



SCHOOL of  
GRADUATE STUDIES  
EAST TENNESSEE STATE UNIVERSITY

East Tennessee State University  
**Digital Commons @ East  
Tennessee State University**

---

Electronic Theses and Dissertations

Student Works

---

5-2016

# Women and Healthcare in Appalachia: Impeding Circumstance and the Role of Technology

Ashley Cano

*East Tennessee State University*

Follow this and additional works at: <https://dc.etsu.edu/etd>

 Part of the [Community-Based Research Commons](#), [Community Health Commons](#), [Community Health and Preventive Medicine Commons](#), [Family, Life Course, and Society Commons](#), [Health Information Technology Commons](#), [Health Services Research Commons](#), [Medicine and Health Commons](#), [Rural Sociology Commons](#), and the [Women's Health Commons](#)

---

## Recommended Citation

Cano, Ashley, "Women and Healthcare in Appalachia: Impeding Circumstance and the Role of Technology" (2016). *Electronic Theses and Dissertations*. Paper 3057. <https://dc.etsu.edu/etd/3057>

This Thesis - Open Access is brought to you for free and open access by the Student Works at Digital Commons @ East Tennessee State University. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of Digital Commons @ East Tennessee State University. For more information, please contact [digilib@etsu.edu](mailto:digilib@etsu.edu).

Women and Healthcare in Appalachia:  
Impeding Circumstance and the Role of Technology

---

A thesis  
presented to  
the faculty of the Department of Sociology and Anthropology  
East Tennessee State University

In partial fulfillment  
of the requirements for the degree  
Master of Arts in Sociology

---

by  
Ashley Nicole Cano  
May 2016

---

Dr. Kelly Foster, Chair  
Dr. Martha Copp  
Dr. Melissa Schrift

Keywords: health, rural populations, Appalachia, trust in physicians, barriers to healthcare

## ABSTRACT

### Women and Healthcare in Appalachia: Impeding Circumstance and the Role of Technology

By

Ashley Nicole Cano

For decades, healthcare access and quality in central and southern Appalachia have trailed the rest of the country. Entrenched poverty and low educational attainment compound healthcare problems. This study examines the healthcare obstacles women encounter in southern and central Appalachia and analyzes how technology use, such as Internet searching and social media affect women's healthcare decisions. Data were analyzed from four focus groups conducted with women from the region. Results indicate that seeing a physician or not did not influence women's propensity to search the Internet for health-related information or to seek support through social media sites. Additionally, women reported facing many barriers including trust in local physicians, access, availability, cost, and quality of healthcare. These issues often impede women's access to preventative care and place burdens on their health and an already strained healthcare system.

Copyright 2016 by Ashley Cano  
All Rights Reserved

## ACKNOWLEDGEMENTS

There are many people who have offered me support, not only through the writing of this thesis but throughout my entire educational experience. First of all, I would like to thank my family. My husband Angel for your never-ending patience on all the sleepless nights, support on the days I was ready to quit, and unconditional love. My boys, Aydan and Ashton, for smiles on a rainy day and hugs and kisses that always make it better. Mom, thanks for watching the kids on a moment's notice and took my place as cook, chauffer, teacher, and anything else you needed to be at any time you were needed.

Thank you Dr. Kelly Foster, you have been not only a mentor and teacher, but someone I can look up to and aspire to become. Many others told me I could be whatever I want to be, but you showed me how, with grace and compassion I will always admire. You let me in on this research and it was one of the most rewarding projects I've done. Ms. Cole, you will always be the first teacher who made me believe in myself and gave me the confidence to move on. Dr. Copp, thank you for always being on top of things, keeping me on top of things, giving me encouragement and thoughtful advice, for knowing my potential and my limitations sometimes better than I know them myself, and for always having an open door and willingness to listen. Thank you Dr. Schrifft for never hesitating to say yes when I ask you for things last minute and for the time and consideration you've always given me.

Finally, I want to thank the women who took the time to participate in our focus groups and give insight into their lives that became the foundation of this project. Without you, this research would not be possible. There are many more people who I would like to thank, too many to name, but know you are all appreciated and I will be forever grateful.

# TABLE OF CONTENTS

	Page
ABSTRACT.....	2
ACKNOWLEDGMENTS .....	4
Chapter	
1. INTRODUCTION .....	8
2. LITERATURE REVIEW .....	10
The Appalachian Region.....	10
History .....	10
Geography.....	11
Poverty.....	12
Education .....	13
Barriers to Healthcare in Appalachia.....	13
Availability and Access.....	14
Cost.....	14
Health Literacy .....	15
Trust in Physicians.....	16
Women and Healthcare.....	17
Women as Gatekeepers.....	17
Technology and Healthcare .....	18
3. METHODOLOGY .....	20
Focus Groups .....	20
Moderator Guide.....	20
Criteria for Selection.....	21
Recruitment.....	22

Coding.....	23
4. RESULTS .....	24
Coding Scheme .....	24
Analysis .....	26
Justification for Health Information Choices.....	26
Internet.....	26
Doctors.....	28
Knowledge Acquired from Previous Experience .....	32
Home Remedies.....	33
Family and Friends .....	34
Trust and Distrust in Medical Professionals .....	35
Trust in Physicians.....	37
Doctors in it for the Money.....	38
Social Media and Health Information.....	39
Health Articles on Facebook and Passive Uptake of Health Information .....	40
Reading Health Related Articles on Facebook .....	42
5. DISCUSSION AND CONCLUSION.....	44
Limitations and Direction for Future Research.....	46
REFERENCES .....	48
APPENDICES .....	51
Appendix A: Moderator Guide .....	51
Appendix B: Eligibility Screener.....	53
Appendix C: Flyer for Focus Groups.....	55
Appendix D: List of Codes from NVIVO 11.....	56
Appendix E: Original “Kissing Bug” Post on Facebook by Warrior Zen.....	58

VITA..... 59

## CHAPTER 1

### INTRODUCTION

Women from the central and south central Appalachian region are at-risk for poorer health outcomes, due in part to low levels of education, high rates of poverty, and limited access to healthcare services (Appalachian Regional Commission 2015). There are often many barriers they must face in order to obtain healthcare which include limited physical access, availability, cost, and a general lack of health knowledge, known as health literacy (ARC 2015; Escarce and Kapur 2006; Wilson, Kratzke and Hoxmeier 2012). As of yet, these barriers remain a significant issue for Appalachia and may contribute to disproportionate rates of morbidity and mortality. Residents of this region experience higher rates of cancer, the second leading cause of death in the United States, obesity, diabetes, and other chronic diseases more often than anywhere else in the nation (ARC 2015; Behringer and Friedell 2006).

Technology increasingly plays a role in obtaining healthcare information in the form of ready access to web pages, searchable medical databases, and social media. More than 80 percent of Americans have used the internet to gather health information in the past year (Pew Research Center 2014). In this project, I wanted to understand the role technology plays in the healthcare decisions of women in central and south central Appalachia<sup>1</sup>. Based on findings from the four focus groups conducted, women in central and south central Appalachia are using the internet to gather information on health issues using websites such as WebMD and search

---

<sup>1</sup> This thesis is part of a larger project to look at medical decision-making among women in Appalachia. The larger project, "Medical Decision Making in Southern Appalachia: The Social and Technological Mechanisms that Impact Health & Wellness in Southern Appalachian Families" was funded by East Tennessee State University's Research Development Committee. Dr. Kelly N. Foster is the Principal Investigator for this grant.

engines such as Google. The internet is not used in lieu of seeing the doctor, rather as a supplementary source for verification or additional information and was often used in tandem with traditional home remedies, support from family and friends, and personal knowledge and experience.

Participants justified their use of the various sources of health information by talking about the barriers they faced when trying to see a doctor, including cost, lack of insurance, the availability of doctors in the area, and trust in physicians.

## CHAPTER 2

### LITERATURE REVIEW

#### The Appalachian Region

##### History

The Appalachian Mountains were named after the Apalache Native Americans who occupied the region during its discovery by the Spanish in the mid-sixteenth century. It wasn't until the late seventeenth century that the region became well known and occupied by Europeans, who were drawn to the mountains by the popular fur trade. By the early eighteenth century, large numbers of Scotch-Irish, German, and other European immigrants had settled in various parts of the Appalachian Region (Drake 2001).

By the end of the Revolutionary War, many of the Native Americans that had occupied the area had been killed or driven out of power. Some states such as North Carolina and parts of what is now Tennessee gave 100 acres of land to the head of any family who was willing to settle and farm in the mountainous region. The Appalachian Mountains were a haven for settlers of this time, surround by pristine forest with abundant supplies of water, meat, and building materials. This drew thousands of pioneers from all walks of life to the area (Drake 2001).

By the end of the eighteenth century, the United States moved toward a more unified government as the Constitution replaced the Articles of Confederation. The mountainous regions and the people that inhabited them were typically opposed to this new stronger form of government (Drake 2001), feelings that are still evident in rural parts of Appalachia today.

Kentucky was designated a commonwealth and joined the United States as the 15<sup>th</sup> state in 1792. A large influx of residents confused land boundaries, creating feuds both within and between states. The early Kentucky government was corrupt. Land and tax rights were governed by justices of the peace, positions appointed by the governor. This only widened the existing economic inequality as many officials were in the pockets of the elite, a practice that still exists in parts of rural Appalachian Kentucky. Sentiments of contempt for the government and economic downturn are still evident in today's Appalachian Kentucky and other parts of rural, central Appalachia (Frontline 2006).

### Geography

The Appalachian Region of the United States is named for the ancient Appalachian mountain range that reaches from New York to Mississippi. The total area of the Appalachian Region is 205,000 square miles (ARC 2015) and includes portions of 12 different states including Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Virginia, and all of West Virginia.

The Appalachian Regional Commission (ARC) was developed in 1965 by an act of Congress and has since been part of the economic development of the region through partnerships with local, state, and federal government agencies. ARC divides the Appalachian Region into five sub-regions: Northern, North Central, Central, South Central and Southern Appalachia. Central and south central Appalachia contains the densest portions of impoverished counties, residents with the poorest health within Appalachia, and the most counties designated as having a physician shortage; therefore it will be the primary focus of this study (ARC 2015).

## Poverty

The Appalachian region as a whole has lower-than-average income rates in comparison to the United States and Central Appalachia has a considerably low income rate. Central Appalachia includes all of the Appalachian portions of Kentucky as well as parts of Tennessee, Virginia, and West Virginia. The per capita income for the entire Appalachian region is 81.8 percent of the US average, while the Appalachian portion of Kentucky is only 65 percent of the US average. Appalachian Ohio counties have a per capita income of 75.8 percent of the US average, Appalachian Virginia's per capita income is 74 percent, Appalachian Tennessee is 79.6 percent, North Carolina 77.8 percent, and the state of West Virginia is 79.4 percent (ARC 2015). Poverty rates are in tandem with income for the Central Appalachian regions. Appalachian Kentucky leads the nation in the highest levels of poverty at 163.8 percent of the national poverty level. Other Central Appalachian states also have poverty rates considerably lower than Appalachia as a whole and the United States. Appalachian North Carolina's poverty rate is 122.6 percent of the national level, the highest aside from Appalachian Kentucky and Appalachian Ohio has a poverty rate 114.2 percent of the national average, the lowest rate in Central Appalachia (ARC 2015).

The declining economy in southeastern Kentucky can largely be attributed to the decline in coal mining. Coal has been the foundation of central Appalachia's economy since the early nineteenth century. A series of economic booms and busts in the coal industry since then has ended more recently in a permanent decline of coal mining jobs. A result of cheaper natural gas and modernized mining equipment requiring less laborers, the job losses have ravaged the economy and spiked unemployment rates over the last decade (Valentine 2016).

## Education

The educational level of central Appalachian residents is much lower than that of the rest of the Appalachian region and the nation. The ARC reports (2009-2013) only 12.7 percent of adults age 25 and older in central Appalachia have a bachelor's degree or more. In Northern, North Central, and Southern Appalachia at least 22.2 percent of the population has a bachelor's degree and South Central Appalachia has a rate of 18.4 percent. The national average for those with at least a bachelor's degree is 28.8 percent. The educational contrast between sub-regions are vast, however there are also stark contrasts within central Appalachian states. For example, in non-Appalachian portions of Kentucky 13.9 percent of the population has less than a high school diploma and 24.7 percent have a bachelor's degree or higher while in Appalachian portions of Kentucky 25.2 percent have less than a high school diploma and 13.3 percent have a bachelor's degree or higher (ARC 2014)

## Barriers to Healthcare in Appalachia

Appalachians endure disproportionately poor health in comparison to the rest of the country (Behringer and Friedell 2006). Women in Appalachia are at particular risk of experiencing barriers in obtaining healthcare for themselves and their families, including the availability of and access to physicians, cost of treatment, trust of doctors (especially those considered outsiders), and health literacy rates (AMA 2007; McGarvey et al. and Cohn 2010).

The World Health Organization (WHO) lists some of the primary indicators of health as income and social status, education, physical environment (including employment), social support networks, genetics, health services, and gender (2016). Appalachian women are

generally at risk in the majority of these indicators simply because they live in the Appalachian Region.

### Availability and Access

The overall socioeconomic status of a population is an indicator of its general health (Escarce and Kapur 2006). Central Appalachia has a low socioeconomic status compounded by a shortage of physicians and the country's most severe health problems (Baldwin 1999), a concern that has gotten better in parts of Appalachia in recent decades but continues to be an issue for those in rural areas. As in many parts of the world, absolute contrasts exist in the socioeconomic status within populations as much as between populations in Appalachia.

Rural populations must overcome additional barriers when accessing healthcare. Rural portions of Kentucky, for example, had a primary care physician to patient ratio of 1 to 2,251 while the urban areas had a ratio of 1 to 1,452 in 1995 (Baldwin 1999). Although these numbers have gotten better over the past couple of decades, the lower number of physicians available to populations in rural areas compared to urban areas remains a significant problem. Rural parts of Appalachia can be especially geographically isolated. Forty-two percent of Appalachians live in rural areas (Wilson et al. 2012) and 70 percent of rural counties in Appalachia are designated as overall health professional shortage areas (Welch 2011).

### Cost

Income plays a role in practically every facet of one's life, influencing decisions made on a daily basis about everything from the food we eat to the stress we encounter. Many Appalachian women are in low-income households and are at risk for making poor healthcare

decisions based on their financial means. The Kaiser Women's Health Survey (2011) reported that 24 percent of women across all income categories reported delaying or going without medical care they thought they needed due to cost. When broken into categories by poverty level, 46 percent of women with income less than 100 percent of the poverty level reported delaying or going without medical care they thought they needed due to cost, while for those women who were at or above 300 percent of the poverty level this number was only 11 percent. This is particularly relevant to the population under study for this project due to their generally low income and high rate of poverty (Ranji and Salganicoff 2011).

### Health Literacy

Poverty has an impact on many different aspects of an individual's life, including a concept known as health literacy (ARC 2015). Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Kutner, Greenburg, Jin, and Paulsen 2006: 3) and is an important concept to consider when trying to understand how and why people make the healthcare decisions they do.

A general knowledge of healthcare is required to navigate the healthcare system, and there are specific demographic groups at risk of inadequate healthcare due to this lack of knowledge. In 2003, the U.S. Department of Education and National Center for Education Statistics measured health literacy in adults (Kutner et al. 2006). Participants were measured based on four performance levels, with scores ranging from 0-500: *below basic (0-184)*, *basic (185-225)*, *intermediate (226-309)*, and *proficient (310-500)*. Scores were based on whether or not they could complete a given task, the difficulty corresponding to performance level.

Education was highly correlated with health literacy scores. The average score given to respondents with less than a high school diploma was 184, the upper-end of the lowest *performance* category, and only 1 percent of respondents in this group scored *proficient*.

For respondents with a bachelor's degree, the average score in health literacy was 280, well into the *intermediate* category, and 27 percent of these respondents scored *proficient*. Only 12.7 percent of central Appalachian residents have a bachelor's degree or more, compared to 28.8 percent of the United States (ARC 2015). Overall, for each increase in a respondent's level of education their score also increased (Kutner et al. 2006).

Poverty was correlated with health literacy scores as well. The average score for respondents living below the poverty threshold was 205 while those living at or above 175 percent of the poverty threshold had an average score of 261. The average score of respondents increased as their percentage above the poverty threshold increased (Kutner et al. 2006).

Health literacy is important to understand and address for a variety of reasons. An understanding of instructions from healthcare providers, prescriptions, care for chronic conditions and preventive care are all contingent upon health literacy (Parker and Jacobson 2012). According to the National Academy of Sciences, "poor health literacy is a stronger predictor of a person's health than age, income, education level, employment status, and race" (Parker and Jacobson 2012: 1). Considering the significance of demographics as predictors this is a powerful statement.

### Trust in Physicians

Trust is not only a barrier to obtaining healthcare in Appalachia, it is also a critical factor in patient-physician communication, patient adherence to doctor's orders and medications, and

the use of preventative care by patients (McAlearney et al., 2012; Nelms et al. 2014). The Appalachian population has historically been less trusting of both outsiders and medical personnel (Nelms et al. 2014). This creates a double-burden for physicians migrating to the region for experience in rural health. There has been an influx of foreign physicians in rural Appalachia in recent years. This is largely due to benefits that are given to physicians willing to practice in parts of Appalachia designated as having a significant physician shortage. The ARC has one such program in which physicians willing to practice for at least three years in rural Appalachia may have immigration requirements that are typically required for foreign-trained physicians to practice in the United States waived, known as the ARC J-1 Visa Program (ARC 2015). While this is an attempt to supply Appalachia with much needed help with the severe physician shortage faced by some areas, the issue of trust in physicians, particularly those who are foreign, and often only temporary can be deterring to patients.

## Women and Healthcare

### Women as Gatekeepers

According to the US Department of Labor (2013), approximately 80 percent of the healthcare decisions in families are made by women. Women not only care for themselves when they fall ill, but are also caring for their children, spouses, and oftentimes other family members such as aging parents.

As the cost of healthcare rises, income for working-age women remains stagnant. Working mothers are often at an increased disadvantage when their children fall ill. Forty-eight percent of working mothers miss work when a child falls ill and 47 percent of those do not

receive pay (Ranji and Salganicoff 2011). This can be especially difficult when the woman is also the primary breadwinner, an increasing situation in American households. In 40 percent of households with children under the age of 18, women are the sole or primary breadwinner, and 60 percent of these families are headed by single mothers (Matoff-Stepp et al. 2014).

The burden of this responsibility for low-income women is especially difficult. Jobs paying low wages offer little or no health coverage, placing a double burden on women as they try to obtain healthcare.

In 2010, 48 percent of working-age women – an estimated 48 million people – reported that because of cost they did not fill a prescription; skipped a recommended test, treatment, or follow-up; had a medical problem for which they did not visit the doctor; or did not see a specialist when needed – an increase from 34 percent in 2001. (Robertson and Collins 2011: 6)

The trend of delaying or neglecting treatment due to cost is more prevalent among women who are at or below the poverty level, and women without the resources to obtain appropriate healthcare are likely to turn to other sources, such as friends and family or the internet.

### Technology and Healthcare

The internet is a popular tool in obtaining healthcare information. The majority of adult internet users, about 79 percent, have searched for health information online in the past year, most of those being women. Seventy-nine percent of female internet users have looked up health information online, compared to 65 percent of male internet users (Pew Research Center 2014; (Madden and Zickuhr 2011). The internet is more accessible than ever before with the increased availability of mobile networks such as smart phones. More than half of US adults who own a

smartphone use it to search for health information and 1 in 10 have a healthcare app on their phone (Pew Research Center 2014).

The increase in internet accessibility has resulted in a surge in social media use as well. Women in particular influence and are influenced by healthcare decisions through the use of social media. Almost 70 percent of females who use the internet use a social media website, and almost half of all people on social media reported information from those sites would affect their healthcare decisions (Fox 2011).

## CHAPTER 3

### METHODOLOGY

#### Focus Groups

The four focus groups held for this study were located in Perry County, Kentucky; Smyth County, Virginia; Unicoi County, Tennessee; and Washington County, Virginia. The sites were chosen due to their location in central and south central Appalachia. Each focus group consisted of between five and ten women and lasted a total of 60 to 90 minutes. Food and beverages were offered as well as \$25 in cash to each participant as a show of appreciation for their time and attention. Dr. Kelly Foster was the moderator for each focus group.

#### Moderator Guide

The moderator guide used at each focus group was developed through a collaborative effort among myself, Dr. Foster, and other students in the larger research project. An extensive literature review was performed on the main topics of interest, such as the way healthcare decisions are made by Appalachian women and the role technology plays in these decisions. As we brought in articles and held discussions, there were several themes that emerged and were later considered when constructing the moderator guide. Based on published literature, Appalachian women were facing multiple barriers when attempting to access healthcare. Therefore, we decided to include some of the more prevalent barriers in the moderator guide, including cost, access, availability, and the quality of healthcare providers. Additionally, home remedies seemed to be popular in Appalachia, so this was another topic we included. Through

the literature review, we discovered women were making the majority of healthcare decisions in their families and the internet was a key part of their choices. Therefore, we decided the role of the internet and social media in the process of healthcare decisions would be a central theme. We wanted to know whether they were going to the internet when illness first presented, and if they were, were they substituting it for a doctor's visit? We were also curious as to whether or not women were posting their health issues on social media, such as Facebook, and if so were they getting advice?

Over the course of four to six weeks of literature review and discussions, our team constructed the moderator guide. A mock focus group was used to test the instrument and make final revisions. After the mock focus group, it was clear that there were certain topic areas that were going to require more discussion during the actual focus groups. For example, it seemed that the issue of trust came up repeatedly in different circumstances throughout the mock focus group, so in the final moderator guide we expanded the areas for discussion on trust. The same moderator guide was used at each focus group to ensure consistency (see Appendix A).

### Criteria for Selection

The criteria used for selection of the participants involved five basic conditions. The first condition for selection was gender. We were looking at females only in this study due to the fact that women make most of the medical decisions in families (Fox 2011) and utilize more health services than men (ARC 2015). Second, participants had to be at least 18 years old although we loosely preferred women 25 years and older as they are more likely to make healthcare decisions for themselves and potentially family members as well. Third, we wanted to ensure our participants lived in central and south central Appalachia, therefore we recruited from counties

within the region. Fourth, we wanted to make sure participants had a sufficient family history and likely identify as Appalachian, thus required women to be at least a third generation resident of the Appalachian region. Lastly, a significant part of the study was looking at the effects technology has on medical decisions, therefore it was required participants use the internet at least three times per week. A screener was used (see Appendix B) during recruitment to ensure that each participant met all conditions.

### Recruitment

Recruitment was accomplished through a variety of methods including flyers, face-to-face, traditional media like newspapers and radio public service announcements, and through social media. The flyers (see Appendix C) were posted on Facebook through the ETSU Department of Sociology and Anthropology's Facebook page and through the Facebook page for the Applied Social Research Lab (ASRL). Flyers were also printed and copies distributed at various stores and public places in counties where the focus groups would be held. Personal contacts were used in some locations through phone calls and e-mails as a recruitment strategy. Face-to-face recruiting was also utilized by myself and others by going to locations and talking to potential participants from local public places, such as grocery stores and convenient stores, where we would also leave flyers. Once contacts were made with potential participants and they agreed to participate in the focus groups, either face-to-face or phone calls to the ASRL, they were screened according to the criteria and their contact information was gathered. Final participant selections were contacted two days prior to the corresponding focus group to confirm attendance.

## Coding

The focus groups were audio-recorded and later transcribed by an independent professional transcription company. Additionally, I took notes at each focus group. The transcriptions and notes were used for qualitative analysis. There were particular themes that I coded for based on information we were seeking as well as themes that emerged through open coding. The software program NVIVO version 11 was used to keep coding organized and easily accessible. I developed a total of seven major codes and 37 sub-codes (see Appendix D). Analysis and results revealed five major themes among focus group participants.

## CHAPTER 4

### RESULTS

#### Coding Scheme

The seven main codes found throughout qualitative analysis of the focus groups were: 1) source of health information, 2) the internet and health information, 3) social media, 4) barriers, 5) trust, 6) what health information they are using the internet for, and 7) the type of health facility used.

A major theme I was searching for when conducting the focus groups was the source of health information Appalachian women were using. Through the focus groups I learned these sources included coworkers, friends, family, the internet (health websites such as WebMD) and Google, social media sites, doctors, pharmacists, and previous experience for things like a common cold or allergies.

The role of technology in healthcare information and decisions was of particular interest and the internet turned out to be a popular choice. Questions that were asked in the focus groups were “do you use the internet regularly to search for health information?” and “does this have an impact on your healthcare decisions?” I discovered that the major reasons women were going online for healthcare information was to *look for doctors or specialists in their area*, to *verify or understand a doctor’s orders*, to *understand and gather more information on prescriptions*, to *look up home remedies*, to *look for support groups* and often to do a *primary search* for specific information related to symptoms they were having.

According to the Pew Research Center (2014), 87 percent of Americans are using the internet and 76 percent of females who use the internet are using social networking sites such as Facebook. This is consistent with what we experienced in each of the focus groups. Regardless of age or location, all women with the exception of two across all focus groups used social media. The use of social media in reference to health information brought about several sub-categories including: *posting for personal health information or advice, not posting for personal health information or advice, posting in closed groups, passive uptake of health related information, reading health articles on social media, not reading health articles on social media, and friends posting on social media.*

Although there seemed to be countless sources of healthcare information and the uses of the internet and social media were prevalent, there were several barriers to accessing medical care referenced in each focus group. Barriers to receiving healthcare were *cost, insurance, trust, the quality and quantity of doctors and healthcare facilities, and access* (such as transportation issues).

Trust was a barrier in receiving healthcare that emerged in analysis, however it was such a prevalent topic in many different aspects of healthcare that it was expanded on and developed as a code itself. Sub-codes of trust were *trust in doctors, no trust in doctors, and doctors are just in it for the money.*

The reasons participants are using the internet in terms of seeking health information varied. Aside from primary searches for healthcare information, other themes emerged including *use of the internet to look for doctors or specialists, verify and understand the doctor's orders, understand and gather information on prescriptions, look up home/holistic remedies, and search for support groups* on specific illness or topics such as breastfeeding and cancer.

A final topic that was added on was the type of healthcare facility participants were utilizing. Whether or not a participant went to the *emergency room, a walk-in-clinic, a family practitioner, or specialist* may have been due to availability or cost and seemed to play a key role in their experience.

### Analysis

I found five major categories emerged when I examined the coding scheme holistically. They include: *justifying the health information choices made, trust and distrust of doctors, reading health articles on Facebook and a passive uptake of that information, and the role of social media and health advice*. The barriers women face when trying to obtain healthcare information is a noteworthy part of this section, as it is intertwined with the reason women utilized these sources of health information.

### Justifications for Health Information Choices

Participants had a variety of motives for choosing the source of health information they do and the barriers they faced when deciding whether or not they should see a doctor. Although specific choices were made based on their individual situation, the larger picture shows similar trends in rationale. The internet, doctors, knowledge acquired from previous experience, home remedies, and family and friends were the most popular choices. Each will be examined in terms of the rationales given by participants for their utilization.

Internet. One of the primary goals of this project is to determine the extent to which at-risk women are using the internet to self-diagnose for themselves or a family member in lieu of

going to the doctor. I did not find this to be the case in the focus groups. Even so, the internet was the most cited source of health information throughout all focus groups. WebMD was the most commonly used website for health information and Google was the most popular search engine. Some participants, coworkers and mother-daughter pairs, accused each other of being “Google Doctors” or of having their “Google MD,” alluding to the fact that they are going online and looking up symptoms to try to diagnose themselves. The most popular reason for going online in reference to health information was to do a preliminary search of symptoms the participant or one of their family members had been experiencing. Although few participants were using the Internet exclusively to diagnose themselves, it was often used as a supplement before and/or after seeing a doctor. As one participant in the Kentucky focus group said:

I’m trying not to do it as often now, but I still do especially with my daughter. If there’s something new that is something that I haven’t seen before, I’m up all night, and I’m searching. I’m on Google and WebMD and all that stuff... And I freak myself out. Then I call the pediatrician, and he says, “I told you not to do that.” Or I’ll go to him and say, “This is what’s going on,” and he’ll say: “I’m going to test her. I’m not telling you what kind of tests I’m doing.” Because he knows I’ll go to WebMD and Google it, or I’ll Google it or something, and I scare myself.

Another participant was more straightforward in her reasons for going online before going to the doctor, “That’s why we go to WebMd, so we know what we're doing when we get to the doctor and they're not telling you all the stuff...”. Interestingly, an underlying concern in her comment is the issue that she does not trust what the doctors are telling her. This is a significant theme among participants and one that is discussed in detail later.

Participants expressed interest in utilizing the Internet to look up symptoms particularly when the symptoms were unusual. One participant explained, “If it’s just a common something that you’ve had before, then I may not look it up, but if it’s something weird that’s going on, then the first thing I do is Google it and see, okay am I dying or what is this.” Many others shared her opinion and were more likely to go online to look up symptoms if it was something they were unfamiliar with.

Finally, another reason several participants went online was to look up medications. Participants who were not familiar with a medication that was prescribed to them or who needed help in deciding what type of over-the-counter medications would be appropriate for them or a family member were likely to use the internet to search for relevant information.

Doctors. Seeing a doctor when illness occurred was not a first option for most participants, however it was a popular source of health information, second only to the Internet. Calling the doctor before going in to be seen was something many of the participants said they did. One participant referred to calling the doctor after going on the Internet, she said “It scares you, so then you call the doctor to make sure you don’t have none of those things that’s on the web.” Another said “I don’t immediately go to the doctor, but when it gets to the point we feel we have to, we call the doctor’s office and say should we come in?”

An interesting concept that surfaced in all four focus groups was online doctors and over-the-phone doctors such as *Teledoc*. Based on what you tell doctors over the Internet or telephone, they diagnose you and send a prescription to your pharmacy. This was an option that most of the participants liked due to the convenience of getting a diagnosis and proper medication without the hassle of going to a doctor’s office. However, it was expressed that this would be convenient

for more common illnesses. One participant explained a scenario in which it would be helpful to her:

If it was something you had if you were prone to sinus infections and you knew you had a sinus infection, just dial her up and say symptoms, and she's comfortable with it and she asks you whatever questions she needs to and she calls in your antibiotic or whatever, that would be wonderful.

Others agreed that the service would be useful for more common and familiar ailments, however for more serious illness or unfamiliar symptoms it would be better to see a doctor in person.

Typically, participants go online or sometimes ask family and friends before resorting to the doctor due to multiple barriers they had to overcome in order to be seen. These barriers included the quality of local doctors, the cost of seeing a doctor, and lack of insurance.

A significant barrier named when trying to see a doctor was the quality of local doctors. Respondents expressed frustration and gave numerous examples where doctors were inattentive, cold, impersonal, rushed, and incompetent. One participant gave her opinion of the quality of doctors in the area:

I've had four kids: two girls and two boys. My mom was diabetic. She had problems. Then I took care of an elderly lady. If I don't like what one doctor says, I go to somebody else. Some of the doctors we don't like around here. We seem to get some of the bad doctors in eastern Kentucky that nobody else wants.

There was an abundance of similar opinions and personal stories. Participants often felt rushed and even "burdensome" to their healthcare provider. As one participant said, "I feel like I'm infringing on their time, especially just the regular doctor. I feel like it's in and out."

Some participants felt the doctors were incompetent due to the lack of attention to the patients and their rushed, impersonal mannerisms. Another participant tells her story:

I went to the ER. He gave me the Z-Pac and sent me on my way. The next morning, I woke up and it's worse. The welts were worse. They were bigger. My eyes had swollen. My hands were swollen. I had to go back for the same exact thing, and then they kept me overnight for observation. But, yes, you shouldn't have to go twice in a row for the same thing.

The quality of local doctors was a significant barrier in seeking healthcare and a major reason participants used the Internet for health information. Not far behind quality was the issue of cost.

When asked what role cost played in their decision to see a doctor, one respondent said "It plays a factor whether you jump right out there and go or try to tough it out." Many women agreed that cost is the deciding factor in how long they wait before seeing a doctor, if they see one at all. The cost of seeing a doctor varies, however it is rarely cheap or affordable, particularly for residents of central Appalachia who are generally poor with less disposable income. For those who have insurance, fears of high co-pays and perceptions of greedy insurance companies who would work with the doctors to collect as much money as possible were other barriers to seeking care. One respondent explained:

I had went to my oncologist and I wanted them to do the genetic testing, which is in their same office. I said, "Okay, when I come back for my next appointment, let's schedule both appointments at the same time," and they wouldn't because the insurance company would not get two copays, one for the visit and one for the genetic trait. Did I ever go back to get the genetic? No, because you can't take off that much work.

Other participants agreed that doctors were known to schedule two different appointments if there were two issues they needed to be seen for, rather than address both in the same visit. This was a way for the insurance companies to collect two co-pays.

Most respondents agreed that besides co-pays for doctor's office fees, missed work was a factor in seeing the doctor. Many respondents did not have a job that gave them paid sick time. Missing a day of work when living paycheck to paycheck could be the difference in getting a bill paid or not. One respondent said "Sometimes it's not just a co-pay it's a matter of getting off work. That's a resource you have to think about," and nods around the room indicated most others agreed. Not only were they paying out high co-pays or office visits, they were also losing money in the form of missed work.

Along with cost and issues of missed work, lack of insurance or insurance with a small number of in-network providers and high co-pays was another common barrier to healthcare in the focus groups. One participant commented, "Whether you have insurance or don't. Or even if you have the insurance, can you afford the \$75 copay to go to the emergency room? I think, especially in this economy now, it's, 'can I afford it?'"

Those who have insurance don't always benefit due to copays and deductibles. Those without insurance are at an even higher risk of not seeing a doctor and getting proper medical treatment. One participant spoke about how health insurance through her husband's job is so expensive that he would basically be working to pay for insurance. Another told of how their income is barely above the limit required to get state insurance, such as Medicare or Medicaid, yet they cannot afford private insurance. The consequences of not having any insurance can be risky as many women said they simply did not go to the doctor and would try to "wait it out" at home. One participant describes her experience:

I called Dr. Brown's office, and they said, "Well, it'll be \$50 for you to come in." I thought, I'll just deal with it. I'll just go and buy a whole bunch of stuff and slather it all over me and hopefully I'll get through it. That's what I did. You just live with it until it's gone.

Oftentimes an illness can be taken care of at home, however there are times when a doctor is necessary. If women are having problems seeing a doctor when they are sick, it is unlikely they are going to the doctor for things such as preventive care, putting them at greater risk for future chronic illness and adding to an already over-burdened healthcare system.

Knowledge Acquired from Previous Experience. An important factor participants alluded to when making healthcare decisions was previous experience. Every participant in the focus groups referred to drawing on previously acquired knowledge through experience with certain symptoms or illnesses and that definitely had an impact on their willingness to engage with medical professionals. There were some participants who used their experience as their only source of information in caring for themselves or a loved one. Typically, this included non-serious symptoms and ailments such as allergies and colds. Comments included "you can just diagnose yourself," "as you get older you know more about what's going on" and "moderation [in] self-diagnosing is ok for small things." If symptoms persist or were unfamiliar, participants reported it is at that time they would go a step further and utilize the Internet or doctor.

Drawing on previous experience was not an initial source of health information I was coding for, as it is not an actual, physical source of health information. However, as I was coding, a substantial portion of comments were those related to prior knowledge of treatments for health problems and was often the deciding factor in whether or not to see a doctor. A key

part of previous experience is home remedies that are passed down through generations to be used for basic healthcare.

Home Remedies. Home remedies were the third most talked about source of health information, behind the Internet and doctors. Often home remedies were passed down through the family, however some reported looking them up online. The focus group in southeastern Kentucky referenced home remedies almost four times as often as the other focus groups and there was a larger variety of home remedies mentioned in the Kentucky group. In the other three focus groups in Marion and Bristol, Virginia and Unicoi, Tennessee, the home remedies mentioned were more commonly known and not utilized as often. For example, eucalyptus leaves for pain, essential oils for sore muscles, and honey for colds were among the few specific remedies mentioned. In the Kentucky group there were 17 specific remedies mentioned, many of them said to cure multiple health conditions. This is not surprising considering southeastern Kentucky sits in the heart of central Appalachia and is often cited as the most rural and traditional compared to other parts of the region (ARC 2015). This is also evident in the fact that this particular focus group had the highest dissatisfaction and least amount of trust with their local medical community.

Moonshine was quite popular and reported to cure numerous ailments within the Kentucky focus group, as one respondent said “our dad always took moonshine and made cough medicine out of it. Anything that you could buy over-the-counter for an illness, our dad had a remedy using moonshine”; another comment followed “It’s strong; and if it’s done right, it’s good and strong, and it kills everything. It burns it out: toothaches, sore throat.” Many participants had family members who drank vinegar, rubbing alcohol, or ate Vick’s VapoRub.

Yellow root, Bloodroot, Ginseng, Elm, Catnip tea, and Birch tea were all cited as first aid treatments or cures for various ailments.

Family and Friends. Family and friends were a common source of health information for the focus group participants. Younger participants particularly expressed reliance on their mothers for advice as a first source of information. When asked broadly what the process for getting treatment for a health condition was when sick, the following exchange occurred:

**Respondent 1:** I'm going to be honest. I ask my mom. I'm still at that age. I'm 23, so I still ask, "Mom, what do I do?"

**Respondent 2:** That's me.

**Moderator:** You guys call Mom.

**Respondent 1:** Call Mama and Mama knows. "My mom probably should know this."

**Moderator:** What do mamas do?

**Respondent 3:** I am Mom. If it's something that needs a specialist, if I think something's wrong with one of my kids who needs... I ask around. I talk to the people I work with and say, "Who's good at this," or, "Who can I bring..."

This was an interesting exchange as the daughter asks her mother for health advice, who in turn asks friends. Mothers were a popular source of health information and were referenced as a source of advice more than sixty times throughout the focus groups.

A pattern that was observed throughout the focus groups was not only asking family and friends, but asking family and friends who were specifically in the medical field. Most people knew someone close to them in the medical field and felt comfortable asking them for healthcare advice. A participant from the Marion, VA focus group stated:

The nice thing is we're in Appalachia, we're a small community, everyone knows everyone, so at least you can call somebody. It is either a parent or a friend or, "Hey, I do know a doctor." Probably everybody here can say that they know one doctor, at least somewhat personally. That you would say, "Hey, if your children needed to get..."

She trailed off as others spoke up agreement.

Participants often used friends and family in conjunction with the Internet to guide their choices in whether or not to go to the doctor. As another participant explained:

I like WebMD. I go there for a lot of stuff. If the kids are put on a new medicine or I'm going into town and the kids are coughing, might as well stop by because they're fairly quick, where I go. Yes, I stop by, and they'll put them on medicine, and I'll say, "They have this and this". And I'll go home and search the medicine. I'll search all this different stuff and go from there. A lot of times, I'll just go ahead and take them to the doctor and go from there. (*Laughs.*) If it's little stuff or if I think it's really bad, I'll always ask *her* [her mother was present at the focus group and is who she was referring to].

Friends and family were the fourth most referenced source of health information and were often used in conjunction with the Internet or as a precursor or follow up to the doctor rather than a sole source of information.

### Trust and Distrust in Medical Professionals

Trust in healthcare providers was a concept I was interested in from the beginning. Throughout the focus groups trust emerged as a significant factor in when and where women decided to see a doctor. Previous literature indicates trust is oftentimes a deciding factor in the degree of healthcare sought as well as the extent to which provider's instructions are followed

(McAlearney et al. 2012). There were a few participants who expressed trust in their primary care practitioners, however the vast majority did not trust local doctors and oftentimes felt they were simply “in it for the money.”

There was a general consensus among focus group participants that distrust played a factor in decisions on how they would go about treating a sickness or ailment. As in all focus groups, the topic of trust came up repeatedly. In reference to trust of physicians, one Kentucky focus group participant replied “I don’t trust them. I’m not going to tell them anything. I don’t believe them.” There was some agreement and as one conversation progressed, another participant said “That’s why we probably try to doctor ourselves first.”

Similar conversations occurred at the Bristol, Virginia focus group where one participant was very leery of her local hospital and doctors:

I tell all my friends, don't let friends and family stay in their hospital by themselves. I know there are nurses there that mostly take good care of you, but do not leave an individual alone in a room in a hospital. They need someone there to watch out for them and take care of them.

Local healthcare providers in the rural areas where most participants lived were not trusted as much as doctors in larger cities, as another participant explained:

I would feel like if I were to see not a particular doctor but just any local doctor in this area, and I’ve seen it with my own family members, they would go in, have no idea what’s wrong with them, sick for two weeks, nobody can answer anything, and then they’re like, “Oh, well let me give you this antibiotic and you just go on your merry way and we’ll see if that helps. If not, we’ll bring you back and then I’ll charge you another co-pay and then we can do it again.”

Comments such as “my doctor, I don’t trust” were common and frequent during discussions on trust in healthcare and determined to be an integral part of the decision-making process as it relates to healthcare.

Trust in Physicians. Although distrust was significant and pervasive in the focus groups, there were some doctors that participants did trust. Pediatricians, regardless of their location, were trusted. No one had anything negative to say about pediatricians and when positive comments were made, there were head nods and agreement. In the Marion, Virginia focus group, participants were asked “do you trust doctors around here?” and an immediate response was “just the pediatricians;” there was head nodding and “I agree,” “yes” remarks made in support of this notion. One participant went into more explanation, “They were my doctors, and the pediatrician side of it, they really just seem like they’re there more for the right reason and to actually dig and find out what’s wrong with my child.” Mothers indicated they were also much more likely to take their child to see the doctor than they are to see a doctor themselves. There was complete agreement that if the women themselves got sick, they are more willing to wait it out than if their child gets sick. If their child is sick, they are taken to the doctor without hesitation. One participant sums it up with “Moms come second. Kids come first.”

Another group of doctors who were trusted more often were specialists. Some participants suggested since specialists are likely caring for more serious conditions they are taking their patients more seriously. One respondent said her “Gynecologist is much more attentive” and another followed with “Specialists will be just a little more attentive, especially if you’re being referred.” There was collective agreement that specialists spend more time with their patients and are to be trusted more than general practitioners.

Doctors in it for the Money. Over the course of the four focus groups, there was an emerging theme that, although is related to quality and trust of doctors, was distinct enough to stand out. Particularly in the Unicoi, Tennessee focus group, participants thought the educational foundation of some of today's doctor's was based more on a business model than a patient-centered, caring model and that technology is playing too large of a role in the knowledge they should obtain:

They're taught so much different now, it's like they come out on an assembly line and aren't as caring about their patients or knowledgeable. They're so dependent on technology, they won't do anything without it, it seems. Everything is electronic so when computer goes down, they don't know what's going on and can't do anything. They sit there the whole time on their computers like they just don't care.

It was voiced that doctors work with insurance companies to see as many patients as they can in a day, contributing to the rushed and hurried nature of office and emergency room visits. As one participant in the Marion focus group said, "They're reviewed on how many tests they've had ordered, prescriptions written. Which is really sad." Another participant in the Bristol focus group said "Yes, they probably don't always care. It's the money and maybe 8 or 10 patients an hour."

Cost in general was an issue for most of the participants, and many of them thought the cost was exasperated by the greed of doctors and insurance companies. It was a barrier that stood in the way both financially and emotionally for many of the participants and a reason many of them would give for not seeing a doctor.

## Social Media and Health Information

From the beginning of the project, the effects of technology and social media on healthcare information was a factor I wanted to explore. I knew from literature that women gave and received support from online communities and social media. This support was also influential in healthcare decisions they made for themselves and their families. (Fox 2011). California Healthline (2012) reported almost half of Americans were using social media websites to get advice on health conditions and obtain healthcare information. Interestingly, I found that although women in the focus groups mostly denied posting or gathering health information from social media, throughout further conversation we learned they actually were obtaining health information from Facebook, just in a more passive manner.

When asked in the Bristol focus group “Would you ever put that sort of stuff on your general Facebook page or would you ever reach out and ask people what to do generally on your Facebook page?” the answers were “no,” “no,” “no,” and “I don’t.” This was common in all groups: no one reported posting on social media asking for healthcare advice unless it was in a closed, personalized group such as a *cancer survivors* or *breast feeding* support group.

Participants did report seeing friends sometimes post on Facebook asking for more personal advice on a health issue. A respondent from the Kentucky focus group commented:

Both of my kids, I have several of their classmates’ parents who are my friends on Facebook. If they get on there and they say, “So and so came home from school today, and he’s throwing up,” or, “He came home and took him to the doctor, and he has pinkeye,” I say, “Kids, this is what you do. Wash your hands. Don’t touch anything.”

This type of scenario, replying to a friend’s post offering health advice, was more common. A few participants reported they would talk to friends on Facebook about health issues through

private messages. One respondent described her communications when asked if she used Facebook for healthcare advice, “I don’t do it out there for everybody, but if I have a friend then I might private message and say I’m dealing with afib, what do you think about that?”

Based on the focus groups, it did not appear that overall posting about personal health problems or reading about them from friends were very common. There seems to be some acknowledgement that Facebook pages are open for more general consumption and a desire to limit the amount of personal sharing. However, reading health related articles that show up in their Facebook newsfeed or posted by friends was more common even if participants did not immediately recognize that they were actually readers of health related articles.

Health Articles on Facebook and Passive Uptake of Health Information. The Bristol focus group participants were asked “when you’re on Facebook and you’re looking through your feed and seeing stuff pop up, just browsing to kill time, do you ever see health-related stuff pop up?” and the responses were “sometimes,” “yes sometimes” and “I do.” Then they were asked “do you click on it and read it?” to which they answered “no,” “not really,” “sometimes,” and “not individual health-related stuff.” Some participants in other groups said they would read the articles if a friend had posted it, others would read it if it were from a trusted site such as the Susan G Komen Breast Cancer Foundation, and some would read the articles if the information was related to something they were experiencing. Many participants said they did not generally read health articles on Facebook.

As the conversation continued and more particular health-related articles were discussed, it became apparent that some participants actually were reading the health-related articles often whether it was directly relevant to them or not.

The pattern was apparent across all focus groups when the particular subject of the kissing bug was raised. According to the CDC (2016), the “kissing bug,” also known as Triatomine, are bugs that typically reside in rural parts of South America yet have been found throughout the southern half of the United States. The bugs can carry a parasite that cause Chagas disease (CDC 2016), however only about half of all kissing bugs in the United States carry the parasite and actual transmission requires the parasite to enter the body through broken skin, the eyes, or mouth (WHO 2016). Although the kissing bug is rare in the United States and the chances of being bitten by a bug carrying the parasite then having it enter the body are also rare (Lee 2014), it spread quickly on Facebook (see Appendix E). Websites such as warriorzen.com dramatized the threat of the kissing bug with the headline *Dangerous ‘Kissing Bug’ That Attacks Your Face Spreads to More than Half of U.S.* (Warrior Zen 2015). The article began with

A dangerous insect known as the ‘Kissing Bug’ which is notorious for attacking the faces of its victims and even killing them, has crawled its way into the United States, reported incidents in more than half the country. The kissing bug, which is also called the Triatomine bug, resembles a cockroach and sucks the blood from its victims’ faces. Death from the kissing bug is extremely rare, particularly in the United States. However, despite the fact that this is not really a problem here in the United States, virtually everyone in our focus groups had heard of or read the Facebook post on the kissing bug and were successfully quoting some of the information and misinformation. One participant who had not heard of it pulled out her cell phone during the conversation and did an online search. This is an indication that they were, in fact, reading health-related information online and that some passive uptake of information was happening. This is informative when considering public health campaigns that

involve social media. Perhaps they did not view something like the kissing bug as health-related, or they do not realize how often they do look at health information until conversations about it happen. Either way, there was a passive uptake of health information observed throughout all focus groups and with many participants.

Reading Health-Related Articles on Facebook. Most participants gathered their information not directly from Facebook posts, but from posts with health-related articles attached. As one participant reported:

If it's an article, it's typically for me going to be I think I possibly have this. That's the hypochondriac coming out. Oh, well my pinky hurt yesterday. Maybe I have this disease. (*Laughs*). If it relates to has your pinky hurt lately, I'm going to click on it just to see if I have something, (*laughs*) which I think is a bad thing to do because then it just leads you into worry.

Some acknowledgments of gaining health information came from specific types of posts on Facebook regarding weight loss ads. A participant in the Marion focus group reported "There's always weight loss things," to which another participant followed up with in detail:

Oh, I hate those things that pop up. It will show like a bunch of fruit in the picture and a big glass of water with some lemon and lime. And, then you don't want to ever. Then the heading will be so misleading. It will say something like, "Drink this every day to improve your life and health, blah, blah, blah." And, then when you click it, it's like a link to Dr. Oz and his BS or something.

This sparked another conversation on ads. Facebook ads with catchy titles and links to further information were sometimes viewed then considered unreliable, as one participant explained:

I've seen on fb where it might say something like "top ten symptoms of ovarian cancer" and if it's something I'm interested in I may click on it but it leads to a big black hole.

After a couple times you realize you don't get any credible information you don't do it anymore. Now I scroll past it because I know it'll just lead to a lot of advertisements.

Participants gathered health information from social media sites in a variety of forms. Only two participants did not have social media accounts, therefore did not use them as a source of healthcare information.

## CHAPTER 5

### DISCUSSION AND CONCLUSION

Appalachia embodies a unique culture bred from generations of independent and hard-working people, however the distinctions do not end there. Central and southern Appalachia contain some of the most poverty stricken counties in the country (ARC, 2015). The foundation of a community is its economy and it can affect all other aspects. Education and healthcare are inevitably linked to the economy and there is consistent correlation between the three. Therefore, it is no surprise that the status of healthcare in central and southern Appalachia is strained, creating difficult conditions for local consumers. Individuals are forced to make decisions between healthcare and other necessities due to the tremendous barriers they must overcome.

The purpose of this study was to understand the process and resources that women in Appalachia, who are making the majority of healthcare decisions for themselves and their family members, use and to what extent. Qualitative analysis of focus group content revealed women in Appalachia are using the Internet as a source of health information, yet they are not using it exclusively or in lieu of seeing a doctor as expected. The Internet is used as an initial source of information, then often a follow up to doctor's orders or prescriptions. Social media plays a role in the seeking of health information as well, however sites such as Facebook were more useful as a source of support but typically in closed support groups – not in general open postings. Most participants did not post on Facebook asking for personal healthcare advice, however, reading health articles that were interesting or relevant and sharing health advice in closed groups, such as cancer survivor's groups, was common.

There seemed to be a bit of reluctance on part of some of the women in the focus groups to admit to using the Internet as a source of health information. This was more pronounced in the older women with adult daughters in the focus groups who would “call out” their mothers for using Google before deciding to see a doctor. There was hesitation and quick glances around the room when asked about use of the Internet and social media for health information. Perhaps it is not socially desirable to look up healthcare information online because, at least in this study, participants would admit to being told by their doctors not to go online due to the overwhelming and “scary” information they were finding. Few participants admitted to telling their doctors they had searched their symptoms online, and those who did were comfortable with their doctors and expressed trust in them.

For those who did not trust their doctors, there was no mention of communication as there was when participants spoke of local pediatricians or doctors they did trust. There were conversations among participants about foreign doctors who were hard to understand due to a heavy accent, and who were discounted as trustworthy because of their often temporary positions. The qualifications of doctors were not a stand-alone issue; it was always imbedded in a conversation of trust. Due to distrust of outsiders, there is likely not much these doctors can do to earn trust in small communities aside from staying in practice beyond the required length of time and forming relationships with patients in the community.

It was clear how important trust was in seeking healthcare when women began to talk about their children. Pediatricians were trusted throughout all focus groups and there was no hesitation on the part of women when it came to decisions on their children’s healthcare. None of the barriers that women considered when it came to their own health were present when a child was sick. Perhaps this was part of being a mother and the seriousness of that role. Mothers

admitted to “waiting it out” or trying home remedies to avoid paying to see a doctor, or seeing a doctor they did not like, however this was not the case with their children. All mothers admitted to taking their child’s health more seriously and would always take them to the doctor if they were ill beyond something familiar, such as a cold. Overall, when trust was present other barriers were not as prevalent issue.

### Limitations and Directions for Future Research

Limitations to this research include the small number of focus groups conducted and a lack of discussion on mental health services. Central and south central Appalachia cannot be generalized based on this study alone. Future research could expand to include a broader geographic area with a larger number of focus groups to get a more generalized understanding of the impact of technology on healthcare. Additionally, mental health was not discussed in this study. Mental health is part of healthcare and would be an excellent way to expand on this study to understand the effects of technology on mental health and the barriers, particularly trust and the Appalachian culture, play on receiving mental healthcare services.

Despite these limitations, the information gained from these focus groups gives in-depth insight into the patterns of decision-making among Appalachian women in a world where technology and social media make health information readily accessible. Future research could address the impact of foreign doctors on trust between patients in rural Appalachia and the medical community. Research to understand the point of view from both doctors and patients on trust issues could reveal ways to negate the issue. There was mention throughout the focus groups of doctors asking patients not to go online to look up health information. The way this impacts the patient-doctor relationship and communication efforts on part of the patient should

be considered for future research as well. This study brought up unexpected notions of trust in the medical community and the impact it has on rural healthcare as well as the impact technology does and does not play on these relationships. Subsequently, the groundwork is in place for future research that could expand on these topics and make headway in the issues rural Appalachian residents face when trying to obtain healthcare.

## REFERENCES

- American Medical Association. 2007. "Health Literacy and Patient Safety: Help Patients Understand: Reducing the Risk by Designing a Safer, Shame-Free Health Care Environment." Retrieved March 1, 2016 (<https://www.pogoe.org/sites/default/files/Health%20Literacy%20-%20Reducing%20the%20Risk%20by%20Designing%20a%20Safe,%20Shame-Free%20Health%20Care%20Environment.pdf>).
- Appalachian Regional Commission. 2014. "Education - High School and College Completion Rates 2009-2013." Retrieved February 28, 2016 ([http://www.arc.gov/reports/custom\\_report.asp?REPORT\\_ID=61](http://www.arc.gov/reports/custom_report.asp?REPORT_ID=61)).
- Appalachian Regional Commission. (2015). *The Appalachian Region*. Retrieved February 21, 2016 (ARC.gov: [http://www.arc.gov/appalachian\\_region/TheAppalachianRegion.asp](http://www.arc.gov/appalachian_region/TheAppalachianRegion.asp)).
- Baldwin, Fred D. 1999. "Access to care: overcoming the rural physician shortage." *Appalachia* 32(2): 8-15. Retrieved February 20, 2016 (<http://eric.ed.gov/?id=EJ593803>).
- Behringer, Brude and Gilbert H. Friedell. 2006. "Appalachia: Where Place Matters in Health." *Preventing Chronic Disease; Public Health Research, Practice, and Policy* 3(4): 1-4. Retrieved February 20, 2016 ([http://www.cdc.gov/pcd/issues/2006/oct/06\\_0067.htm](http://www.cdc.gov/pcd/issues/2006/oct/06_0067.htm)).
- California Healthline Daily Edition. 2012. "Consumers turning to social media to search for health information." Retrieved March 02, 2016 ([californiahealthline.org: http://californiahealthline.org/morning-breakout/consumers-tapping-social-media-to-access-health-information/](http://californiahealthline.org/morning-breakout/consumers-tapping-social-media-to-access-health-information/)).
- Centers for Disease Control and Prevention. 2016. "Health Indicators Warehouse." Retrieved February 23, 2016 (<http://www.healthindicators.gov/Indicators/Selection>).
- Drake, Richard. 2001. *A History of Appalachia*. Lexington: The University Press of Kentucky.
- Escarce, Jose J. and Kanika Kapur. 2006. *Hispanics and the Future of America*. Retrieved February 24, 2016 ([http://www.ncbi.nlm.nih.gov/books/NBK19905/pdf/Bookshelf\\_NBK19905.pdf](http://www.ncbi.nlm.nih.gov/books/NBK19905/pdf/Bookshelf_NBK19905.pdf)).
- Fox, S. 2011. *Medicine 2.0: Peer to Peer Healthcare*. Pew Research Center: Internet, Science and Tech. Retrieved February 18, 2016 (<http://www.pewinternet.org/2011/09/18/medicine-2-0-peer-to-peer-healthcare/>).
- Frontline. 2006. "A Short History of Kentucky/Central Appalachia." Retrieved March 28, 2016 (<http://www.pbs.org/wgbh/pages/frontline/countryboys/readings/appalachia.html>).
- Kim, Eun-Jin, Loren V. Geistfeld, and Sharon B. Seiling 2003. "The Disenfranchised Poor: Rural Low-Income Women and Health Care Decisions." *Consumer Interests Annual* 49: 1-7. Retrieved February 28, 2016 (<http://www.cehd.umn.edu/FSoS/projects/ruralspeak/pdf/disenfranchised-poor-03.pdf>).

- Kutner, Mark, Elizabeth Greenburg, Ying Jin, and Christine Paulsen. 2006. *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy*. U.S. Department of Education: Washington DC: National Center for Educational Statistics. Retrieved February 29, 2016 ([http://nces.ed.gov/pubs2006/2006483\\_1.pdf](http://nces.ed.gov/pubs2006/2006483_1.pdf)).
- Lee, Jolie. 2014. "What is Chagas Disease (Spread by Kissing Bug)?" *USA Today*, August 5. Retrieved March 4, 2016 (<http://www.usatoday.com/story/news/nation-now/2014/08/04/kissing-bug-disease-chagas/13576845/>).
- Luce, Carolyn Buck, Sylvia Ann Hewlett, Julia Taylor Kennedy, and Laura Sherbin. 2015. "The Power of the Purse: Engaging Women Decision Makers for Healthy Outcomes." Retrieved February 23, 2016 ([http://www.talentinnovation.org/\\_private/assets/PopHealthcare\\_ExecSumm-CTI.pdf](http://www.talentinnovation.org/_private/assets/PopHealthcare_ExecSumm-CTI.pdf)).
- Ludke, Robert L., Phillip Obermiller, Jeff Jacobson, Thomas Shaw, and Victoria Wells. 2006. "Sometimes It's Hard to Figure: The Functional Health Literacy of Appalachians in a Metropolitan Area." *Journal of Appalachian Studies* 12(1): 7-25. Retrieved February 20, 2016 ([http://webcentral.uc.edu/eProf/media/attachment/eprofmediafile\\_1817.pdf](http://webcentral.uc.edu/eProf/media/attachment/eprofmediafile_1817.pdf)).
- Madden, Mary and Kathryn Zickuhr. 2011. "65% of Online Adults Use Social Networking Sites". *Pew Research Center*. Retrieved February 21, 2016 (<http://www.pewinternet.org/2011/08/26/65-of-online-adults-use-social-networking-sites/>).
- Matoff-Stepp, Sabrina, Bethany Applebaum, Jennifer Pooler, and Kavanagh. 2014. "Women as Healthcare Decision-Makers: Implications for Health Care Coverage in the United States." *Journal of Healthcare for the Poor and Underserved* 25(4): 1507-1513. doi: 10.1353/hpu.2014.0154.
- McAlearney, Ann Scheck, Jill M. Oliveri, Douglas M. Post, Paula H. Song, Elizabeth Jacobs, Jason Waibel, J. Phillip Harrop, Kenneth Steinman, and Electra D. Paskett. 2012. "Trust and Distrust Among Appalachian Women Regarding Cervical Cancer Screening: A Qualitative Study." *Patient Education and Counseling*, 86(1): 102-126. doi:10.1016/j.pec.2011.02.023.
- McGarvey, Elizabeth L., MaGuadalupe Leon-Verdin, Lydia F. Killos, Thomas Guterbock, and Wendy F. Cohn. 2010. "Health Disparities Between Appalachian and Non-Appalachian Counties in Virginia USA." *Journal of Community Health* 36(3): 348-356. doi:10.1007/s10900-010-9315-9.
- Nelms, Emory, Ling Wang, Michael Pennell, Mary E. Wewers, Eric Seiber, Michael D. Adolph, Electra D. Paskett, and Amy K. Ferketich. 2014. "Trust in Physicians Among Rural Medicaid-Enrolled Smokers." *The Journal of Rural Health* 30(2): 214-220.
- Parker, R. M., and K. L. Jacobson 2012. *Health Literacy Fact Sheet*. Emory School of Medicine and Public Health: National Academy of Sciences. Retrieved March 01, 2016

- ([https://iom.nationalacademies.org/~media/Files/Activity%20Files/PublicHealth/HealthLiteracy/HealthLiteracyFactSheets\\_Feb6\\_2012\\_Parker\\_JacobsonFinal1.pdf](https://iom.nationalacademies.org/~media/Files/Activity%20Files/PublicHealth/HealthLiteracy/HealthLiteracyFactSheets_Feb6_2012_Parker_JacobsonFinal1.pdf)).
- Pew Research Center. 2014. *Social Networking Fact Sheet*. Retrieved February 24, 2016 ([pewinternet.org: http://www.pewinternet.org/fact-sheets/social-networking-fact-sheet/](http://www.pewinternet.org/fact-sheets/social-networking-fact-sheet/)).
- Ranji, Usha and Alina Salganicoff. 2011. "Key Findings from the Kaiser Women's Health Survey." *Kaiser Family Foundation*. Retrieved February 21, 2016 (<https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8164.pdf>).
- Robertson, Ruth and Sara R. Collins. 2011. "Realizing Health Reform's Potential; Women at risk: Why increasing numbers of women are failing to get the healthcare they need and how the Affordable Care Act will help." Retrieved March 2, 2016 ([http://www.commonwealthfund.org/~media/files/publications/issue-brief/2011/may/1502\\_robertson\\_women\\_at\\_risk\\_reform\\_brief\\_v3.pdf](http://www.commonwealthfund.org/~media/files/publications/issue-brief/2011/may/1502_robertson_women_at_risk_reform_brief_v3.pdf)).
- US Department of Labor Employee Benefits Security Administration. US Department of Labor. 2013. "Fact Sheet: General Facts on Women and Job Based Health." Retrieved February 21, 2016 (<http://www.dol.gov/ebsa/newsroom/fshlth5.html>).
- Valentine, Katie. 2016. *New Bill Would Clean Up Abandoned Coal Mines And Jump Start The Appalachian Economy*. Retrieved March 28, 2016 (<http://thinkprogress.org/climate/2016/02/04/3745852/reclaim-act-appalachia-coal/>).
- Warrior Zen. (2015). "Dangerous 'Kissing Bug' That Attacks Your Face Spreads To More Than Half Of U.S." Retrieved March 4, 2016 (<http://www.warriorzen.com/kissing-bug.html>).
- Welch, Wendy. 2011. "Self Control, Fatalism, and Health in Appalachia." *Journal of Appalachian Studies*. 17(1/2): 108-122. Retrieved March 2, 2016 (<http://www.jstor.org/stable/41446937>).
- Wilson, Susan, Cynthia Kratzke, and Jill Hoxmeier. 2012. "Predictors of Access to Healthcare: What Matters to Rural Appalachians?" *Global Journal of Health Science*, 4(6): 23-35. doi:10.5539/gjhs.v4n6p23.
- World Health Organization. 2016. "Chagas disease (American trypanosomiasis) fact sheet." Retrieved March 6, 2016 (<http://www.who.int/mediacentre/factsheets/fs340/en/>).
- World Health Organization. 2016. "Health Impact Assessment." Retrieved February 22, 2016 (<http://www.who.int/hia/evidence/doh/en/>).

## APPENDICES

### Appendix A

#### Moderator Guide

#### GENERAL SCHEDULE FOR FOCUS GROUP

- I. *Introduction and thank participants for agreeing to come*
- II. *Explain group guidelines and tell the group how long the focus group will last*
- III. *Address confidentiality (audio-taping, note taking, etc.)*
- IV. *Participant Introduction*
- V. *Discussion Topic Questions:*
  - *See moderator guide questions that follows*
- VI. *Closing*
  - a. *Offer participants to share any final thoughts, questions or concerns*

#### FOCUS GROUP MODERATOR GUIDE

Don't want a local person.

1. How do you make medical decisions
  - a. Family
  - b. Internet
  - c. Social Media
  - d. Friends
2. Previous HealthCare experiences. Does that impact decisions? Accessibility
  - a. How often do they go?
  - b. Do they go for regular check-ups?
  - c. Cost
3. Have they had difficulty getting health information? What actions did you take and how did you eventually get that information?
4. Have you ever gotten a diagnosis that you did not understand [health literacy]. What did you do?
  - a. Did ask doctor
  - b. How did you get that information
5. Traditional family remedies. Can you explain and how it works. Look at the interplay between traditional and familial/complementary medicine.
  - a. Do they look for alternative medicine on the internet
  - b. Would you ask your doctor about alternative medicine or go elsewhere
6. Use of technology (Does social media/technology have any impact on your medical decision making).
  - a. Internet
  - b. Social Media
  - c. Engaging doctors/medical personnel through SM/Internet

- d. Passive engagement with public health
- 7. Would you let researchers monitor your FB feed
- 8. Do you use the Internet regularly to search for health information?
  - a. Why
    - i. Geography
    - ii. Trust
    - iii. Privacy
    - iv. Money/Insurance
  - b. Why not
- 9. What types of health care problems send you to internet what types send you to doctor what about to family?
  - a.
- 10. Inter-cultural influences on families
- 11. [SM/Internet as a risk] Do you ever self-diagnose via SM or Internet INSTEAD of going to the doctor?
  - a. Geographic accessibility

## Appendix B

### Eligibility Screener RDC Focus Group

*[IRB NOTE: We have the following script if a person calls to screen in to the focus group. I am also programming the following questions into a web-based screener so that if people want to go online and answer the questions then we can contact them to confirm. I am hoping that this will allow people to find out more information any time during the day so that they can screen in even if we are not at the office.]*

*[NOTE TO RESEARCHER: Always have this screening form and a list of Appalachian counties with you when speaking to a potential focus group participant]*

**Researcher: Thank you for your interest in participating in the focus group. We have a few questions to ask before we can confirm your participation.**

**Q1. In what year were you born?**

**Q2. What county do you currently live in? [Check to make sure the county is considered part of Appalachia]**

**Q3. We are interested in talking to people whose families have been in Appalachia for several generations. Did your parents and grandparents (on either side) come from this region/county? [Work with respondent to determine if they are at least 2 generations in Appalachia]**

- Yes, both parents and grandparents are from this area or another Appalachian area.
- No, only one generation or neither generation

**Q4. Do you make medical decisions for yourself and/or other family members?**

- Yes

- No

**Q5. Do you use the internet at least 3 times a week (this can be on your cell phone, a computer or a tablet device)?**

- Yes

- No

*[If they are over 18, live in Appalachia, have 2 generations family back in Appalachia, and use internet at least 3 times a week then they qualify. Follow script:]*

**Thank you. It looks like you do qualify for our focus group. We will be holding the focus group on [DATE] at [TIME]. You will be paid \$25 for participating in the discussion which should last about 60 minutes. While the discussion will only last an hour, you will need to come 15 minutes early to fill out paper work and can expect to stay about 15 minutes after to get your \$25 and so that I can answer any questions you may have about the research after participating. All total, the time allotted should be about 90 minutes. If you are interested, I can reserve a spot for you.**

**[If yes] Okay, great. Could you please give me your name and your preferred method of contact [email, cell, mail are all fine]. We will contact you a few days before the focus group to confirm that you are coming.**

*[If they are NOT over 18, live in Appalachia, have 2 generations family back in Appalachia, and use internet at least 3 times a week then they qualify. Follow script:]*

**Thank you for calling about our focus group. Unfortunately you do not meet all the criteria to participate. Have a good day.**

## Appendix C

### Flyer for Focus Groups

# Women of Appalachia: Health and Technology Focus Groups

**Are you a woman who is 18 or older and from Appalachia?**

**Do you make all of the medical decisions for yourself and/or members of your family.**

**Do you use the Internet on a regular basis?**

**Receive \$25 for participating!**

**Come join the conversation about technology and the role it plays in making health decisions for you and/or your family. The focus group will last around 60 minutes and refreshments will be served.**

**Participation is confidential and you will not be linked to your answers in any way.**

**WE WANT TO HEAR FROM YOU!**

**FOR MORE INFO, DATES, OR TO RSVP:**

- Visit us online at [tinyurl.com/health15](http://tinyurl.com/health15)
- Call us at **423.232.0862**
- Primary Investigator, Dr. Kelly Foster
- Project Manager, Morgan Jones



## Appendix D

### List of Codes from NVIVO 11

Name	Sources	References
1. Barriers to Accessing Care	7	188
1a. Cost	6	45
1b. Lack of Insurance	6	37
1c. Quality	7	72
1d. Quantity	6	14
1d1. Transportation	2	4
1e. Trust	6	20
2. Social Media	7	42
2a. friends posing on social media	6	10
2b. Not posting on social media	4	7
2c. Not reading health articles on social media	2	2
2c1. Reading Articles on social media	4	15
2d. Passive Uptake of Health Related Info	5	15
2e. Posting for Personal Health Info or Advice	1	1
2f. Posting in Closed Groups	4	6
3. Sources for Medical Information	1	2
Coworkers	4	7
3a. Doctor	7	53
3a1. Doctor on phone or internet	4	18
3a2. Pharmacist	3	6
3b. Family	7	40
3b1. Friends	6	21
3c. Internet and Google	7	71
3d. Never Search Online	5	9
3e. Other Social Media	7	29
3f. Previous Experience	7	16
3f1. Home Remedies	7	52
3f2. Religion	1	1
4. Things that help access care or get med care	2	3
5. Trust in Medical Professionals	7	51
5a. Do Not Trust Doctors	6	19

5b. Feel Doctors are out for Money	5	11
5c. Trust Doctors	6	20
6. Type of Medical Facility	5	24
6a. Clinic	4	11
6b. ER	5	8
6c. Family Doctor's Office	1	2
6d. Specialist	1	1
7. What are they using internet for (ref to med info)	0	0
7a. Look for Doctors or Specialists	1	1
7b. Look for Support Groups	3	5
7c. Look up Holistic Remedies	4	7
7d. Primary Search for Info	5	16
7e. Understand Prescriptions	4	9
7f. Verify Doctor's Orders	2	2

Appendix E

Original “Kissing Bug” Post on Facebook by Warrior Zen



**Dangerous ‘Kissing Bug’ That Attacks Your Face Spreads To More Than Half Of U.S.**

A dangerous insect known as the ‘Kissing Bug’ which is notorious for attacking the faces of its victims and even killing them, has crawled its way into the United States, reported...

WARRIORZEN.COM

VITA

ASHLEY NICOLE CANO

- Education: Hondo Public Schools, Hondo, Texas
- B.S. Sociology, East Tennessee State University, Johnson City,  
Tennessee, 2014
- M.A. Sociology, East Tennessee State University, Johnson City,  
Tennessee, 2016
- Professional Experience: Assistant Student Instructor East Tennessee State University:  
Johnson City, TN, August 2015 – May 2015
- Graduate Assistant, East Tennessee State University, College of  
Arts and Sciences, 2014-2016