal support services	Level of pre-and-post-school child care.
	Support for social interaction	Extent of inclusiveness of housing and environmental design (e.g., meeting places, lighting, layout).

Appendix D

Moderator's Guide

Moderator's/Interviewer's Guide **Hancock County, TN** **Research Project**

- Aim:** To create an environment whereby recruited participants can inform the study of perceptions of health in Hancock County and its contributing factors, challenges and barriers. The information collected will inform the project and larger body of literature and work. Participants therefore will be required to talk about how they feel about and how they perceive health, which should not be sensitive topic areas. At the end of the focus group all information will be transcribed and compiled into an aggregate report to be analyzed using trend and thematic analysis.
- Sample:** The sample population will consist of multi-sector community members, all residing in Hancock County. Each focus group will consist of around 8-10 participants in order to sustain manageability and control.
- Equipment:** Pens, recorder, back-up recorder, flip chart paper, board (to park thoughts), sticky labels (name badges), timer (to time each section), my contact details, help contact details (for individuals who may become stressed or distressed) and spare written consent forms.

I. Background/Introductions

The moderator will:

- Introduce yourself and thank participants for agreeing to come.

Thank you for volunteering your time and coming this morning/afternoon. My name is Paula Masters and I am a doctoral student at East Tennessee State University. I'll be moderating our discussion today. It is important that you know and understand that you can withdraw from this research at any stage. It is also important that you have signed the written consent form before we continue any further. If you have not signed the written consent form can you indicate that now?

- Explain group guidelines and how long the focus group will last.
 - *I estimate this discussion group to last no longer than 1 ½ hours. During this time I will be asking you to contribute in a number of ways to our research topic that primarily focuses on perceptions of health and contributing factors.*
 - *I am here just to facilitate the session today and therefore you should feel free to express your thoughts and feelings on this chosen topic without any expectations from me. I am interested in*

hearing your thoughts and points of view even if it is different from that which others express in the group. However, if at any point you feel distressed by anything we have/are discussing, you are free to leave at any time. If applicable I will provide information of agencies who will be able to help, although I am unable to offer personal comment and advice.

— *I'm going to make every effort to keep the discussion focused and within our time frame. If too much time is being spent on one question or topic, I may park the conversation so that we can move on and cover all of the stages and also to ensure that all participants have a chance to give their input. If we have sufficient time, we will revisit parked thoughts in the order they were parked. If thoughts/conversations are parked I will write them in a list format on the board.*

- Address confidentiality

We will be audio-recording the discussion because we don't want to miss any comments. But we will only be using first names today and there will be no names attached to the comments on the final report. Therefore, you are assured of complete confidentiality. As the discussion will be recorded it is best if one person speaks at a time.

Participant introduction

On that note, please introduce yourselves to one another – first names are fine. (Write names on labels.)

II. Discussion Topics

Explain process:

There will be three areas in which I will be asking you to participate in today. Each area is a topic related to the overall intent of the focus group and each will have a number of questions. Your answers will also be written down as we go even though it is being recorded. This just strengthens our collection of your answers. The note taker today is [NAME] also from the University. They are aware of all confidentiality and will ensure it is maintained. Let's Begin.

Topic Area 1: Definition of Health and Health as a Priority

What does health mean to you?

PROBE...

What contributes to that?

What does health mean to Hancock County?

PROBES....

Community-

Businesses-

Families-

Faith-

How is health incorporated into daily living?

How does health affect quality of life?

PROBES...

Physical health-

Mental Health-

Emotional Health-

Topic Area 2: Contributing Factors and Social Determinants

What do you think contributes to the health of Hancock?

Social Factors

How do social factors such as social networks and groups, personal relationships, social services, contribute to health?

PROBES...

What resources are available for health?

How are they accessed?

What social structures and/or networks around health exist?

How do those function?

How is health made a part of daily conversation, activities and life?

How are residents provided support toward health?

Education

How does education contribute affect health?

Economic

What about economic status such as income or other financial resources, how does that affect health?

Physical Environment

How does the environment contribute to health?

What are other contributors to health in Hancock?

Topic Area 3: Community Culture and Perceptions

How does the current culture support health?

What do you think the overall perception of health is in Hancock?

PROBE...

What drives that perception?

What barriers or challenges exist?

III. Closing and Demographic Data Collection

- Offer an opportunity for any short final comments participants would like to make.
- *Thank you very much for your input today. We are just about out of time. Are there any last comments that anyone would like to make? The information you provided is key to this topic and will inform further research and projects. It is important to note again that your identity will remain confidential at all times.*
- Allow time to complete demographic document
- *In front of you is a confidential document that asks demographic questions. We are not asking your name, so there is no way to identify you. Please complete that and simply place it face down in the middle of the table.*
- *If you should wish to contact me in relation to this research or would be interested in taking part in further aspects of my research then please take a copy of my contact details.*
- *Thank you so much!*

Appendix E

Meeting/Field Notes

Team Member Notes 1-de-identified

FG 2

Female participant over 60, worked with childrenNo native accent.

Male participant, over 60, retired, moved to HC about 40 years previous. Saw the flyer in the paper and decided to attend. Spoke of drug recidivism.

What does health mean to you?

Good health –ability to do what you want, functioning well, able bodied, ABLE to contribute to society.

Health is precious. Something that has to be worked [hard] at.

Makes a decision to be in good health [individual behavior]...those that care.

Situations that lead to less health focus in individuals.

Health—personal action; if I get sick or need medical assistance, I will do something. Including home remedies—plant based (catnip tea and sleeping a lot—NOT SOMETHING I AM

FAMILIAR WITH

Gardening—40 years ago, everyone had a garden. Less common now. Makes the connection between health and diet.

Having Hardees in town—even though all kids get free breakfast in the morning at school, parents pick up drive-through on the way to school.

Poverty—feelings that there is personal responsibility—make choices against one's health.

Health is more integrated into the schools—more sports options and physical activity which has a positive impact on self-esteem.

--Hope kids stay in the county—

Cancer walks and other one offs—but what impact does it have on daily life?

Simple decisions to improve health.

More health fairs come in but not from within.

Medical related clinic—good!

Dental clinic at the Jubilee but no one showed up.

Need for intrinsic motivation desire to be able to play with grandkids.

Female participant had a cancer wakeup call. Health has to be at the top.

Topic #2: Social determinants

What is leading to poor health instead of good health?

-Smoking

-water supply-rural/poor, children unable to take baths lowers self-esteem

-increased rates of cancer in farmers from roundup

-sewage dumped into the Clinch river—does this impact how people use it?

-complex

-Social- desire to get back to nature 30-40 years ago a group of outsiders moved to HC, less meat, some of their kids intermarried with local kids.

Greens-grocery

Veterans moving into the county, seeking healthcare, finding it more accessible. Work done by Appalachian Service Project (ASP) helps to support veterans etc.

From the medical resources/framework-the county is in good shape. More hc resources than before. Including the school based clinic. The consortium establishment, clinic, Dr. _____return/_____. For those with complex issues or complications, well that's a different story. Need for transportation for the really rural individuals.

They stated that it might be different for them because they chose to live there. There is an understanding that they might have to drive 3 hours for some fun things.

Bright people –move and leave because there are few social things to do.

Age difference is part of their difference in prospective.

There is a need for drug counseling as well as groups for grief and cancer.

Churches have groups but they focus on church.

They have a successful music program at one church for kids after school and parents often come as well to socialize/fellowship. Faith is the bedrock not school.

Chamber also provides activities.

Greens grocery is not the best food option

Education/health—breakfast, local food. “White bread is cheaper.”

There is health education in schools—sexual health and health and nutrition.

Economic factors—DHS food stamps, TANF, Medicaid. Any education on health? WIC does counseling.

There are economic disparities in food choices.

Those without health insurance—wait until this are really bad; lack of access to health messaging around smoking.

Physical environment—

Farm issues, inhaling pesticides, hearing and sight protection issues.

We do have very clean air!

There is a trash problem—beer cans and debris on the side of the road.

Sewer issues.

Friendly but nothing to do.

Health is governed by drugs and cancer. Reasonable reason for pain meds but then they get addicted.

Teenager deaths from drinking and driving.

Issues of rurality.

6500 pop. With 3 fulltime pharmacies!

FG 3

8 participants of varying age and genders.

What does health mean to you?

Life.

Way of life

Live life—feel good.

Contribute to community

Ability to do the things you want to do.

Feel, community.

Wellbeing

Guided by your actions

Mental, physical, spiritual

Health for hancock?

Bad health

Drugs as and outcome and a need for support to combat the issue

There are facilities available for healthcare—blessed

Health is taken for granted

All know those addicted

Healthcare workers live in HC therefore, more money to go back into the communities

Spiritual health

Giving back to the community

Health workforce = better workforce

 Cut missed hours

Worry about kids when they are out of school for the summer

SNAP people often get quantity over quality

Not going to eat health foods if the kids do not see it/eat it at home

The move off the farm→to fast food.

Nobody exercises.

There are more sports for kids but no adult sports centers

Teachers do fitness competitions

Good food is expensive

Change in the family dynamics—women having to leave the home (said by an older gentleman)

Bad health takes up time and money

Being sick takes away from the family. Leads to a financial cycle (bad)

Mental health is drastically effected by quality of life

 Seeing more issues in younger and younger people.

Kids want attention

Culture

 Does not support health

Gardening has been lost but there is the garden program in the school

Schools provide the bridge

Why do you want more than they have?

 --some just want to draw a check

More people are aware of health

Health professionals come through the schools

Drug, alcohol use in adolescents “everyone does it”

Depression linked to lack of options.

Contributes to poorer health

-well water, runoff, poor water

Social groups

Different clubs not available anymore

Womens club-focuses on education, beautification, don't have time, don't make time

Churches-but some do not want to be judged

Resources

-city park-exercise equipment

-soap (?)

-common things

School based clinic

Perfect attendance

Government assistance

School based clinic available after 3pm

Mental health center-telehealth

Dental hygienist

Better education=more health=better gainful employment

People do not want to go into debt

Geographical isolation

Trash→no pride

Allergies

Good city water; not all have access

High rates of cancer-oakridge

Terrain, distance, 10 miles is not far in urban areas, but very far in rural areas.

Team Member Notes 2-de-identified

FG 1

Males 2; Females 5; Child 1 (did not participate in discussion)

What does health mean to you?

Being able to function well; To help yourself; I means everything to me.

Mental Health; Health with no stress

Mind, body and soul

Walking

Taking care of everything

Being able to do your yourself and beyond that, for others

What contributes to that? To the idea?

Systemic good health is a state of mind; Positive outlook on life; Values/morals, lifestyle, faith, this is a small community.

What does health mean to Hancock County?

It's not as big a priority as we think it is rather than in big cities where people are healthy; people here are just getting by and being able to pay your bills and take care of your property is health. It's "meat on your bones." Because of the area we live in and the poverty and people are working hard. Your garden is what you have; you are healthy when you have a little more. Being really thin here means that you don't have enough food at home. Having more ('meat' on your bones) here is perceived as healthier. As a woman, it's hard to be really fit. "Look at her with her tight little pants on." And we don't want to be in too good of health because in this little town people will think you're trying to be better than you are. In a bigger city, it's the opportunity for training. It's changing here. (Girls on the Run) alters perceptions. Picking out a girl who has lost 20 pounds this summer with the help of grandmother. Being able to kayak the river / some people may need to be more educated on eating the right foods, not the wrong foods like gravy and biscuits, potatoes.

Put faith into daily living. If you lose your health and you are not working, it can devastate a family. Keeping strong and healthy for your family means to keep pushing to provide.

In the schools, the backpack program and healthy snacks for those with free and reduced price lunches helps to change those areas where food is scarce.

The new Smucker factory coming in over the mountains and donut breaks may change that (laughter)

Even new businesses have a hard time trying to come in because we don't have a good, healthy population here because of addiction (question about addiction stats in the county – Paula will send)

Is it incorporated into the faith community?

Spirituality does, yes. "Pray for me." Thoughtful; lifting a person up. We think about sickness more than health. We depend on the Lord if something happens, Doctors are good but God does the healing. Our health is not important until something happens.

We like anything fried. If I pray over food then God will sanctify it. We don't think about it until we get sick. A newly married older couple remarked that when the partner wants to do something, then they feel younger. Being newly married helps them feel younger and more healthy too. She said

before marriage, she was not taking care of herself and she was diabetic. It helps to have a spouse or family member looking out for you so you are more cautious.

What do you think contributes to the health of Hancock County?

A lot / big time / big role / daylight and dark / depression

They are able to do anything but then they don't want to participate. Mothers who are at home with children/grandchildren makes them drained and spiritually depressed and diabetic – She just “needs a new man.” (laughter) They are beaten down with the routine of life.

We take care of our own in this area. Old people are not in nursing homes. Mentally and spiritually we do have to step away from our obligations; feeling guilty that we are not taking care of everybody. If you were out going to the gym, then you would feel that you should be serving, taking care of others, because in this area if someone is not taking care of their kids, or grandkids, there is no one else. No child care here. Life gets harder and so you put yourself on the back burner.

What else?

Education. What is good for yourself.

It's good we have a park.

Poverty: we can't buy good fruit so we buy Little Debbie cakes because they cost less and will last longer. There is only one grocery store. If you have a car, you can drive out of the county for fresh food which is seen as a luxury.

What are networks?

The Senior Center gets people moving and communication helps. The Jubilee Center does a lot for young people. The Hancock Arts is a motivator for children and adults with a workout class. Girls on the Run gets children out of the house mentally and physically.

For those people who are out, they have to search for it. We eat a lot during church functions. Cars are important to being able to get out but they are expensive to run.

Informal structures? Social groups?

Walking partners at the high school track; kayaking on the river; our family picks beans, cans food. Living off the land helps a lot - planting. (laughter - 'Try Doris' salsa') ut not everyone does that.

Social networks?

NO. At the high school, the kids probably not doing a lot in the afternoons but sitting there doing the phones, behaving doing nothing. Adults are the same.

It's up to the individuals. They do a lot of nothing, sitting in a chair.

Being with a group helps a lot. Really isolation leads to depression.

Who puts it forth?

Someone has to spark it. The Johnson City women who came in with the Girls on the Run was the spark for women. You get the feeling everything is okay. Someone has to shake us up. See the fruit of it, seeing the benefit, helps.

How does health come up in general conversation?

“I'm sick.” “I have a headache.” “I don't feel good.” Conversations always revolve around the negative.

People don't want to hear our positives.

Don't be too good; don't shine too bright. We do talk about what we should do.

We're all creatures of habit, set in our routines. It's like getting a shiny new car, we promise to take care of it, but then we get back into the old routines.

We have Pizza Plus, Michaels, Subway, Hardees – not a lot of healthy food choices.

Does education lead to healthier lives?

It could contribute that to health? i.e., New Year's (resolutions?). In the school system, maybe, but when parents are at home on welfare, they think "I've got to get by this month. I'm working 2 jobs." So there is no time to prepare healthy meals, for example.

What are your resources?

In the women's club, they talk about a community garden, but it's just talk.

Parents in the home providing good examples.

Girls' soft ball team. In between games, families drive through the fast food joints. Knowledge doesn't seem to help. What we put into our bodies is what we get out.

The hospital – Our healthcare is good but we are all in survival mode. There is a hospital but there is not a walking area in the park. We don't see the bigger picture. It's not what you see driving through town.

How about out in the remote areas of the county?

We see both ends – some people want to be in solitude and do their own thing and some people are really isolated. The generations are handicapped by the government because they have received assistance for so long, it's learned helplessness; it's a 'right' to receive government help. And it will take generations to get it out of us. People have a better quality of life on welfare than if they had a regular job.

Do jobs lead to better health in Hancock County?

It's limited because there are not a lot of jobs. If you want to work then you have to drive out of the county. Attracting factories is hard because getting in and out of here is hard – location. And the drugs.

But there is business and people who want to work do work. People who don't want to work, don't.

Farmers can't get help like they used to. People don't want to do that.

Why?

Government assistance – What's the incentive to work? If I am working, though, my health will be better, but it pays to not work. What you see people doing in your family is what you will do.

How does the physical environment affect health?

Transportation – you need a vehicle to get to good health care; you have to drive 45 minutes to get to a gym.

The ratio of cancer is high here. "The mountains clog up bad things here." The location does that.

Farming? Terrain or landscape?

Yes, if you're out working the land and keeping active; if you have a full time job at farming, but the majority don't do that. You can't make a living working off the land. It costs so much to live. When bigger things come along, it puts people out of business.

But the land is why we're still here. Having your feet in the dirt makes us healthier. The benefits far outweigh the disadvantages. What we value is different. Walking in the woods for example.

Does the current culture support health?

It depends on my family and work in life choices – living in this place, I have no regrets, I can breathe, there is no humidity; no hurricanes.

People are moving in, building houses, so it helps with the culture.

Our idea of Hancock County is changing. Before, we counted on factories but now it could be a retirement area. With recreation opportunities, the treasures of Hancock County are opening up. This is not Kingsport.

There is a slower paced living here. Peace and Quiet. Cigarette smoking is rampant here though. Drugs are ruining lives, and young people.

What is your overall perception of the health?

Health is the last thing we think about. Exercise and running is the last thing. Farming is how the average person gets out and works out.

Thumbs are the only body part that gets exercise when the young people are on their phones.

Health begins at home.

We have programs out there but you can't make someone come in.

When we hear someone have health problems then we might take it as an example (of what not to do.)

Sneedville is growing and 20-40 year olds are not taking care of themselves. We are just getting our kids places. Yoga classes are on YouTube. We can get stuff is we want it. It's back to the individual.

What are the barriers and challenges? To health in general?

Tradition. Kids are at school, but people won't do what we need to do. Stubborn people. Habit. It takes a long time to change and we are slow to change.

But there is change. The conversation is becoming different. For instance, when someone goes to ETSU and brings the conversation back home. People are coming back home.

Health is a state of mind. I can do this/I can't do that is how you perceive your health. While delivering meals to the elderly, one person observed: Some people are sick and do a lot and some are not sick but feel they can't do anything.

After the session, one person came back to say that the use of seat belts was an indication that she was taking her family's health more seriously partly because there have been so many care accidents in the past two years, including several deaths on the basketball teams. She is more conscious of the importance of seatbelts.

FG2

Males 1; Females 1 **Both participants were over 65 and not native to the county, though they both had lived in Hancock County for over 40 years. They came during the 1970's. For the first 10-15 minutes there was general conversation to get acquainted and share professional and family backgrounds.**

Research information and introductions

1. What does health mean to you?

One major aspect is that being in good health means the ability to do what you want to do, to function well as opposed to just getting by in whatever aspects of life are important to you. Able because if you're in good health, you can navigate, exist, and contribute to society.

I agree that overall health changes with age or whatever comes up and you have to make decisions to continue whatever health options you have. Health is very precious to me.

I work hard at staying in good health. It's natural now. One makes decisions for good health and does that if you can.

2. What does health mean to Hancock County?

If you have folks who are conscious of staying healthy. But people through their poverty experience, don't take medicine correctly or fall down, that's unhealthy. Large populations in county can't make the link between conscious health decisions to stay healthy. Tobacco causes poor health in the mountains. Maybe because they know it's not good for them but a more general concept of health is not on the top of their consciousness. They abdicate respect for their own health or wellbeing and rely on home remedies.

I went to homes and little old ladies with sores or deplorable conditions use plants grown outside the house to take care of it. Child protective services reports widespread use of catnip tea to calm babies. "Children slept all the time."

Jewelweed balm is used daily for topical application (insect bites and poison ivy). The population goes back a generation to a common body of knowledge that was shared for useful medicinal helps. Over time this has become less relevant to people's lives and now not everyone has a garden which impacts their diet and health. When Hardee's opened here, we thought it was not going to work but now we go through to the window because it's faster.

Schools here qualify for the free breakfast for everyone but they have to throw the food out because instead of bringing the kids early enough, parents drive through Hardees and pass up a free breakfast. They expressed aggravation over the choices people make over health that goes against their good health.

How is health incorporated into daily living?

In our schools, there were no activities for girls but now we have lots of kids in sports who get a better perspective on health and realize important outcomes and greater self-esteem a lot and girls see how much it's done if they stay in the county they can pass it on to their children.

When my kids were in school years ago there were not the opportunities so it's an improvement. There are walks for cancer but whether it reflects back on daily life, I don't know. My wife and I spend time thinking about health, mental health, spiritual health, emotional health, (We are retired) and how to get people to make simple decisions that impact their health.

The Health Council; Health fairs; Counseling one-on-one is an important personal intervention and is possible.

In Morristown, there is an effort to get people to walk with trails in parks but it's small percentage of the population, but it is valuable and people who come are interested. The fact that it's available is great and makes an impact.

Dental health: You can see that Jubilee brought in a team of dentists for oral care. Everyone signed up but no one showed up for days 1-3. There was very little response because people didn't take the initiative to take advantage of it.

3. How does health affect the quality of life?

I see people half my age who can't walk up my hill; it doesn't make sense. I can't pretend I have the same ability I had when I was younger but my body works for me. My mind is in pretty good shape. Young people have a lot of energy. I want to be an active participant for my grandkids and to be able to play.

Cancer was a wake-up call and arthritis. Cancer was a life change. Life is too precious to ignore so make yourself as healthy as you can be. I walk every day. Grandchildren and health are at the top.

4. What do you think contributes to the health of Hancock County?

Poor health negatively contributes and cigarette smoking is #1. All those previous activities in the past that kids did as a matter of course. The ruralism of people that are poor affect the water supply for the overall county. The well water is not adequate and getting water from the river and springs when the wells have dried up is bad. We got water off the roof and filtered it through the cistern. It affects the ability to take baths, brush teeth and when people can't do that, it affects their self-esteem. Farmers who use Roundup has led to high cancer rates here. Families who are digging around in the dirt have cancer. Raw sewage is pumped into the Clinch River. What kind of management is that? Fines and contractors were brought in but no criminal charges have been filed yet. We swim in that river so does that have an impact on people?!!!

The sewers are not maintained properly. Sewage has been put into the river for 10 years. The city engineers don't understand it. Storm water runoff still runs into the river.

The issue relates to health. Recreation in the river is affected because people have the means to recreate it is unhealthy. But poor people don't think about it though they fish in the river.

Our granddaughter did get sick from swallowing river water.

Social Factors?

Anecdotally, people who moved into the county 40 years ago were back-to-nature types. Some of the kids intermarried with local folks. We've noticed that there is less and less meat the gatherings now and at holiday events with the exception of deer which people have killed. (Referring to the fact that purchasing meat for large groups is expensive.)

I went to the American Legion picnic and they had cheap hot dogs and day-old bread donated. The donation was so large that I got it re-donated for the vacation Bible school. The VBS is using the hot dogs. We are conscious of doing with what you can get. (rather than choosing good foods)

What of the veterans seeking health care in a special way. It is getting easier. They are a self-contained social group but they have a lot of health needs. Iraqi vets with missing limbs are referred to Appalachian Service Project (ASP) for house modifications. There needs to be more involvement and less self-containment. The VFW is closed and is a personal liquor store.

What resources are available?

The medical framework of Hancock County is in great shape. The ER at Hancock Hospital was great and the school-based healthcare, and the Rural Health Consortium (RHC). I feel like the

county has a good level of care. The helicopter transport has saved people's lives. The facilities are good.

I was satisfied with the hospital and RHC and the school clinic too. We are getting a 'new' doctor who is coming back in to practice. The basic care is good; for complications, I have to travel to Knoxville, Morristown and Johnson City. For the poor, there is maybe less transportation.

We have chosen to live here; if we want to do something else (nice restaurant, movies, concerts), it is 3 hours round trip, then that's a choice we make. But people who have grown up here, there's nothing and they have a different sense of home. Older people have a different mindset than young people.

The beauty and quiet

What are groups and services that are not healthcare?

Mental Health. Frontier Health has no full-time drug counselors every day. Do poor people have any mechanisms? _____ has a support group for grief. Church groups are focused on the church. We have a children's music group (at church) because there is no music in the county (schools) and we are drawing population from the poorer areas of the county. Tutoring after school at the church and not incorporating art at the school. There is an informal support group for parents who are always there sitting in the back of the church hall (Methodist). The pastor talks to them. The Baptist church has a teen age group. We have a good start. People realize if we don't do it for our children... We want more for our children so Hancock County doesn't die.

Social Networks?

The Hancock County Arts and the Chamber of Commerce provide activities and events and recreation and a sense of community. Schools and churches.

The grocery store doesn't have a whole selection of vegetables or organic food but we can't expect that.

How is health made part of the daily conversation?

The Health Department: conversations revolve around drugs and cancer and people see it as a plight. The drug piece is the cause of a certain amount of crime.

Education?

Jubilee (Methodist mission) has had efforts to provide more or local food for school lunches. The health educators at school is important and has had an impact because of information about topics like STDs, pregnancy, etc. The 4-H extension agent does health and nutrition education so children are impacted more than adults.

Economic impacts of health?

How much has the department of Human Services and food stamps had the opportunity to talk about and counsel the beneficial resources for children. WIC has continuity and would be an asset. White bread is the only option for the poor. It reflects economic disparity. It's a historic case that people who don't have health insurance are more reluctant to deal with preventative medical services until they end up in the ER. This is another impediment to poor people plus transportation or the social norms which also affects access to care.

Schools mandated whole wheat bread and the kids threw it away because it wasn't what they had at home. Education is the key and the family milieu should be reinforcement. Kids are caught

smoking at school but the mom buys the cigarettes for their children because that's how they grew up.

How does the physical environment contribute to health?

Farm issues are inhaling or ingesting herbicides and pesticides. Hearing and eye and nose precautions are not taken. But we have clean air. Cities have pollution. People appreciate it. There is a trash problem. People throw stuff out and law enforcement needs to fine people. There used to be a litter control officer but it offended people. We are fortunate here for the clean river.

5. How does culture support health?

Appalachian, rural (the Melungeon identity is dying as people marry out and don't continue the identity), soup beans, cornbread, sweet tea.

Rural areas are geared toward more fresh vegetable and fruit but there is a disparity between those who have and those who can't.

People are moving in here. For those folks, land is inexpensive and because of the clean air and the ability to have a garden. The county has 3 community-based events. But (distance from specialized) medical care, drugs, people cruising the streets is not culture that supports health. Young people are driving drunk or stoned because of no place to go so they go out and do these things away from the house.

Some mental health and some economic problems give lack of resources circular causes.

What do you think is the overall perception of health of Hancock County?

The population is split between people who moved in and people who have lived here for generations. People here are so friendly though.

Health is governed by drugs and cancer. People who have good health take in events and can get out of town, but for people who don't have the money.....

The death of teenagers from drinking and driving shows that the percentage of drugs and drinking deaths are high. Risk taking is high.

Social media is a challenge; kids don't listen.

What barriers exist?

Drugs and adults who become addicted. Prescription drugs turned into addiction but the youth don't have that original introduction. Case in point - We have 3 full time pharmacies in a county of 6,500 people.

Final comments?

1. There is a full-time doctor now who lives here but also practices in Morristown, but now he is seeing patients here.
2. Grocery shopping: One person shops at the co-op store and the Whole Foods in Knoxville and freeze the excess. The other person shops some at Greens (local grocery) but also buys fresh produce and freezes.
3. All health is personal. When you ask a person, "How are you?" they will tell you or say something like "so, so" or "fair."
4. The county map (for sale) was paid for by the last of the funds from the sale of the hospital and highlights the location of all the health facilities.
5. There is always something that holds you here.

FG3

Males 4; Females 4

While collecting the group, people seemed to know each other, share common interests and engaged in small talk about family, parenting stories, who's sick, people who are aging, etc. They discussed people moving into the valley from out of the county. Typical start of conversation: "How are you today?" "Oh, fair"

Research information and introductions

1. What does health mean to you?

Life. Way of life/ way to live your life and in a manner where you feel good and contribute to the community.

Health gives you the ability to do what you want to do.

Health is how a person feels, the community.

Health develops well-being, how the rest of your life will go, for good or bad. It is left up to you and the healthcare facilities.

Mental health, physical health, spiritual health and each affects each of the others.

2. What does health mean to Hancock County?

It's a long reaching thing. The main threat is that controls bad health is drugs which have a negative impact. Years ago, Hancock County was far behind but we would catch up but we wish it didn't. People have to combat it with attitudes – the community and kids. The future of Hancock County is important to me and my family.

The availability of healthcare is good. We are blessed with facilities compared to years ago. We are rural and what other places take for granted, we don't always have. Being local and knowing people, you know who a lot of them are (drug-users).

In the Community?

There used to be few health professionals in Hancock County but now there are more and so there's more money here to be circulated.

Drugs – The Mission is going to start its own rehab instead of going outside the county. We are in the Bible Belt so we push it (Christianity) but other people leave it out outside the county.

Healthcare in the community – a healthy workforce means people can work and it cuts down on missed work hours.

How is it incorporated into daily living?

What we eat and what we put into our bodies. People at the food store buy Little Debbie cakes instead of the good groceries. Children eat well at school but they like the unhealthier options like they're used to at home.

Obesity has increased drastically as people came off the farm and no experience, now they are on cell phones.

We should be paying attention to sanitation, cleaning and exercise. We have a variety of sports that we didn't have when I was a kid. (at school)

Adults lack sports centers. We are always running after the kids. The school system had a competition for school teachers once a year.

Healthier things are expensive and the drive-through is easier with kids. Men used to be the breadwinners and women were home to cook meals but now women are working. The family dynamics have changed. Mothers are not home with the kids. Between 1960 and 1990 we changed from at least one adult home to none.

3. How does health affect the quality of life?

In many ways – poor health takes up time to go to doctors, spending money on medicine. A sick family member takes time away from what you want to do. The financial impact is that you can't work as much. When people are on disability, it taxes the system more but the money is not there.

Mental health affects the quality of life massively to take care of children and yourself. Kids don't have the structure at home when there are mental health issues so the home is disorganized and personal and social skills go by the wayside. The future of the kids is diminished.

Everything has become impersonal and it weighs heavily on teachers. Kids demand attention so teachers become the mom, nurse, etc.

Kids are taking home extra snacks from school. I go into people's homes and I see dirt floors, kids running around hungry, all over Hancock County.

5. How does culture support health?

Healthy eating - It's easier to grab a burger. We all used to have a garden but now we don't and now teachers have to teach everything, even how to garden and where vegetables come from. At school, healthy snacks are thrown away. The kids don't even try to taste it.

EMS had food to pass out to needy people who were happy to get it. People don't want anything better anymore, except handouts. Parents pass the attitude on to their children.

"On the draw" means kids expect to "draw" a check like their parents, not to be an artist.

What do you think is the overall perception of health of Hancock County?

People in healthcare think it's good enough. People in Hancock County spread the word. Even if they're dissatisfied, they don't want to make it better. Education is the key. People talk about it but don't do anything about it.

Kids think it's not going to happen to them. Drinking is rampant. Poorer counties have more drinking, more depression, more drugs. All is driven by money. To combat poor health, it has to be driven by money.

Depression leads to not seeing any future. Most people who are really not religious turn to drugs. 'All my friends do it' is their attitude. At the high school, I've heard girls say they're going to have a baby so then I'll have somebody to love me.

What barriers exist?

State funding – The Health Department does stuff – monitoring, surveillance, etc. - that we don't see. And crime makes a difference. Grant money requires utilization of the grant money so sometimes we don't apply.

What social structure and/or networks exist around health?

Knowing what's available, like money things.

The water is getting polluted- well water – with run off that you didn't used to have.

Advocacy and civic groups?

There is a lack of formal groups.

Clubs that used to do different things like the Lion's Club collecting glasses. (they were from out of the county)

The Women's Club plants flowers and has a focus on scholarships.

People think they don't have the time for these things. The nursing faculty could do more research and education people about health – it could make a big difference.

Churches could do more but they don't.

Seniors get together informally outside the church building.

Word of mouth spreads information like a new diet when people are talking things up.

Getting meetings started and keeping it going is rough.

What resources are available?

Soap and water

The group that meets at the city park but only a few people go.

Common things – people cough in your face, don't wash their hands – simple thing that could stop the spread of diseases. School based health thing is a good thing, but they don't take home the lessons. Stay home from work or school if you are sick. Kids come to school sick so they can go to the school clinic and get help. There are no babysitters because both parents work.

How does education contribute to or affect health?

WIC vouchers, public housing, school-based health, food stamps, electrical assistance, and parents can come after 3 pm to the school clinic.

Mental health by tele-net for kids, the grocery store. There is a dental hygienist after school with parents' signatures, school counselors.

Better education leads to more awareness and more healthcare. The DARE program was eliminated – the officers didn't care to go for training. More employment to provide better jobs and more pay.

Economic contributions?

Some people could take their family members to the doctor; some can't afford the insurance or to get help. In-between people have pride that won't let them get help.

Physical environment?

We have clean air. Our geographic location limits economic growth and revenue. People don't care to drive across the mountains to get health care.

Trash is everywhere. People have no pride. Allergies affect our health, confidence levels. The city water source is contaminated by the old zinc mine but some people's access to good water is limited.

There is a high rate of cancer because of the winds that come from the west (Oak Ridge). The Clinch River is cleaner.

What are the barriers and challenges?

The terrain and distance. 10 miles is not far on a straight highway but 10 miles is a long time on a county road.

Final comments?

Schools are the best system for getting health-related things to the community. They have contact with everyone in the county. School-based healthcare was a blessing.

If social media can link up to carry good messages to the kids, that would be good. We have a lack of creativity, imagination and motivation in this county.

FG6

Males 2; Females 7 (2 F did not participate in discussion- outside county service providers) 11 + 3 ETSU

What does health mean to you?

Diagnosis

Fitness – eating healthy, being healthy

Overall well-being

Exercise, medications, supplements

Hospital

No illness, mental or physical

What contributes to that?

Behavior and life style

Genetics – one generation to the other

Stress

Environment and support systems

What does health mean to Hancock County?

Survival, for some of our people

Living from day to day / waking up another morning

Having a meal

Being drug free

Or coping with addiction

What does health mean for the community or the families of Hancock County?

Relatively what everyone thinks is good health but not always in daily living.

More and more but not when everyone had the farms

More for school-age children with physical activity at home. There is not a lot going on at home.

Once a week PE at school. More sports are offered but everyone can't participate.

No exercise at home because of all the phones – What are you doing with that?

Diet at home is fast food. Not cooked food in their diet. Who know what's in it?

Is health incorporated any other way?

Church groups that work with youth

Does health affect the quality of life?

Yes

Our future is about obesity, diabetes, and blood pressure issues.

A large percentage of obesity here and is rising. There is a lack of awareness about proper diet.

Hancock County is the poorest in health in the state – 93rd out of 95 counties.

On Saturday or Sunday, no one is outside; the kids don't play outside.

How is mental health, social health, emotional affected?

People eat the best they can but we can't know how stressed people are, lack of sleep from stress.

The cycle of repetition with grandparents taking care of the children, they turn to other things to cope with stress.

What are resources for health in Hancock County?

Frontier mental health, health educators, churches, guidance counselors at school

Are they used?

Yes

How does the current culture support health?

Farming, but now that is gone/

Industry can't replace it, not tobacco. More gardening has not replaced it. There is no fitness center. People travel out of the county to go to fitness centers.

What are the barriers and challenges?

Time; money is always a factor; equipment – these are not in the community, the location; distance to resources; accessibility, transportation

What contributes to poor health?

Majority of families with children are in custody because the biological parents are addicts.

Social networks supporting health?

Small friend groups that get together but mostly indoors. There is a group of ladies that work out at the high school because there is good parking and lighting.

How about non-physical social groups?

The tobacco settlement money expenditures have been good

We had a 5K two weeks ago.

Not currently but Parks and Rec has a planning grant that was just received so the public can say what they would like to see, like a multi-purpose building with an indoor track, a practice gym, etc.

Where do people go for health?

Mostly outside the county or on country roads. There is a 2-mile loop here (Elrod Falls?) but no structured something

People with exercise equipment (but is mostly is a place to hang clothes)

Where do people go is they're seeking emotional health?

Frontier Health and Youth Villages

CEASE organization is new

Pastors and church prayer groups

Facebook lets emotions air out

How does education contribute to health?

Awareness

In school access to fields and gymnasiums

There is a general understanding of how each part plays and has an effect on overall health but it's much more – what's happening to your body – with spiritual health and all of that – not just one thing.

An opportunity for children

Adults?

Coordinated school health has a challenge to lose weight and eat better fruits and vegetables

There is a wellness program with the Health Department staff

Healthier Tennessee promotes small steps to incorporate healthy choices

How does economics affect health?

It affects it all – parents are working to pay the bills and provide the necessities, not more but the bare essentials. The financial stress takes its toll. Parents primary concern is the kids. People are not buying fruits and veggies because there is no time to prepare them.

Eating health is expensive but fewer people know how to prepare and grow good food.

Diagnosis and maintenance and medications requires travel and the financial means to do that. People cut corners and don't go to the hospital so when they are sick, the diagnosis ends up costing more.

What financial resources support health?

Grants

Schools cost money. The Health TN grant – ACES/Healthier Brains for elementary schools – music and movement after school

How does the physical environment affect health?

It doesn't but it could, because lack of facilities. But we have fresh air and a clean river – Elrod Falls is here and we are developing that but mostly people go out of town.

There are not a lot of people participant at games – time is challenging and sleep is important

Anything else?

Yes, a lot of resources are spent commuting out of the county so that takes people's time and money.

1:15 pm Wrap up

You are asking to learn what the community wants to work. This is the same premise the Economic and Community Development Board is using to build the call center. A lot of planning is needed to get the capital to make it happen.

Team Member 3-de-identified notes

FG5

Definition of Health and Health as a Priority

Physically, spiritually, mentally. Everything works in your body like it's supposed to. Overall well-being. You don't notice until you get older. Better choices. Health is an afterthought/until people are sick. As moms, you put everyone ahead of you. Free from illness. Minor surgery can turn into major problem. Weight and diet. Should prevent.

Community – depends on the group.

No organized fitness activities. Used to be more community activities – now technology.

Incorporated into daily living - Exercise has to be a priority. On the back burner. More reactive than proactive. Fitness affects quality of life – absolutely. [8th lady arrived] Make it a priority.

What about mental/spiritual life?

It's cyclical...if one is bad, so is the other! Healthy looking people can be unhealthy. Did outdoor things that required walking...talked at the dinner table. If you don't feel good, you won't be social. You need family, friends, outings, work. Some people go to Morristown to the gym/lift weights and exercise. Some people work in Morristown. Feel vulnerable. Stigma to mental health issues/emotional health. Might be changing for the younger people. Early intervention matters. Stress today leads to mental health issues.

Contributing Factors and Social Determinants

Food is fattening now. Some families will discuss it with children. Most don't. Growing up, we didn't talk about health. Stop exercise after sports stop.

Social Networks

Not completely absent in social structure – but is in family structure. It's hard to get children to eat healthy. Women's club is a social network. Healthy eating is discussed at school...churches, social networks. Just that...schools and ballgames. Facebook may be ruining social networks. Hard to fit in. _____ has a support group. There are not resources, facilities, organized groups for adults or kids. Kids love music but there's nothing for them. No art or music. If you're not athletic, there's nothing. People (used to) visit and interact. *Drug abuse mentioned at 7:25 PM. No early intervention and treatment.

Mental health services? Mission and First Baptist.

Education *When you know better, you do better. Salad bar. Education about food at school. More money (people have), more access. There is good here! Clean river, air quality without factories. Land not contaminated. Not safe in the park though... Float the river. Tourism around the river. Church contributes to spiritual health. Spirituality in some form is important.

Community Culture and Perceptions

Come together around tragedy – neighbors there when needed. Need help for Hancock cancer patients. Relay for Life used to be here.

Barriers

Cost and time...after working all day. No place to leave children. Afraid to go get started. We can't do the plank...

Hancock County Project Focus Groups Field Notes

Hancock County Arts, downtown Sneedville

Met Paula Masters (co-PI) and Kris Bowers (TNIPH evaluator) at 8:18 AM at McDonald's in Rogersville, TN. Grabbed coffees and hit the road. There are 3 ways to go from Rogersville to Sneedville. We went down Highway 11-W (4-lane) to Mooresburg, tiny community in Hawkins County and turned Northwest on Highway 31 toward Sneedville (Hancock County). 18 miles to Sneedville on a 2-lane highway. 8 mile stretch is fairly flat. The remaining 10 miles are curvy with hairpin turns. The paradox of Hancock is the stunning beauty of the mountains but the isolation they cause! The Clinch River rolls through the mountains - above Sneedville is one of the cleanest rivers in the United States. 69 degrees and a clear sunny East TN summer day. Perfect day to visit Sneedville. Turn due North – still on 31 into Sneedville. Arrived at Hancock County Arts (HCA) at 8:55 AM. HCA is a nice 3,500 sq. ft. building on the second main artery of downtown Sneedville. The building is kid-friendly, brightly painted, well-maintained and cheerful – but empty. Paula, _____ and Kris are setting up. I took photos inside and outside the place. I had a long conversation with _____ about plans for HCA. She might sell or lease it to Wellmont. She has a great idea for grief counseling for children. Lots of death recently – young adults (accidents, murder, overdose, car wrecks). Person 1 arrives with a little girl (her grandchild) – got snacks, hanging out...9:45 AM. A woman and her daughter (granddaughter?) arrived at 9:52 AM. Grabbing breakfast snacks and settling in. A gentleman arrives. It's now 10:04 AM and we're waiting for a couple of women to arrive. 10:09 AM and still waiting...Focus group began at 10:11 AM. Paula Masters explained the consent form. 8 participants in the focus group – 2 males, 6 females – estimated to be 3 under 40 and 5 over 40 years of age. Purpose. How do you perceive and describe "health"? Participant form. A few seemed nervous about speaking...What is health? "Meat on their bones". Young girl under 18 couldn't participate. Touched on nutrition. Nervous laughter. Person 2 led the conversation. Bad knees...climb up on that roof anyway. No healthy workforce. God...healing...God does it. I'm southern, I like fried. A late middle aged couple have only been married about a year – changed their lives. Anecdotal – "Girls on the Run ladies came to town and started running through town." "Don't shine too bright." It's "talked about every now and then." Education...knowledge about it... "The Welfare". "Handicapped by government." "Used to be an embarrassment, now it's a right." Jobs? Drive out of town, teach, farm...drive out of town. Location, location, location. Those who want to work – DO! 2 ladies in the group were quiet. What you see your family do – you do. Transportation to a specialist. Physical environment. Cancer rates high. Can't make a living – living off the land. Feet in the dirt...in what God has made. One lady had moved to Hancock County from outside and loved it – chose it. Widow. Young people and drugs are a problem. Lots of smoking. Don't think people in Hancock think about health. Comes last. social media...parents don't make them get off. One woman had to get up and tend to her 4 year old grandchild during the focus group. Florescent lights in the building flickered off and on. Barriers. Habits and "stubborn people". People leave Sneedville...but they are coming back (like Paula)... FINAL COMMENTS – "Health is a state of mind." Ginny Kidwell reported Hancock

County data from the County Health Rankings & Roadmaps report. Participants asked what they can do to improve health... Talking. Focus on positive note. Finished at 11:20 AM. They really responded to encouragement and positive comments about Hancock. Packed up and heading out the door at 11:35 AM. Rolling out of town at 11:40 AM. DEBRIEF: Went great! Traffic accident on the outskirts of town. Back in Hawkins County at 11:55 AM. Winding down the hairpins...81 degrees. Mimosa trees are lush this year. Down off the mountain at Noon. Back to 11-W at 12:04 PM. Getting an education was never mentioned during the focus group. Health education, yes, but not the value of education. Driving past TRW (local manufacturing plant) in Rogersville at 12:15 PM. Back to McDonald's at 12:18 PM EDT. Kris and I got back in our own cars, and we all three went our separate ways toward home.

River Place at the Clinch

Ginny Kidwell met Paula Masters and Kate Beatty at McDonald's in Rogersville at 8:06 AM. Going to Hancock County a different way, since we are going to a different part of the county. Out 11-W to Highway 70 and up toward Kyle's Ford situated on the Clinch River. 70 North at 8:10 AM toward Pressman's Home – a narrow 2-lane highway with curves. Newspaper boxes are for the Kingsport Times. Went by a place where there had been a recent rock slide. Beautiful little valley. Still in Hawkins County. To Hancock County line at 8:33 AM. Entering Kyle's Ford (community) at 8:36 AM. Took a photo of the old Kyle's Ford School. Riding around – just killing time, since we are so early. No cell service, so we are driving toward Sneedville where there is Verizon service, which I have. Finally got cell service at 9:02 AM to phone home. Turned around and headed back to the venue for our focus group on the Clinch River. Back to River Place at the Clinch – a cute tourist place/old fashion general store with café-style restaurant with 4-5 workers without much to do. We are conducting our focus group in a large room on the second level. A female participant arrived and told an “American Legion story” – got too militant, so they closed it. Reopened it with a state-supervised mission. 10:00 AM – we have 2 participants (1 male & 1 female) Neither of them seemed to have native accents. Male had lived 40 years in Hancock. Female was from Iowa and had lived 35 years in Hancock. Both were active in the community. Session started. Question-“What does health mean?” Answer: “Ability to do what you need to do...”. “Cases of Mountain Dew”. Smoking...surely everyone has heard it is bad for them. Home remedies, like “cat nip tea”. *** Literally everyone in schools qualify for free breakfast/lunch/Blanket approval. “Over Home Happenings” – Facebook. This was an easy free-flowing conversation. It seems like these folks, originally from someplace else, care more about health factors and outcomes than “native” Hancock County folks. Seem to have a broader and more objective point of view. Question: What contributes to Hancock County health? Ironic laughter. “Cigarettes” and “ruralness of poor people” ... water supply...wells dry up (640 ft.) Save rain water from tin roof and collect in a sistern and then filter. Poor people can't afford it. High cancer rates were mentioned. “Raw sewage from Sneedville dumped into the Clinch River” – wonders what county people really think of that. “Waste water system”

drains into sewer and overloads the system. Social anecdote – “Back to nature” movement 30-40 years ago. Less and less meat among his social network. ***American Legion gives away cheap hotdogs and day-old buns. Veterans moving in. Seeking healthcare...instead of moving to Johnson City or Virginia. Discussion about resources. Medical infrastructure is good. Health consortium. Goes to persona physician in Morristown. Chose to live here. Drives 3-hours roundtrip for movies, symphony, etc. Frontier Health (mental health services) doesn't have the resources to offer services. *** _____ “Joshua Stone” grief therapy mentioned. Other support groups through churches. First Baptist has a teenage group. Music. People know HCA and her work. Male participant used to be involved with the Chamber. Provide at least recreational activities, but very little community-based activity going on. ***Health conversation – around drugs, cancer and crime. ***Education...to provide better health education. He doesn't know much about health education in the classroom. Easier to impact children than adults. ***Income/economic status. Does DHS counsel, she wonders? Those without health insurance wait until an emergency. “White bread” – literally. Physical environment-“Farmers” don't take precautions for hearing, intake, fertilizer, eye protection. Hancock County does have clean air to breathe. Trash problem. PSA. Mulungeons mentioned twice (beans, cornbread and sweet tea). Dominant culture. Why would you go to Sneedville...? Not much that culture does to support healthy living, especially for teenagers. Time: 11:25 AM. Going to jail – “Crime Beat” have real problems...economic and mental health. No resources. Difference in those who live here, those who come in from elsewhere. “Health is governed (I say it again) but drugs and cancer.” Teenage driving and drinking... Wrapped up the session and had lunch off the menu. Left to head for Treadway via Sneedville for our afternoon focus group at the volunteer fire hall.

Treadway Fire Hall

Zipped through Sneedville at 12:55 PM. 85 degrees at 1:00 PM. Heading to a subdivision of nice homes to get the key to the Treadway Fire Hall from _____. Sunny with puffy white clouds. Wandering around on Copper Ridge Road at 1:09. Turned left on Greenbrier Road. Lovely view of the small mountain range. Stopped at Mrs. Maxey's house (I took photos) at 1:15 PM. Heading back toward the Fire Hall at 1:18. Arrived at 1:24. Hot weather! Maybe the hottest all summer so far. We are set-up and ready to go with the focus group at 1:53. 5 folks have arrived by 1:56. 7 by 1:58. 3 couples and one individual thus far. Great venue –volunteer fire department community center/staging room – complete with kitchen, tables, chairs. A lady was chatting about all the “new people moving in” that she doesn't know. She worked the election and used to know everyone. Not anymore. Chatted about a local boy going to the Grand Ole Opry...Focus

group finally started at 2:09 PM EDT. Went through inform and consent as in all the others...started recording. Off Paula went – she has facilitated all 3 focus group sessions. “Life”. “Way of Life”. What is health was the question...How the rest of your life is going to go. “Well-being”. Spiritual and Physical health. The first mention of “drugs” at 2:20 PM as a problem.

Hancock used to be behind in everything but it didn't take long to catch up with the drugs. "Plan on living here the rest of my life." Facilities and services are better now. Healthcare sector has become part of the local economy. Mentioned the mission. Paula mentioned spiritual health. One more guy joined the group – appears to be part of a couple. So... it's 3 couples and one father-daughter combo. Obesity is an issue – used to be 2-3 fat students in schools. Now many of them. Sanitation. Cleanliness. Exercise. More sports. No gyms or sports centers. Adult fitness needs to be encouraged. Little Debbie Cakes mentioned a couple of times. Family dynamics have changed drastically. No mothers at home. One guy used to work at the phone company – in Hancock County, mothers were always home with the kids. Years later, moved to Morristown and Knoxville and found about 10% at home. Used to be able to walk across the mountain – weighed 135 lbs. and carried 30 lbs. of tools. Final count – 8 people. All participants have heavy local accents. Poor communication skills in the community now. Family life is bad. Burden on teachers. "Current culture does not support health." Fast food. No gardens. "Somebody give me something (they say at school). I don't have to bring a snack." Accident where kids got killed – drugs and alcohol/teens drinking. "Hard to get adapted and hooked on good health." Depression... jobs... turn to drugs and alcohol. Well water pollution – drinking water and run-off. No more active local civic, service groups – Kiwanis, etc. People don't have time to do community things. Note: focus group participants did not eat much – just a few. However, several grabbed snacks afterward. Social media is really good in Hancock County now. Informal networks – seniors, women who get together to lose weight. "Soap and water." Common sense to stop colds and flu. School-based health has been a really good thing. Schools were a focus because there were 2 teachers present. The better educated people are about health, the better they do. DARE program was good but funding was cut. *Better education, better jobs, take care of your family. Segue into Economics. Lots of people are caught in the middle..."(We've) got clean air." Geographic location – economic growth – trash and litter. Allergies are bad in this area... Told this area has a high rate of cancer from winds from Oak Ridge. Clinch River is clean. Holston River is dirtiest. Barriers – Terrain/10 miles on a country road is a long time. 3:05 PM – Final Comments... Best service we have... schools. Social media too. Lack creativity and innovation and motivation. Paula said we would report back to participants. "Here's what we learned... were we right?" Done at 3:09 PM. Loaded and in the car at 3:28. Taking key back. 87 degrees. Good deal. Back to Highway 31 at 3:41 PM on the way down the mountain. Mooresburg at 3:54. On 11-W at 3:55 heading north. TRW at 4:06. Back to McDonald's Rogersville at 4:09 PM.

Hancock County Arts, downtown Sneedville

Left Greeneville for Rogersville at 3:00 PM to meet Paula Masters at McDonald's in Rogersville. From there we will head to Sneedville to conduct a focus group. This will be our fourth for this project. Paula is concerned that we won't have a good turnout for this one, but hopefully, we will. We went to Walmart for sandwiches, fruit, water, etc. to feed participants. To McDonald's at 4:10 PM... waiting on Paula to arrive... she arrived shortly at 4:14. Left

McDonald's at 4:18. Raining and 74 degrees as we head down 11-W. Turned off 11-W at D&R Market onto 31-N through Mooresburg. Puffy low clouds craped over the sides of the low mountain range. Lots of roadside trash at 4:42 along the switch backs. Hancock County line at 4:43. Turned on 33-N at 4:56. Arrived at Hancock County Arts at 5 PM. Set-up and ready to go at 5:14. 5:22 and nobody is here yet – scheduled to start at 5:30 PM. Nobody ever showed up, so we loaded up and headed out at 5:46. Drove downtown to see a building that had burned and been torn down. The building where Paula's dad's clinic was had also been torn down. PHOTOS. Heading out of town at 5:54. It has stopped raining. The Mission has moved to First Baptist Church and there were several cars parked in the parking lot. There were also cars at the funeral home. Perhaps we didn't advertise as well this time. Back down on the flatter straighter road at 6:10 PM. Back to Mooresburg at 6:15. Sun and clouds mixed – back on 11-W. Back to Highway 66 at 6:31. To McDonald's at 6:32. Heading home at 6:25. Paula heading her own way home.

Hancock County Elementary School

Left home at 4:00 PM heading to Sneedville for the fourth focus group.. 82 degrees and sunny. Traveling Highway 11-E to Bulls Gap. To Bulls Gap at 4:23 PM and turned north on Highway 66. To Rogersville at 4:37 PM. 84 degrees. Stopped at McDonald's for a treat. Back on the road at 4:47. We turned on 31-North at 5:02 PM at the Exxon – 18 miles to Sneedville. Hancock County line at 5:12. Hairpin turns. Treadway at 5:15. Turned on Highway 33 at 5:26. 77 degrees. Passed the Courthouse in Sneedville at 5:28. 2 traffic lights in Sneedville. Got lost...and went through town to the other side of Sneedville. Turned around at 5:31. Pitiful – to get lost. We saw Paula Masters in her car downtown and fell in behind her. We went back in the direction we were going earlier. Arrived at the school at 5:37. Wrong school – high school. Off we go at 5:41. Now we're following Paula back into the town to the elementary school. The beauty (and pitfalls) of a small town. To the elementary school at 5:44. We set-up. Photos. We're waiting for the women's club members to arrive. We're in the Library – nice space and a relatively new school building. Small tables and chairs, low shelves and fairly good book selection. I looked at a Nancy Drew, "Secret of the Old Clock" – Carolyn Keene's #1 book in the series. Low chairs and uncomfortable for an adult. 2 more ladies came in and one brought chow-chow for sale. So, we have a total of 3 participants so far – 6:20 PM. Paula is chatting away. Another lady arrived. And another. 5 ladies here now. Very typical local accent – most of the women appear to be professionals. Another lady arrives. The smell of coffee and a blessing before digging in to the "pot-luck" snacks that have been brought. 6 participants. Another arrives to make 7 at 6:35 PM. They are talking about Scott Niswonger's visit to the school today. Also talking about an explosion at Eastman Chemical Company in Kingsport yesterday. Called their meeting to order at 6:46. Talked about Old Business –Started focus group at 6:53 PM. Another woman arrives at 7:05. Focus group wrapped up at 7:37 PM. Cleaned up and cleared out., Headed down the mountain at 7:50 PM and following Paula Masters. Full moon – big and beautiful. To 11-W at 8:14. Back to Rogersville/66 at 8:29. Bulls Gap at 8:46. Home at 9:12 PM.

Hancock County Health Department

Left home at 9:45 AM. Headed to McDonald's in Greeneville first. Then to Rogersville to meet Paula Masters and Kris Bowers. We are doing another focus group in Sneedville, TN (Hancock County). Arrived at Rogersville McDonald's at 10:32 AM. Paula and Kris were waiting. Arrived in downtown Sneedville at 11:15 AM. We are early, so we are going to ride out to the industrial park to check on the new call center being built as part of Project 95 – a state sponsored coalition of departments (ECD, Labor, etc.). ETSU College of Public Health is a marginal partner in the project. The grading with gravel is all the progress that has been made – flat terrain. Passed Hancock County Arts building coming and going to the industrial park, which is for sale. Arrived at Hancock County Health Department at 11:45 AM. Made our way into a meeting room in the back where another meeting is already in progress – They were filling out a survey related to a parks & recreation grant application. We ate lunch – salad, cold cuts... There were 4 people present who were “outsiders”, so they were “observers” in the focus group process (2 from regional office and 1 from Governor's Health Foundation). There were 8 participants (6 females and 2 males). Fairly elite group. Focus group began at 12:39 PM... what is health? Quick easy answers. Very nice facility with plenty of clean space. A tad cool in the room. The word “drug” was mentioned for the first time approximately 4 minutes into the discussion. “Obesity” 5 minutes later and “Diabetes” immediately thereafter. “Mental health” – quieter... insecurity for children... financial stress... grandparents raising children... pills, tobacco, drinking to cope. Resources? Frontier Health, health education, church, guidance counselors. Are they used? Yes. People who can travel outside the county to go to fitness centers. A few walk regularly at the high school and the park. What are barriers and challenges? Money, time, equipment. Distance to resources, accessibility. Drug addiction of parents of young children. Education? How does it affect? Stayed on the awareness subject – rather than jumping to the correlation between health and education in the literal sense. “We do have fresh air.” 2 cleanest rivers in the USA. Very few local people participating in exercise and recreational activities. Done at 1:10 PM. Left health department at 1:45. Headed on down the mountain as noted in previous field notes from other focus groups.

Appendix F

Invitation Flier

Interested in participating in a local focus group?

Paula Masters, from East Tennessee State University, is hosting 5 research discussions exploring how Hancock County defines health. Anyone over the age of 18 is eligible to participate. Each session will last only 1 ½ hours and all participation is completely voluntary. Each research session will be recorded to capture the information, but no names will be linked to any responses to maintain confidentiality. The sessions will be located throughout the county at locations to be determined. To participate or for more information, please contact Paula at 423-439-4421 or mastersp@etsu.edu.

Thank you!!

Appendix G

Invitation Email

Recruitment Letter/Email

Hello, my name is Paula Masters. I am an Assistant Dean at East Tennessee State University (ETSU). I am conducting a research study that involves looking at how rural populations define health. I am looking for people who are over the age of 18 and are residents of Hancock County, TN. This study involves focus groups which should take about 1 ½ hours. There will be 5 focus groups and take place throughout Hancock County (specific locations to be determined). Please think about participating. Participation is voluntary. If you are interested in participating or have any questions, please contact me at 423-439-4421 or mastersp@etsu.edu.

Sincerely,

Paula Masters, DrPH(c), MPH

Appendix H

Participant Information

Participant Information: Please Circle

Sex: M F

Race: White African American Asian American Indian/Alaskan Native Pacific Islander
More than one Race

Ethnicity: Hispanic Non-Hispanic

Do you identify as (You may select more than one):

Appalachian Yes No

Rural Yes No

Melungeon Yes No

Other: Please
list _____

Age: 18-19 20-29 30-39 40-49 50-59 60-69 70-79 80+

Marital Status: Married Single/Never Married Divorced/Separated Widowed

Educational Obtainment: Grades 1-8 Grades 9-11 High School or GED Graduate Some College
Associates Degree College Degree Master's Degree
Doctoral Degree

Employment: Employed Unemployed Retired Student Disabled

Annual Household Income: Less than \$10,000 \$10,000-19,999 \$20,000-29,999 \$30,000-39,999
\$40,000-49,999 \$50,000 or more

Self-rated health: Excellent Very Good Good Fair Poor

Appendix I

Thematic Codebook

Global Themes	Sub-themes	Definition	Example
Definition of Health	Physical	Physical activity; physical being; human body	"Walking", "being physically active", "weight loss", "function well"
	Mental	State of mind; mental well being,	"how I'm feeling", "have a positive outlook", "Good health is your state of mind"
	Comprehensive/Holistic	Everything; whole body-mind, body and soul; Physical, mental, spiritual, emotional	"Good health means everything to me", "It's mind, body and soul"
	Independence	Individual capability; do for one's self; Live by one's self; self-care	"Can stay by myself", "Take care of myself", "Do for yourself"
Culture	Survivalistic	To continue merely just living, getting by, making it to the next day, focusing primarily on only identified basic needs	"You got bad knees, you climb up on that roof anyway", "I've got to get by this month", "Everyone is just in survival mode here"
	Social Norm-Positive	They way things are, informal shared values/understandings that are good, healthy or promote positive behavior	"Have a positive outlook and just keep going", "We take care of one another", "The land is why we stay", "I can breathe without taking in all the bad stuff", "The benefits far outweigh the negative"
	Social Norm-Negative	They way things are, informal shared values/understandings that are bad, unhealthy or promote negative behavior	"If people have meat on their bones, they are healthy", "Being fit...doesn't she think she's really something", "Don't be too good, don't shine too bright", "There's not a lot of healthy choices", "The people not working aren't cause they don't want to", "We are a stubborn people"
	Fatalism	Belief of predetermination/ inevitability, a submissive outlook	"Doctors are good, but it is all up to God", "Don't think about health until something bad happens", "What's the point?"
	Spiritual/Faith	Values religion, higher being, spirituality	"I pray over my food and ask God to sanctify it", "Pray for me/them, I'm/they're sick", "Your faith is key", "Spirituality, yes. Most definitely"
Social Cohesion	Integrative Norms-Altruism	Volunteering, civic participation, donations	"the school has a backpack program", "Shepherd's Corner hands out food boxes", "The Mission provides clothes and hygiene items"

	Integrative Norms-Tolerance	Tolerance of other's beliefs, behaviors, and lifestyle preferences	"its how you are raised", "they can't help it", "they don't know any different"
	Integrative Norms-Social Contract	Paying more to support others, willingness to do something practical for the people in the community, understanding of division of tasks between men/women-spouse	"feeling bad for leaving after being away at work all day", "we feel guilty if we're not taking care of everyone", "I should be serving instead of taking care of myself", "we, women, feel guilty if we don't have supper ready and everybody is taken care of", "then somebody else is taking care of your kids"
	Social Network	Membership of any organization or club	"small community that supports each other when something bad happens", "church and social supports", "there are no groups", "we have to go 45 minutes just to be part of something healthy"
	Identity-Local/Regional/Community	Sense of pride, sense of community identity, identification with community/regional symbols	"this is a small community, we are not like bigger places and see healthier people", "we take care of one another, like family", "small community that supports each other when something bad happens", "we grew it, we ate it, and did it together", "we come together, we just need to do it for health"
	Identity-Interpersonal	Sense of belonging to family and kinship network	"take care of each other", "its been like this for generations, family to family",
Social Inclusion	Services	Number/proportion using health services, Number of civic/cultural facilities	"you know certain families and so you go ahead and give them extra",
	Social Networks	Regular contact with neighbors, friends, family Negative-feeling lonely/isolated	"there is a grief group", "The Mission helps people who are addicted", "kids can go to the Jubilee center", "if you don't have a car, you can't get into town, and that is where what little is going on happens"
Socioeconomic Security	Financial Resources-Income Insufficiency	Lack of money for health, clothing, food, housing	"people cant afford childcare even it were available", "a lot of kids dont have the money for sports", "these kids only get the food at school", "they go home to nothing and a lot of times take care of the parents",
	Financial Resources-Income Insecurity	Identified in poverty or receiving federal assistance	"there are so many on gov assistance and know nothing else", "these kids have one set of clothes, if that, don't have a way to bathe or eat", "just can't afford it, live pay check to pay check, if they work"

	Housing and Environment	Living in houses without basic amenities, living in households situated in high pollution areas, high crime	"kids go home to a house without water or a way to heat food"
	Health and Care	Insured, adequate clinical providers, adequate time for emergency and specialty care	"there are clinics, in the school too", "the kids have the clinic", "there is no childcare here. If your family isn't stepping up to help, you can't do it"
	Work	Employed versus unemployed	"so many don't work", "many don't want a job cause its easier not to"
	Education	Graduation rates, degree obtainment	"their parents didn't continue school so why",
Social Empowerment	Knowledge Base	Extent to which mobility is knowledge based	"clinic has provided education to the children, they can take it home"
	Labor Market	Provision of skill or trade based training, work-life balance supports	"there is a new industry coming"
	Openness and Supportiveness of Institutions	Existence of public involvement in economic decisions, organizations with work councils or unions	"the Rite-Aid is leaving and no one knew about it", "we have three pharmacies, why"
	Public Space	Monetary and facility support for cultural groups and events	"The Mission", "churches do some things", "the senior center has tried some recipes and things", "the park is sketchy and has needles everywhere"
	Personal Relationships	Provision of services supporting physical and social independence, support services for social interaction	"teach the kids better things", "there is nothing to get involved in"
Cross-Cutting Themes	Assets	Positive infrastructures, behaviors, resources	"we love the land, and it is part of us", "there are increasing programs for children", "the school clinic is great", "piece and quiet here", "the senior center delivers meals", "we are ready to help the kids", "we have got to focus on the next generation"
	Challenges and Barriers	Elements to overcome in pursuing/achieving health or improvement	"people are stuck in the hollers, cant get into town", "we are set in our ways", "transportation is a huge problem", "there's a lot who rely on the gov.", "we don't have anything but fast food", "people have forgotten how to garden and get outside", "we are really isolated from everything"

Appendix J

Disclosure Statements

Kidwell Statement

I estimate that I have been in Hancock County approximately 18 times for the various reasons as are described below. My involvement with Hancock County, Tennessee began in 1994 during a campaign visit with a candidate running for a statewide office. The campaign included a visit with party operatives and elected officials, including a tour of the Courthouse, newspaper office, and local businesses and country stores throughout the county. Since that time I have visited Hancock County, primarily the county seat of Sneedville, on multiple occasions in various official capacities, including as legislative liaison for the Tennessee Department of Education, jobs development specialist with the Tennessee Department of Economic & Community Development, Governor's liaison for Northeast Tennessee, and in my current position at East Tennessee State University as executive director of the Tennessee Institute of Public Health (TNIPH). During my time as executive director, TNIPH has awarded three mini-grants to Hancock County Arts (HCA), a cultural center for youth, (two as part of the Regional Roadmaps series and one as part of the County Health Rankings & Roadmaps annual launch). My primary contact with HCA is _____, HCA director and local resident. I have worked on industrial recruitment and expansion projects with county and city mayors and legislators through the years. I organized a gubernatorial campaign (primary and general) and spoke at club meetings and events in that role. I also attended groundbreaking and ceremonial events through the years.

Although I have a long professional and political history with Hancock County, I do not have any family or personal connections there. However, due to the development of relationships and interactions over time, there could be circumstances that might lead to bias on my part in some situations. Paula Masters, who is the co-PI on this project, is a native of Hancock County and introduced me to _____ whose site we used for focus groups. Since that time, I have worked closely with _____ on a professional level but have also developed a more personal relationship.

Quinn Disclosure

Megan Quinn, Assistant Professor of Epidemiology at East Tennessee State University, has no conflicts of interest to disclose for this project. Megan has not been to Hancock County, Tennessee and is not familiar with the community. She has had no involvement in previous projects. Her only connection to Hancock County is through the principle investigator of this project and anecdotal information she has heard about the county through the principle investigator. Megan is aware of the health status of Hancock County through reports from the Tennessee Department of Health and the County Health Rankings. Megan will be able to complete the project without invoking any personal biases or prior opinions about Hancock County.

Beatty Disclosure

I have been to Hancock County on one occasion as part of this study. I attended two focus group sessions for this project: one at the Clinch River Café and one at the [fire station]. Before going to Hancock County for this project and also since, I have worked closely with Paula Masters, one of the PIs for this study and a Hancock County native, on multiple Hancock County focused grants. Through this work I have learned a great deal about the statistics related to health, education, and economic development in the county as well as about the people who make up the rich fabric of the community. Though I personally do not have any family or personal relations or connections to Hancock County, through my work at East Tennessee I have developed an interest in seeing the county thrive. This may impact some of my interpretations.

VITA
PAULA R. MASTERS

Education:

05/18 East Tennessee State University, DrPH
Major Area: Community Health

8/09 East Tennessee State University, MPH
Major Area: Health Services Administration

12/07 East Tennessee State University, HCMC
Major Areas: Health Care Management Graduate
Certification

8/03 East Tennessee State University, B.S.
Undergraduate Major: Health Services Administration

Professional Experience:

4/18-Present Vice President of Health Programs
Ballad Health System

9/14-3/18 Assistant Dean of Student Services
Dean's Office
College of Public Health
East Tennessee State University

1/17-Present Co-Director
Center for Rural and Appalachian Health
College of Public Health
East Tennessee State University

1/11-3/18 Director
Tennessee Public Health Training Center
College of Public Health
East Tennessee State University

7/11-3/18 Clinical Instructor
Department of Health Management and Policy
College of Public Health
East Tennessee State University

9/13-9/14 President
Tennessee Public Health Association

4/07-1/11 Regional Health Promotion Coordinator
Northeast Tennessee Regional Health Office
Tennessee Department of Health

3/04-4/07 Public Health Educator 2
Washington County Health Department
Tennessee Department of Health

Publications: Brooks B, Blackley D, **Masters P**, Williams C, Mayes G, May, SA, Pack R. Developing an Academic Health Department in Northeast Tennessee: A Sustainable Approach through Student Leadership. *Journal of Public Health Management and Practice*. 2014; 4: 68.

Glenn K., **Masters P.**, Quinn M. Collaboration between Public Health State Government and Academia: Innovative Capacity Building toward Workforce Development. *Frontiers in Public Health*. 2016; 315-323.

Awards and Honors: Delta Omega Honor Society.
East Tennessee State University
Dean's Award: Outstanding Contribution to the College.
Culture of Change, 2017
Distinguished Service Award.
Tennessee Public Health Association, 2016
Dean's Award: Outstanding Contribution to the College.
Undergraduate Advisement, 2016
Dean's Award: Outstanding Contribution to the College.
Asst. Dean of Office of Student Services, 2015
Dean's Award: Outstanding Contribution to the College.
Chair of the Recruitment and Retention Committee, 2014
Dean's Award: Outstanding Contribution to the College.
LIFEPATH Training Center Staff, 2012
Outstanding Service Certificate Tennessee State Capitol, 2010.
Tennessee Public Health Association Group of the Year, 2007.