

2017

# Health Literacy, Availability, and the Need for Educational Resources on Infertility

Amber Louise Dessellier  
*Walden University*

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# Walden University

College of Health Sciences

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Amber Dessellier

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Walden University  
2017

Abstract

Health Literacy, Availability, and the Need for Educational Resources on Infertility

by

Amber Louise Dessellier

MA, Walden University, 2012

BS, Michigan Technological University, 2010

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

Community Health Education

Walden University

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## Abstract

There is a gap in infertility research regarding resource availability within rural communities, yet existing research declares infertility a public health concern. This qualitative study was grounded in the Heggerian phenomenological framework by way of assessing participants' perceptions of and experiences with infertility resources in a rural community. The purpose was to analyze the meaning of those experiences within their world. To accomplish this, Antonovsky's salutogenic theory was applied to investigate the strengths and weaknesses of infertility resources including the availability of resources, participant understanding of, and participants' experiences. Purposive sampling was used and in-depth interviews were conducted with 12 women, ages 24 to 39, who reside within rural communities. Interviews consisted of 60 questions that were designed to examine 13 research questions. Data were analyzed following Ritchie and Spencer's framework, requiring documentation and data classification, through 3 phases: open coding, focused coding, and axial coding. Emerging themes included a need for more resources on infertility, assistance with locating infertility resources, and an association between insurance coverage and use of infertility treatments. Findings from this study indicated a need for additional resources and knowledge regarding infertility in rural areas, also confirming a need for additional research on the topic. Social change implications for this research include developing resources for consumers and health care providers as well as improved provider knowledge. With increased knowledge and resources, these individuals may be able to achieve their goals and cope with the challenges of understanding and dealing with infertility.

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## Dedication

For Camden and Willow, because seeing your little minds flourish as you grow has driven me to be the best mom, person and scholar that I can.

“There will be obstacles.

There will be doubters.

There will be mistakes.

But with hard work,

There are no limits.”

- Michael Phelps

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## Chapter 1: Introduction to the Study

Infertility has always had an effect on women's health to some degree. However, it was not until the 1970s that organizations began to conduct surveillance on infertility (CDC, 2012). After roughly thirty years, comparisons between the data on prevalence of infertility and impaired fecundity in women collected during the 1970s and the early 2000s began to concern public health officials, both nationally and globally (CDC, 2012; World Health Organization, 2015). As there are many potential causes of infertility, research is needed to evaluate the environmental, health, and lifestyle factors that may affect infertility in order to develop and promote educational materials on the prevention, screening, and treatment of infertility and family planning.

Rural communities have additional health disparities as compared to those of urban communities due to often having fewer resources and providers available (National Rural Health Association, 2013). The same is true in regard to infertility care in rural communities, where access to infertility clinics or infertility specialists may not be available, requiring that a primary care physician serves as the only point of contact for possible concerns (Sherrod, 2004). Being the only point of contact may be detrimental in situations where a primary care physician may not be familiar with or up to date on infertility causes, screenings or care (Sherrod, 2004).

Social change implications of this research stem from gaining an understanding of the perceived difficulties and disparities within rural settings around receiving proper infertility care, and providing data on what those within rural settings may be looking for in future resources. This study provided community members across the Upper Peninsula

of Michigan with a forum to voice their concerns regarding any available resources or the perceived lack of available resources. The results of this study may be beneficial to healthcare providers within the community to understand their patients underlying concerns that may not be a topic of discussion during office visits as a means to improve relationships, trust and level of care between infertility patients and their physician.

This chapter contains a background on the issues relating to infertility and impaired fecundity as well as serve as an introduction to the research study itself. In Chapter 2, I present a thorough literature review. In addition, in this chapter I provide an introductory review of the literature also being introduced here as a means of identifying and explaining the gap in knowledge and the need for research. In addition, this chapter includes a background and justification for the use of the descriptive phenomenological approach and salutogenic theory.

### **Background and Problem Statement**

The Centers for Disease Control and Prevention (CDC; 2012a) declared infertility to be a public health priority affecting over 2 million American women. Gaps exist within public health research on infertility in many areas, including education of infertility and its causes, and available information on screening and treatment. In addition to these gaps, additional research is needed on the availability of, perceived value of and need for infertility resources within rural communities (CDC, 2012a) as well as how insurance coverage can impact accessibility of resources and care for infertility. According to the U.S. Census Bureau, in 2010, 19.3% of the population of the United States resided in rural communities (U.S. Department of Commerce, 2014), accounting for a significant

number of individuals who may have additional difficulties seeking infertility resources and services.

Individuals in rural communities must often find health-related information or resources through the Internet (Ruggiero, Gros, McCauley, de Arellano, & Danielson, 2011), as access to care is not always readily available. Seeking such information from the Internet as a primary source of information is a concern as inaccurate or outdated information is often displayed. In addition, these are often potentially unreliable sources, commonly anecdotes based on individuals' opinions or experiences (Geller, 2012; Malik & Coulson, 2010). With the Internet being used by much of the population as a health resource (Singh, Fox & Brown, 2016; Zulman, Kirch, Zheng & An, 2011), it is important that the information presented is legitimate information. Many adults, especially those who are part of the older generations, may not view the information available on the Internet as reliable (Zulman et al., 2011).

Research on educational material to understand the various causes of infertility, readily available resources and information on treatment options should be a public health focus (Sherrod & Houser, 2013). This is needed to help establish updated resources, available to all community members, on infertility. The number and quality of resources that are accessible to individuals in a rural community may also vary based on whether or not they have health insurance and to what extent their insurance covers infertility services (Jain & Hornstein, 2005). According to Schmidt (2007) only 25% of insurance coverage plans include infertility treatment. Of those insurance plans included in the 25%, the exact extent of coverage, coverage offerings and treatments included



varies by state, often due to state mandates on infertility coverage (Schmidt, 2007).

Knowledge gaps covered in this research proposal include those seen within infertility resources, education and screening and treatment availability (CDC, 2012a). One knowledge gap of interest is that of rural health disparities and the impact of insurance coverage for infertility services and their availability in a rural setting (Jain & Hornstein, 2005; Ruggiero et al., 2011; Sherrod & Houser, 2013). Researching these gaps provides data to public health professionals to advance the available resources, education and care of infertility patients in hopes of reducing the prevalence of those who are not able to successfully bear children of their own.

The goal of this study was to explore the availability of fertility resources in rural communities. With the guidance of prior research within the areas of public health and infertility, through this study, I provide additional information on the perceptions of women who may be facing infertility within a rural community. These data contribute to the closure of a knowledge gap in what is available for infertility patients in rural communities regarding the means of resources, education, prevention, and treatment, as well as provide a basis of such resources moving forward. In this study, I also address how the Affordable Care Act and insurance mandates affect resources within rural communities.

### **Purpose of the Study**

The purpose of this phenomenological study was to understand the actual and perceived availability, quality, and additional need for infertility resources within some rural Michigan communities across the states Upper Peninsula. Interviews were

conducted with 12 participants (women between the ages of 18 and 39) to gain insight of how easily women of childbearing age, who may or may not be struggling with infertility, attain information on infertility, obtain infertility services, as well as understand any readily available materials and what additional infertility topics they would like more information about. This study's paradigm followed an interpretivist/constructivist philosophy in which the human experience is the primary focus (Mackenzie & Knipe, 2006). The interpretivist/constructivist paradigm follows the use with qualitative research by investing interest in how lived experiences can explain a phenomenon and contribute to an outcome (Tubey, Rotich, & Bengat, 2015). The use of phenomenology for this study allowed me to explore women's experiences with infertility to gain an understanding of how the participants perceptions of resources and their comprehension of available resources contributes to a lack of infertility care and available resources in rural communities within public health.

The intent of this study was to be descriptive, through the use of open-ended interviews. Descriptive, open-ended interviews allowed me to gather the data on lived and perceived experiences of women who are planning to or currently attempting to conceive, specifically regarding infertility materials and care. This study is also comparative in nature because I explored similarities and differences in experiences based on socioeconomic status factors and insurance coverage options.

### **Research Questions**

Q1: What are common concerns among women in rural communities regarding the topic of infertility?

Q1a: How do community members feel these concerns can or should be addressed?

Q1b: How can infertility materials be created to address these concerns and be more effective?

Q2: What are the community members' perceptions of accessibility to infertility materials within their rural community?

Q2a: What are community member's perceptions of the information provided in available infertility resource materials?

Q2ai: What are community members' experiences with these materials?

Q2aii: How difficult has the community members' experiences been with seeking these materials?

Q2aiii: How well do community members understand the medical information presented in these materials?

Q2b: What additional information would community members' like to see made available within resource materials?

Q3: What impact does insurance coverage or type have on infertility resources?

Q3a: Is there an effect on availability?

Q3b: Is there an effect on quantity?

Q3c: Is there an effect on quality?

### **Theoretical Foundation**

In this study, I followed the theoretical foundation of Antonovsky's (1996)

salutogenic theory. This theory is focused on strengths and weaknesses of available resources and an individual's ability to retain good health (Antonovsky, 1996; Lindstrom & Eriksson, 2005; Morgan & Ziglio, 2007). The use of the salutogenic theory proposes that each person within a community has a stake in any given situation (Antonovsky, 1996), which in this particular study would be an individual's knowledge and lived or perceived experiences with infertility and resources available to the community. This theory also acknowledges that if individuals are only classified as being ill or being healthy, it is likely that those classified as healthy would not be of concern in public health, resulting in the salutogenic theory focusing on the entire spectrum of health (Kramer, Hossain Khan & Kraas, 2011). An in-depth evaluation of the various components of the salutogenic theory is discussed in Chapter 2.

The salutogenic theory applies to a phenomenological approach as they both aim to evaluate phenomenon based on personal experiences. The goal of phenomenology is to determine an underlying cause or understanding of a particular phenomenon, and the salutogenic theory is focused on what fundamental causes or understandings of relationships between resources and health may contribute. The combination of salutogenesis and phenomenology during interviews to gain data on the community member's experiences with infertility resources and medical care as well as gauge the level of comprehension of infertility as a whole. A thorough evaluation and justification of the use of the salutogenic theory follows in Chapter 2.

### **Nature of the Study**

The nature of this research was qualitative. Qualitative methodology is the best fit

for this topic as it provides a means of gaining descriptive information on infertility resources and materials within rural communities. This acquired knowledge can be used to develop a current understanding on the topic of infertility in a rural community, and create future opportunities for research and positive impact within similar communities. The use of qualitative methodology provided me the ability to analyze participants lived experiences and individual perceptions of infertility resource availability (University of Missouri-St. Louis, 2013), and the need and value of resources that will develop a new basis of information regarding infertility within rural settings.

I conducted in-depth interviews using open-ended questions, prompting participants to provide information that is significant to them. These questions also were focused on concerns within the topic of infertility resources within rural communities based on perceptions and personal experiences. The participants were volunteers who responded to recruitment materials or approached the researcher based on snowball sampling. The participants were women between the ages of 24 and 39 who may or may not have had a known infertility concern, suspected infertility problem, or who may or may not planned to conceive children within their lifetime. Insurance information was also a topic in question during the interview process to assist in evaluating any potential impact of insurance coverages on infertility resource availability and value. The interviews were transcribed and coded for analysis based on various thematic categories, detailed within the methodology section of Chapter 2.

### **Definitions**

Throughout this document, key terms that are used are defined here.

*Rural community:* An area outside of a metropolitan area, having a population of fewer than 50,000 people (U.S. Department of Health and Human Services, 2014).

*Childbearing age:* Women aged 18 to 39 who fall within the ages of women most likely trying to conceive, although professionally defined as 15 to 45 (Chandra, Copen & Stephen, 2013; Chandra et al., 2014; CDC, 2014c). Initially, childbearing age for the intent of this study was to be between the ages of 18 and 35, however, one participant included was of the age 39 at the time of her interview but had been struggling with infertility starting at age 33. Additional IRB approval was gained to expand the original age range to include this participant.

*Infertility:* Is the inability of a woman of childbearing age to successfully conceive and carry a viable pregnancy after twelve months of unprotected sexual intercourse (Alesandro, et. al., 2009; Bitler & Schmidt, 2006; Chandra et al., 2013; Evens, 2004; Hamilton & McManus, 2012; Macaluso, et. al., 2010; Yadav, Arora, Saini, Bhattacharjee & Jain, 2014).

*Primary infertility:* A woman is unable to become pregnant after one year of unprotected sexual intercourse or unable to carry a pregnancy to term, resulting in the live birth of a first child (WHO, 2014; Mascarenhas, Flaxman, Boerma, Vanderpoel, Mathers & Stevens, 2013; Johns Hopkins Medicine, 2008)

*Secondary infertility:* Occurs under circumstances when a woman is physically incapable of conceiving or carrying a second pregnancy after the birth of a biological child (Resolve, 2014; Jensen, 2014), or having additional failed pregnancies after a prior

failed pregnancy attempt or live birth (WHO, 2014; Mascarenhas et al., 2013; Johns Hopkins Medicine, 2008).

*Impaired fecundity:* A secondary form of infertility, is a term used when a woman has a difficult time either retaining a pregnancy once conception has been successful, or carrying a baby to term (Bitler & Schmidt, 2006; Chandra et al., 2013).

*Socioeconomic factors:* An individual's income or annual salary (including satisfaction with current financial situation), level or degree of education (highest level of education; type of degree(s) if applicable; GPA if applicable), and occupation (full time vs. part time; benefits; title; length of employment) (Winkleby, Jatulis, Frank & Fortmann, 1992).

*Environmental and demographic factors:* Any known possible exposure to toxic substances or poor air quality, the participant's home and community in which they live (type/size of dwelling; number of roommates; their rating of satisfaction with their community settings and offerings concerning infertility and healthcare) (Office of Disease Prevention and Health Promotion, 2015), ethnicity, race, age, and marital status.

*Private insurance:* Any insurance coverage provided by an employer or union, or may be purchased directly by an individual from an insurance company (United States Census Bureau, 2015).

*Public insurance:* Any insurance that is provided by a government agency, such as Medicare, Medicaid, Tricare or other state or Indian health plans (United States Census Bureau, 2015).

*General Resistance Resources (GRRs)*: Resources that are found both within an individual as well as the immediate environment that are readily available for application towards gaining health (Antonovsky, 1996; Lindstrom & Eriksson, 2005; Wennerberg, Lundgren & Danielson, 2012).

*Sense of Coherence (SOC)*: An individual's ability to understand the scope of a stressful situation and their capability to utilize and understand resources that are available to be applied to a stressful situation (Antonovsky, 1996; Lindstrom & Eriksson, 2005; University West, 2014).

### **Assumptions**

In this study, I made several assumptions based on the method, design, and participants. One assumption of this study was that the participants would express different strategies or ability to cope with infertility, as their backgrounds were different. A second assumption was the honesty in the participants in providing true and accurate responses. These assumptions were important to keep in consideration as there are varying degrees of infertility experienced amongst participants as well as lived experiences with trying to conceive. The possibility of differing perceptions was important to consider during evaluation and outcomes from the interviews and also required that underlying themes be reviewed such as experiences based on lived situations or circumstances, rather than the experience itself.

### **Scope and Delimitations**

In this study, I defined the scope as a women's ability to locate, understand, and use resources for infertility within a rural community. Women's ability to locate



resources is important as it demonstrates the ease of access and understanding of the concern of infertility within the community. The availability of infertility resources also assists in gaining an understanding of the level of understanding of infertility within the community as a whole.

Aside from written resources or health professionals pertaining to infertility being available and easily located, the ability of the information provided to be understood by the community is imperative to being able to promote education on the topic in an attempt to help reduce the number of women who suffer from infertility when medical intervention can reduce or eliminate the causing factor. If the information that is presented to the community is not available and presented in a way that is easily read and has a low comprehension level, the material will not be appealing to the reader, and likely will not be understood which would result in a failure to follow through with infertility screening or any necessary infertility treatment.

Beyond the availability of screening and treatment options, the ability for patients to understand the procedures or medication as well as any long-term directions and possible side effects is important as well. If such information is not presented clearly, it is possible that the instructions would not be followed appropriately, or that the patient may misunderstand instructions for medication or recovery care and worsen or further the cause of infertility.

The scope of the study was women between the ages of 18-35. For this study, it was not imperative that all participants knowingly suffer from infertility. Additionally, the population focused within rural communities and was not discriminated against based

on socioeconomic standing, race, ethnicity or background. Exclusion criteria included male individuals, minor women, or women over the age of 35.

Theories and conceptual frameworks that were considered but not used in this study include grounded theory, ethnography, case study approach, stress & coping theories, and the transtheoretical model and stages of change.

The Grounded Theory makes it possible to understand the meanings of phenomena for individuals (Backman & Kyngas, 1999; Blenner, 2007). The Grounded Theory is used in two ways within public health research, often concerning practice or education (Backman & Kyngas, 1999). It can be used to test a resulting theory (or theories) or interventions found through prior research or as a basis for a series of studies that can be used to modify, verify or elaborate the theory in use (Backman & Kyngas, 1999; Blenner, 2007; Olshansky, 1996). The first method of using grounded theory to test a theory or intervention that has been previously found would not have fit this study, as it is not derived from prior research findings. Regarding the second way to implement grounded theory in a series of studies, this study again did not follow up or initiate a string of studies to be completed.

Ethnography is also another common form of qualitative research methodology that is utilized in public health research. This methodology focuses on individuals within a targeted population along with their cultures and the relationship between the two, resulting in the way individuals live their lives (Anderson, 2009; The Association for Qualitative Research, 2014). Ethnography did not apply well to this study as it would have required a deeper focus on the rural setting and culture with a comparison to effects

on individuals, more so than the lived experiences of those individuals within a rural community.

Case study approach is another qualitative research approach that had potential for use in this study, as the primary focus of case studies is to explore a phenomenon to gain an in-depth understanding (Crowe, Cresswell, Robertson, Huby, Avery & Sheikh, 2011). Case studies are used to “explain, describe or explore” (Crowe, et al., 2011, p. 4) the phenomena, however, it does not focus on examining the lived experiences of the phenomena, which is an important outcome of this research, nor does it incorporate available resources related to the phenomena.

Although stress and coping theories are used when conducting research on infertility experiences at the individual level, such theories do not fit well with this particular study as the focus is not on the types of mechanisms of coping, or how the individuals handle the stress of suffering from infertility. The stress and coping theories are more used for psychological studies than public health based research to discover the mechanisms and strategies used by individuals, as well as the degree of stress they are enduring.

The transtheoretical model of behavior change is followed when evaluating where an individual fall in regard to their beliefs and understanding for needing to make a change to improve their health. Under the transtheoretical model, individuals are categorized into one of six stages of change; precontemplation, contemplation, preparation, action, maintenance and termination (Prochaska & Velicer, 1997). Although this also could have been a possible theory used for this study, it focuses on an

individual's willingness to make changes, such as to find and utilize infertility resources, rather than focusing on the lived experiences of those who suffer from infertility.

The potential for transferability of this study includes similar public health phenomena that may affect a minority within a population, but may need additional resources and materials created; evaluation of resource material for underserved phenomena populations, or health phenomena that may have limited accessibility through insurance.

### **Limitations**

There were several limitations in this study. Limitations in the study design and methodology included a lack of a previously used interview questionnaire and the need for telephone conference rather than face to face. The use of a self-developed non-published interview questionnaire or transcript can take away from the dependability or confirmability of the study if the same interview questions are not narrated, should the study be replicated (Alshenqeeti, 2014). The additional limitation in the design for data collection was the need for completing interviews via telephone. Utilizing telephone interviews inhibits the ability of me to obtain field notes of the participant's physical appearance and body language for analysis with the interview transcript. Lack of physical observation may have led to mistaking a participant's tone of voice incorrectly without the use of visual cues.

Limitations specific to transferability include the phenomena being an under-researched topic of infertility, as there is a great need for additional research on the topic of infertility. In addition, the outcomes of this particular study may not directly correlate

with other health phenomena such as diabetes, where the scope and background may be extremely different.

Concerning dependability, a limitation is that each rural community can have differing outcomes. Although there is a standard definition of a rural community or rural setting the individuals and resources that make up that rural community will vary, ultimately varying the possible number and accessibility of infertility resources from one rural community to the next.

Potential biases that may have surfaced in this study include during recruitment, with selection bias, during the interview process with both interviewer bias and recall bias, as well as through confounding variables. During the recruitment phase, selection bias can be a potential concern if the inclusion and exclusion criteria were not closely followed, and participants were treated differently. Within the data collection during interviews, two possible biases may have arisen – the interviewer bias, and recall bias. Interviewer bias may occur from unintentional non-verbal cues as well as through the reading of the interview questions if not done consistently from interview to interview. The recall bias is dependent upon the participants to have a clear memory of past experiences, and if there is doubt, there is a possibility of having inaccurate data for analysis. Confounding will arise as a concern if there is missing information from participant's background and socioeconomic status, which can have an impact on the ease of their access to infertility screening, treatment, and insurance coverage.

As a means of addressing the previously stated limitations, I created the recruitment materials in a way that clearly describes the inclusion criteria, and is

welcoming to women of all backgrounds and statuses. During the interview, questions were read clearly and as written on the interview transcript to ensure the same delivery during each session. In situations where a participant was unsure of how to answer a question or remember what their response was to a situation, I asked a follow-up questions to prompt the participant to elaborate on their given response, or allowed the participant to ask for clarification of a topic should the participant not comprehend it accurately. In these situations, I then further defined the question carefully so as not to try and direct the participant to an answer. Any unsure responses were noted as such so that the data point would be appropriately analyzed.

### **Significance**

Public health contributions from this study include expanded knowledge on the perception and availability of infertility resources, the understanding of those resources, as well as the experience with the use of services. This expansion of knowledge can provide a basis for understanding possible improvements of existing resources as well as the potential for additional resources for rural communities on infertility. This study also provides insight into direct concerns women within the community have with regards to infertility, available resources, and treatment options, thus being able to tailor future information to the direct concerns that surface during the interviews of community members directly to provide a more personable resource.

This study also provides information from participants as a building block for public health providers to potentially review additional insurance measures or mandates with regards to the coverage of infertility screenings, tests, and treatments that may not

already be in existence, more specifically to the state of Michigan. Experiences, questions, and concerns gathered may promote local health care providers to become more attuned to the issue of infertility and showcase the need for awareness of infertility within the community.

This study has positive social change implications through providing the community stakeholders in public health and health care with a basis of knowledge of where the members in their community stand in the understanding of infertility, concerns of or with infertility, and the perception of availability of resources and care. The results of this study can help stakeholders improve the accessibility of the resources that are available as well as have an understanding of what should be focused on for their community specifically, providing a better experience for women who struggle to conceive.

### **Summary**

In summary, in this phenomenological study, I followed the salutogenic theory, paired with the phenomenological framework described by Heidegger to evaluate the lived and perceived experiences of women of childbearing age in rural communities with regards to infertility. The salutogenic theory allowed for the inclusion of available resources to be an important focus throughout this study to ultimately provide insight into the value of available resources, as well as the community members questions and concerns that may need to be incorporated in future resources.

Within this chapter, I also defined keywords and phrases. These definitions provided a more streamlined reading process as well as to clarify those keywords that

may be understood in multiple contexts outside of this research study. There also were limitations defined for each aspect of the study, from participant recruitment, to data collection and data analysis.

Findings from this study may advance the knowledge of infertility resource availability, perception and use within rural communities both to the local community as well as other public health professionals with an interest in rural community infertility. Social change implications include the ability to discuss resources with participants in regard to the limited materials that are readily accessible, which they may or may not have been aware of, as well as providing the information to the community health stakeholders, such as the health department, local hospitals, and community health offices.

In Chapter 2, I provide a thorough review of the past and current literature on the topic of infertility, infertility resources, rural community health care, as well as insurance mandates with regards to infertility health care.

In Chapter 3, I provide a thorough overview of the Heideggerian phenomenology methodology that I followed along with my research design, recruiting process and data analysis plan.

In Chapter 4, I provide a detail of themes that emerged throughout the coding process, as well as a breakdown of the analysis of each research and interview question.

In Chapter 5, I provide a discussion of my findings from the study and discuss social change implications along with recommendations from the study outcome.



## Chapter 2: Literature Review

As there are many potential causes of infertility, in this chapter, I further discuss how research is needed to evaluate the environmental, health, and lifestyle factors that can affect infertility. The CDC (2012a) declared infertility to be a public health priority, as it affects over 2 million American women. According to the U.S. Census Bureau, in 2010, 19.3% of the population of the United States resided with in rural communities (U.S. Department of Commerce, 2014), accounting for a significant number of individuals who may have additional difficulties seeking infertility resources and services. According to Schmidt (2007), only 25% of insurance coverage plans include infertility treatment.

In this chapter, I review past literature on the topic of infertility, infertility resources, screenings and treatments on availability and use in rural communities. There also will be a discussion of the impact of health insurance and the Affordable Care Act within rural communities on infertility care. A review of the literature on the use of the theoretical methodology and conceptual framework will also be a focus.

### **Literature Search Strategy**

In this review, I used a variety of different research tools to find supporting articles and past research includes PubMed, Medline, and CINAHL databases within the Walden Library. Externally, Google Scholar, the CDC, and the WHO websites were used to find additional resources, as well as subscribing to the American Society for Reproductive Medicine's Journal, Fertility, and Sterility. Within all search engines utilized, only full-text articles were sought to ensure a proper understanding of the

information presented. Search terms and combinations used include, but were not limited to the following: *infertility, health insurance + infertility, insurance, insurance mandates, insurance mandates + infertility, health insurance + rural, infertility + rural settings, infertility resources, infertility resources + rural, women infertility, women infertility resources, primary infertility, secondary infertility, impaired fecundity, health literacy, women infertility + United States.*

### **Address of Lack of Current Research**

There is a lack of research on the topic of infertility materials and resources within a rural setting. In this literature review, I addressed this gap through the incorporation of information that provides a background on the need for research. This information includes the calls to action from groups such as the CDC on infertility in general, and the perceived differences in overall health care between rural and urban communities. Additional attention was applied towards the rural aspect in discussing the possible concerns that women may face obtaining health care within their community as well.

Foreseeable goals regarding infertility placed by the United Nations and NICHD were also discussed. These goals outlined concerns for infertility being not only seen within the United States but globally. These goals covered a range of topics of infertility, from family planning to screening and treatment options being made readily available to all who may require the services, again, focusing on the need for additional information and research to be conducted.

### **Theoretical Foundation**

The theoretical framework that I used in this research was the salutogenic theory, derived from Antonovsky (Eriksson & Lindstrom, 2006; Lindstrom & Eriksson, 2005). The salutogenic theory does not focus on the risk of having a disease or a disease itself, but on the strengths and weaknesses of available resources in affording individuals with the capacity to be in good health (Antonovsky, 1996; Eriksson & Lindstrom, 2006; Lindstrom & Eriksson, 2005; Morgan & Zigilo, 2007; Wennerberg, Lundgren & Danielson, 2012) or help them move toward better health in the health-disease spectrum (Eklund & Eriksson, 2011; Eriksson & Lindstrom, 2006; Perez-Botella, Downe, Meier Magistretti, Lindstrom & Berg, 2014). This theory values each individual within a community regardless of where they may fall within the continuum of a specific illness or disease (Antonovsky, 1996, p. 14), or in this particular study example, in the knowledge and experience of infertility and the available resources.

General resistance resources (GRRs) are major concepts within Antonovsky's salutogenic theory. GRRs also play a large role in this research as much of the focus is directed towards available infertility resources within a rural community (Antonovsky, 1996; Eriksson & Lindstrom, 2006; Lindstrom & Eriksson, 2005; Wennerberg et al., 2012). The second major concept within this theory is an individual's Sense of coherence (SOC; Antonovsky, 1996; Eriksson & Lindstrom, 2006; Lindstrom & Eriksson, 2005; University West, 2014). SOC is broken down into three elements consisting of comprehensibility, manageability, and meaningfulness of the available resources (Antonovsky, 1996; Lindstrom & Eriksson, 2005). The salutogenic theoretical framework

is used through both concepts associated with salutogenic theory – GRRs and SOC, and is discussed further in Chapter 3.

GRRs apply to conducting research on infertility materials through gaining insight on the participants perceived and lived experiences with infertility and available resources within the community. Each aspect of SOC is also applied to infertility material research. *Comprehensibility* accounts for the extent to which an individual perceives and understands materials that are presented to them (Antonovsky, 1996; Lindstrom & Eriksson, 2005) and will focus on participant's ability to understand the topic of infertility, its possible causes as well as available resources and their benefit.

*Manageability* is the extent to which an individual perceives that the available materials can be instrumental or beneficial to their situation (Antonovsky, 1996; Lindstrom & Eriksson, 2005) and will focus on participant's experiences with available resources and potential application of those resources to their health situation. *Meaningfulness* is the extent to which an individual feels it is worth investing time, energy and potentially money towards their situation (Antonovsky, 1996; Lindstrom & Eriksson, 2005, p. 441) allowing focus on the participant's attitudes, beliefs and desired outcomes of seeking infertility materials and resources.

A researcher's use of the salutogenic theory can bring understanding to personal perspectives, understanding and use of infertility resources within a rural area. Evaluating these topics also considers an individual's involvement in the community. The salutogenic theory has the potential to provide needed information to the field of public health on the availability of infertility resources. Gaining this knowledge will allow

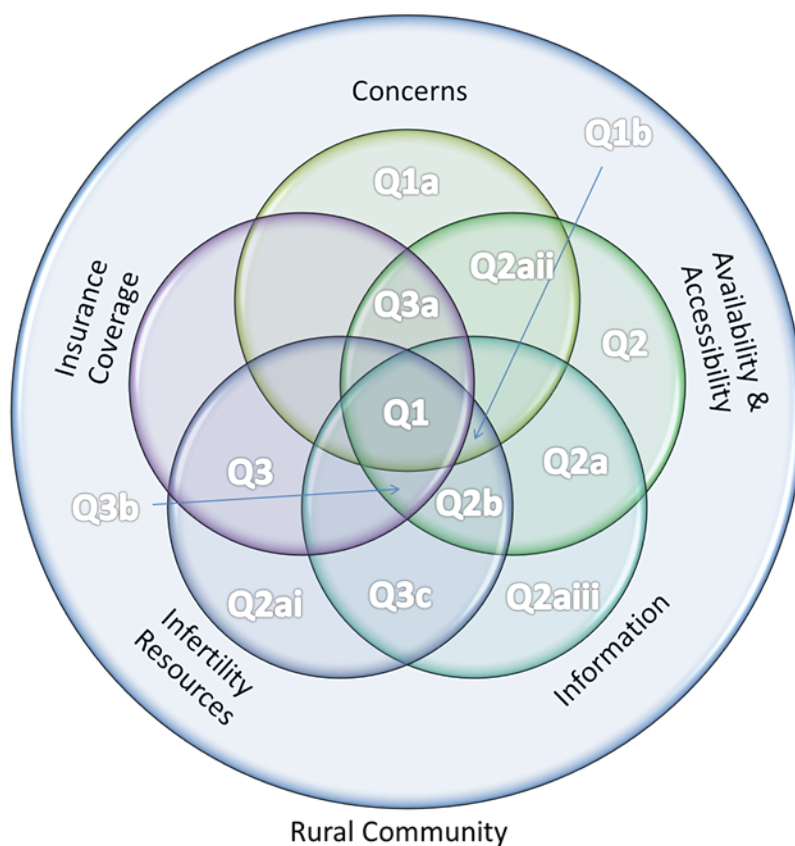
updates to be completed to existing materials, the creation of new materials and provide a larger basis of educational resources, should a need be discovered within health promotion of infertility (Eklund & Eriksson, 2011).

Berg, Perez-Botella, Magistretti, Lindstrom, and Downe (2014) concluded that the application of the salutogenic theory or approach should be utilized to determine best practices in promoting wellbeing within maternal care as opposed to focusing on factors of ill-health or potential risks. This suggestion to incorporate salutogenic theory into maternal care research is also valuable in the examination of infertility care to explore the comprehension of infertility and care options, manageability of infertility and the meaningfulness of care and resource availability (Perez-Botella et al., 2014).

Ferguson, Davis, Browne, and Taylor (2015) utilized salutogenesis as a theoretical framework for their study of the relationship between a woman's SOC with childbearing choices that are made. Ferguson, et al. completed a cross-sectional survey of 1074 women that included participants completing questionnaires to provide information on their SOC score, Edinburgh Postnatal Depression (EPD) score, Support Behaviour Inventory (SBI) score, as well as the participant's pregnancy choices and demographics. Ferguson et al. found that of the participants who scored a higher SOC, they were older, had a higher SBI score and were not as likely to identify a pregnancy condition. Ferguson et al. (2015) also found that those who had a higher EPD score were not likely to have a high SOC, further providing data that individuals with a higher SOC are found to be higher on the scale of overall good health.

### **Methodology Framework**

The methodological framework used as a basis for this research project follows that of Heideggerian phenomenology or hermeneutics. This form of phenomenology follows the notion that a phenomenon or understanding is in a circular movement, which results in a shared understanding (McConnell-Henry, Chapman, & Francis, 2009; Reiner, 2012). This circular movement was taken into consideration when constructing the visual of the framework for this study (Figure 1), as each smaller phenomenon has a union and intersection with each of the others, all within the community as a whole. Within Heideggerian phenomenology there are two pivotal aspects of phenomena – the *Dasein*, which is the act or meaning to exist or be, and *In-der-Welt-sein*, the Being-in-the-world with the underlying meaning that individuals not only exist within their world but are submerged and an important piece of that world (McConnell-Henry et al., 2009; Pascal, 2010).



*Figure 1.* Methodological framework. The framework illustrates the relationships between concerns felt by individuals within a rural community concerning infertility, the availability & accessibility of materials and resources, information available on infertility, infertility resources as well as insurance coverage.

Pascal (2010) discusses another valuable piece of Heidegger's basis of phenomenology being that of a researcher's beliefs, experiences, and preconceptions playing a very important role within the conducted research. Heidegger theorizes that it is impossible for a researcher to be completely unbiased and impartial to research (McConnell-Henry et al., 2009; Lowes & Prowse, 2001; Pascal, 2010; Reiners, 2012). In addition to the researcher's beliefs, experiences, and preconceptions playing a vital role within Heideggerian phenomenology, the inclusion or acknowledgment of the

researcher's values, experience, and knowledge can enhance the research through relationships (Inwood, 2000; Pascal, 2010) within the phenomena and meanings. The direct relationship of the researcher's beliefs, experiences, and preconceptions within this study will be outlined in more detail in Chapter 3.

Phenomenology has been used within conceptual framework for research and methodology within various health, human and social services concentrations. Pingel, Sirdenis, Sullivan, Ramazotti, and Bauermeister (2015) used phenomenology as a basis for their research to understand both the needs and experiences that are seen within individuals of Middle Eastern (ME) decent, who also belong to the Lesbian, Gay and Bisexual (LGB) community. Pingel et al. (2015) performed both focus groups and in-depth interviews to gather data on lived experiences of participants followed by a thematic analysis of the collected data to identify patterns in the population with regards to their identity, community, gender roles and experience with access to healthcare. Based on this research, Pingel, et al. (2015) found that the experiences uncovered that many of the individuals who fall into both the ME and LGB communities feel they need to make decisions on what information to compartmentalize and share with healthcare individuals who serve their community. Information was also analyzed on the challenges that are seen within the participants when it comes to daily interactions within their community as well as with their family and friends (Pingel, et al., 2015).

In another study, completed by Little (2012), hermeneutic phenomenology was used as a research design framework to evaluate the experiences of individuals with medical herbalism as a way of gaining an understanding of the use and context of



medical herbalism within the United Kingdom. Like Pingel, et al.'s (2015) study, in-depth interviews were used to gather data from participants then analyzed through the use of van Manen's and Kvale's framework (Little, 2012). Through her study, Little discovered that herbalism aligned more closely with participants expectations of an effective form of health care as they reported it met the goals, purposes, and methods that they would expect and want to see within health care (Little, 2012).

Little (2012), Pingel et al. (2015), and Dancet, Van Empel, Rober, Nelen, Kremer & D'Hooghe (2011) conducted a phenomenology based study conducting fourteen focus groups in which participants were asked to share both the positive and negative experiences they had encountered with regards to infertility care. Dancet et al. also evaluated the participants' priorities with regards to infertility care, which they were able to categorize into ten different dimensions. The ten dimensions uncovered were further broken into two separate categories. One category being system factors: information, the competence of the staff and clinic or office, coordination, accessibility of care, continuity, transition and physical comfort. The other category regarded human factors, such as attitudes and relationships with staff members, level and means of communication, the level of involvement that the patient has with their care options, as well as privacy and level of emotional support (Dancet, et al., 2011). From their results, Dancet et al. (2011) developed an interaction model of what patient-centered infertility care looks like:

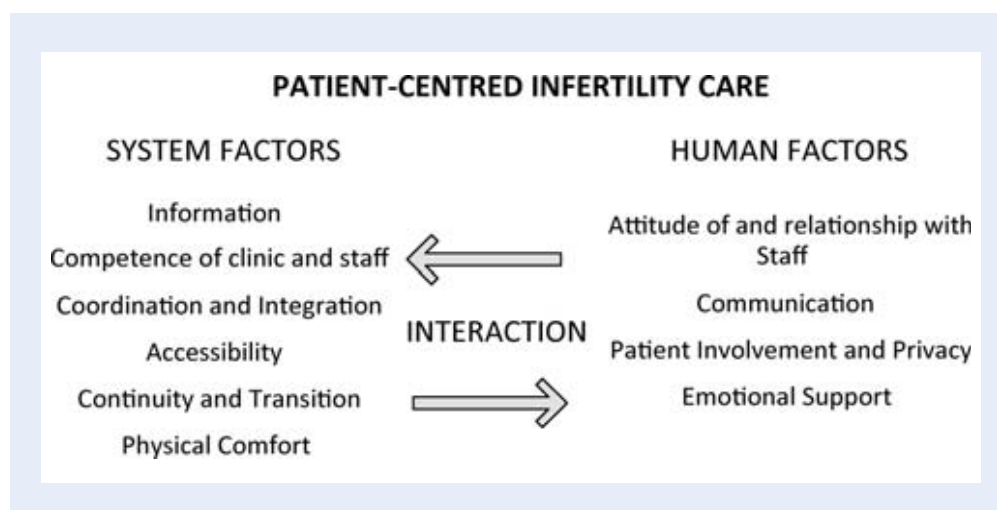


Figure 2. Patient-centered infertility care interaction model. From “Patient-centered infertility care: a qualitative study to listen to the patient’s voice” by E.A.F. Dancet, I.W.H. Van Empel, P. Rober, W.L.D.M. Nelen, J.A.M. Kremer, and T.M. D’Hooghe, *Human Reproduction*, 26, p. 829. Copyright 2011 by the Oxford University Press. Reprinted with permission (Copyright Clearance Center).

Figure 2 demonstrates the interaction between both the system factors and human factors. The interactions found are potentially two-sided with the system factors not only having a direct impact on the human factors, but the human factors possibly imposing a direct effect on the system factors and outcomes (Dancet, et al., 2011).

Another study, conducted by Goundry, Finlay and Llewellyn (2013) utilized phenomenology as a means to evaluate possible relationships with college students contracting sexually transmitted infections (STI’s), and infertility. Goundry et al. (2011) used focus groups for data collection on topics such as what the student’s understanding of definitions for STI’s, the types of STI’s, infertility as well as what their beliefs are on the topic. After the data was analyzed through the use of the Framework Analysis Approach, where the focus groups were transcribed verbatim followed by classification

by themes and subthemes, it was discovered that there is a need for more education and resources for college students on the topic of STI's and infertility (Goundry et al., 2011).

Another phenomenological study was conducted to evaluate the personal experiences of men who suffered from severe infertility and had undergone treatment to help reverse infertility but had failed. Johansson, Hellstrom, and Berg (2011) completed interviews with male participants on their experiences after undergoing the treatment to learn it had failed with the hardships that followed. There were four common themes of driving forces or means of handling the failed treatment: a feeling of inadequacy or feeling of redress, marginalization, chivalry, and the extension of the participant's life by starting a family (Johansson et al., 2011). The overall findings of this study lead the investigators to believe there is a need for creating treatment guidelines and a basis of knowledge of gender-specific perspectives in addition to couples who may be experiencing infertility.

### **Data Analysis Framework**

The framework used for analysis within this research project follows that of Ritchie and Spencer, which includes careful transcription and audio revision of interviews, followed by coding and charting of the interviews before interpreting the collected data (Gale, Heath, Cameron, Rashid & Redwood, 2013). Within the coding and interpretation of data, three categories, or levels, were utilized. These included thematic analysis, or the categorization of things and ideas based on interview responses; typologies that cover the cataloging of individuals or processes; and explanatory analysis, covering why participants do or think the way they do (NatCen, 2012).

Ritchie and Spencer's framework analysis has been used in the healthcare field on topics of nursing research (Ward, Furber, Tierney & Swallow, 2013), genetic testing (Darr, Small, Ahmad, Atkin, Corry, Benson, Morton & Modell, 2012), sexually transmitted infections (Goundry et al., 2013) and stem cell research (Ehrich, Williams & Farsides, 2010). Each example follows the same framework for analysis: reviewing the readings of interview transcripts to evaluate emerging themes and subsequent subthemes within the gathered data (Darr et al., 2012; Ehrich et al., 2010; Goundry et al., 2013; Ward et al., 2013) allowing for careful analysis of smaller data sets, followed by managing and documenting the data analysis through means of indexing, charting and mapping results (Stepney, 2014).

### **Literature Review**

This section will outline the past and current literature on infertility. Although there is very limited research available on the lived perceptions of infertility resources within rural communities, various articles elaborate on pieces of this proposed research. A section will be devoted to the past research studies that have been completed with regards to the topics of infertility, infertility resources and health care within rural settings. An additional section is provided to discuss the background information of various aspects of the research such as health insurance mandates, types of infertility screening and treatments as well as possible resources utilized for infertility information.

#### **Past Research**

Goundry et al.'s (2011) study, which was previously introduced where focus groups were conducted to gain information on college students experience and

knowledge of the link between STI's and infertility, showed most male respondents reported that additional information on STI's and infertility would be beneficial as they did not realize or know the possible link between untreated STI's and infertility occurrence later in life. Goundry et al. (2011) also discovered that of respondents that were aware of a possible link between untreated STI's and infertility, it was not common for the participants to realize it could also affect fertility in men, where most indicated issues with women. An important take away from the work by Goundry, Finlay and Lewellyn (2011) was that when participants were prompted with the question "Do you worry about whether you can have children?" some responded with "Yeah" or "Yeah all the time". Furthermore, most of the participants agreed that discussions about infertility and childbearing should occur more frequently at their age, stating "This is the age where you have to start thinking, if I'm going to be infertile by the time I'm 30 then I need to plan my life around having children early," (Goundry, Finlay & Lewellyn, 2011). This understanding coincides with the need for additional educational and resource materials being provided on the topic of not only infertility but STI's also (Goundry, Finlay & Lewellyn, 2011).

Another study, completed by Nachtigall, MacDougall, Davis and Beyene (2012) examined the attitudes and beliefs of parents' in regard to the costs associated with infertility treatment, specifically in vitro fertilization (IVF), as well as the degree to which insurance coverage was applied. This study was completed using open-ended interviews with a total of 95 participants (60 women, and 35 men), recruited by physicians, who had experienced childbirth after undergoing a successful round of IVF

treatment. In total, 426 patients were sent letters extending an offer to participate, with 27% (115 individuals) indicating interest. Of those who expressed interest, and were successfully reached, the total participants resulted in 60 women, and 35 men. Of those who participated, only 45% had insurance coverage to assist with costs of IVF treatments with another 19% having partial treatment coverage. The remaining 36% of participants did not have any assistance from insurance coverage with the cost of IVF treatment. The median out of pocket cost for families who participated was found to be \$10,000, \$20,000 and \$27,000 for those with IVF insurance coverage, partial coverage, and no coverage respectively (Nachtigall et al., 2012).

Nachtigall et al. (2012) found that the participants, regardless of insurance coverage or lack of, perceived the costs associated with undergoing IVF treatments as high, however, upon having a child, felt that the costs were minimized by the joy of having conceived and delivering a healthy baby. Other findings included the support of insurance to cover IVF treatments (with women being twice as supportive than men) as well as a large range of beliefs and attitudes towards insurance covering costs of IVF (Nachtigall et al., 2012).

Sherrod (2004) completed a random phone survey study that evaluated urban versus rural areas with regards to infertility experience with the use of descriptive statistical analysis. Participants included a total of 450 subjects, with 65.6% living within an urban area, and 34.3% being rural compared to the estimated 75% urban and 25% rural population within the United States (Sherrod, 2004). Overall, Sherrod found that the number of participants who reported suffering from infertility was approximately 10%,

which is comparable to that of the current prevalence of infertility (2004). Of those who indicated issues with infertility, nearly 80% were from urban areas, and 20% from rural with no significant difference in likelihood to seek assistance between those in urban or rural areas. The significant difference found was that those within urban areas were more likely to have insurance coverage that would meet infertility treatment needs than those in rural settings as well as the same participants having a higher level of satisfaction with the care received (Sherrod, 2004). Additional findings to note from Sherrod's study include fewer individuals within rural areas having private health insurance than their urban counterparts, as well as having a much higher travel time and distance to receive infertility care (2004). Recommendations stated by Sherrod, based on his research include advancement of health care, education and research on the topic of infertility, with particular consideration for the availability and access to health care within rural communities. Sherrod also expresses a need for further research to gain "a better understanding of the impact of infertility for those who live in rural areas" with qualitative research studies providing "the fullest understanding of this phenomenon of infertility and rurality" (2004, p. 82).

Although Bennett, Wiweko, Bell, Shafira, Pangestu, Adayana, Hinting and Armstrong's (2015) study was conducted in Indonesia, the results arrived at comparable conclusions as Sherrod (2004), Nachtigall et al. (2012), and Goundry et al. (2011). Bennett et al. (2015) set out to evaluate the knowledge and needs with regards to infertility of women, aged 18 to 45 in Indonesia. The study was completed using a cross-sectional survey design with 212 participants being women between the ages of 18 and

45, who were literate, highly education with most belonging to an urban area being middle or upper-class citizens (Bennett et al., 2015). The interview questions used were created in a way to “generate information about current sources and levels of information among patients, to identify knowledge deficits, and to provide insight for developing a more comprehensive approach to patient education for Indonesian infertility patients” (Bennett et al., 2015, p. 366). Such questions included requesting participants to provide a list of the various sources of infertility information that had been accessed before the most recent OBGYN appointment. The responses were categorized into 13 different types of sources: OBGYN, friends, family, internet, midwife, religious figure, birth attendant, and radio. The most common sources include the participants OBGYN (77%), friends (44%), internet (31%) and family members (23%). The authors found that those who had a higher level of education were more apt to refer to the internet or magazines, whereas those with a lower level of education were more inclined to seek information from their doctor (Bennett, et al., 2015). Questions were also asked to gauge the participant’s general understanding of reproduction and infertility. Bennett et al. (2015) found that the majority of the participants were able to accurately articulate that infertility can be caused by both male and female factors, not only being a female deficit. Additional questions on the duration of menstrual cycles, fertile time and signs of ovulation were evaluated. Most participants were able to accurately provide typical cycle lengths and determine when the most fertile window is for a woman with 60% being able to specify possible signs of ovulation (Bennett et al., 2015).



When asked about causes of infertility, 10% of participants were unable to state a cause of male infertility, and 11% were unable to state a reason for female infertility. Follow up questions with relation to the types of infertility treatments, for either men or women, were asked. The authors found that most participants were not able to accurately define types of treatments, leading to the realization of literacy concerns with the medical terminology being referenced or broadcasted through resources. A final topic covered by Bennett et al. was that of interest in the desire of participants to be able to access and receive additional information on infertility. The majority (87%) of the participants answered yes, they would like to have access to more information on the topic, with their detailed responses being classified into causes of infertility (25%), how to successfully conceive (20%) and ways to improve fertility (15%) (Bennett, et al., 2015).

Based on the findings of Bennett et al. (2015) it is important to have additional resources developed on the topic of infertility not only in the United States but also in other countries. Bennett et al. (2015) discuss the additional need of advancing infertility care within health care practice through improved education opportunities for the medical personnel to ensure proper clinical care is provided.

Sherrod and Houser (2013) conducted a similar study that looked at the perceptions of available resources for individuals in rural settings. Survey research was completed through the use of a Capstone Poll phone interview design, where a total of 237 respondents were contacted. Of the participants, 42.8% knew a couple who suffered from some difficulty of conception, and 12.29% reporting having a personal issue or tie to difficulties with conceiving. Questions that were asked to participants included their

knowledge of the leading medical cause of infertility, with only 89 providing an answer and the other 148 unsure. Another question evaluated whether the participant felt that an individual who suffered from infertility would seek help or assistance with their concerns, with 76.27% responding with yes, they felt individuals who suffer from infertility would seek assistance, and the other 16.53% responding that they did not feel assistance would be sought. More specifically, participants were asked who or where specifically they believed someone with infertility would seek treatment. Answers provided can be found in Table 1, with the most common resources being stated as doctors (50.63%), an OBGYN (9.70%), or a fertility specialist (8.4%) (Sherrod & Houser, 2013).

Table 1

*Who to seek help from*

Type	N=168	%
Doctors	120	50.63%
Fertility specialists	20	8.4%
OB/GYN	23	9.7%
Friends/family	4	1.68%
Clinic	9	3.79%
Male doctor	1	0.42%
Spiritual advisor	1	0.42%
Adoption agency	9	3.79%
Church/Pastor/pray	6	2.53%

Sherrod & Houser (2013). Participant responses to "Who to seek help from". From "Infertility help-seeking: Perceptions in a predominantly rural southern state" by R.A. Sherrod and R. Houser 2013 (2), 110 - 121, p. 15. Copyright 2013 by the Online Journal of Rural Nursing and Health Care. Adapted with permission.

An observational study completed by Van de Belt, Hendriks, Aarts, Kremer, Faber and Nelen (2014) compared the questions sought through demand-driven information with the supply driven information to evaluate whether or not the consumers

questions and concerns of infertility were readily being addressed. Demand-driven information was obtained through three means; online discussion forums monitored by the infertility clinic and attended to by nurses and doctors (accessible only by patients of the clinic), phone consultations (with nurses) and education sessions held for infertility treatments before beginning a treatment regime. Supply-driven information was gathered from 2 available leaflets displayed within the infertility clinic (Van de Belt, et al., 2014).

Both leaflets contained information on various stages of infertility and treatment. The first leaflet was composed of seven chapters – General information, information about reproduction, a fertility assessment, available treatment options, information on the infertility clinic’s team, other information such as the costs associated with treatments and insurance that is accepted at the clinic, and contact information – providing 36 pages of information. The second leaflet was targeted towards two specific infertility treatments, IVF and ICSI, consisting of six chapters. The chapters included general information, pre-treatment steps and information, treatment options and procedures, ICSI, additional information, and information on the clinic’s team (Van de Belt, et al., 2014).

To analyze both the demand-driven and supply-driven information, five categories were used to rate “findability”: “(1) Yes: information fully available in leaflets, (2) Partially: the subject is mentioned, but the present information is not sufficient to answer the question, (3) No: no information at all available in leaflets, (4) Contact needed and no information available in leaflets and (5) Contact needed and partial information available in leaflets.” (Van de Belt, et al., 2014, p. 3). The authors further defined each category into a purpose. The first category being the questions that

are well defined within the leaflets, categories two and three being the areas for needed improvement due to a “lack of information” (Van de Belt, et al., 2014, p. 3), and categories four and five being used to note a difference in general and personal questions or information requests (Van de Belt, et al., 2014).

Findings of the study were calculated from 193 usable pieces of data collected from demand-driven information sources of an original 234 collected. Two of the demand-driven sources, the online forums, and phone consultations both had the most common questions belong within categories of blood loss during the treatments, as well as side effects from any medications. During the education meetings, the most frequent questions were about medication use and directions, and treatment schedules. With comparisons of the questions to availability in the printed materials 11.9% were only partially answered, and 39.4% were not addressed at all within the leaflets. Only 20.2% of questions asked by consumers were completely addressed and answered within the leaflets (Van de Belt, et al., 2014).

Black and Frazer (2012) evaluated concerns of possible abnormal gynecological symptoms in regard to infertility stating that many women in rural communities “tolerated and coped with [the symptoms] until the severity is such that it leads to an inability to carry out daily household tasks or to physical collapse” (p. 572). Based on their findings of determinants of reproductive morbidity Black and Fraser (2012) developed the framework seen in Figure 4.

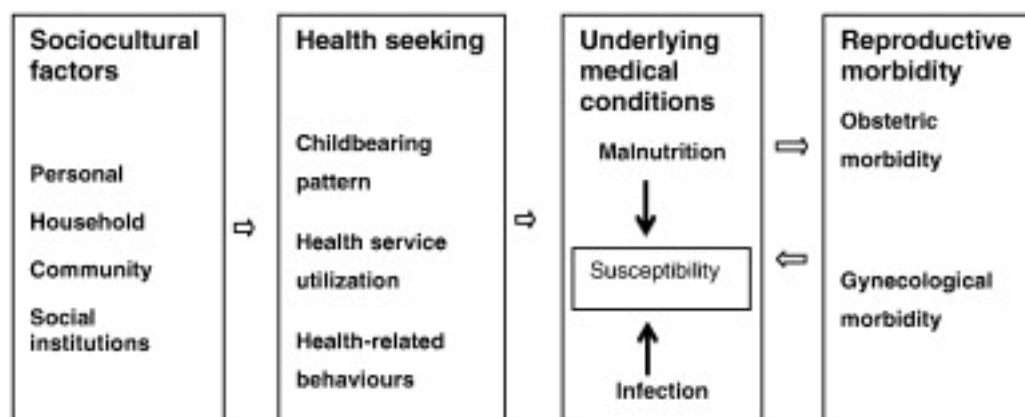


Figure 3. Black and Fraser (2012) framework for determinants of reproductive morbidity. From “The burden of health associated with benign gynecological disorders in low-resource settings” by K.I. Black, and I.S. Fraser, 2012, *International Journal of Gynecology & Obstetrics*, 119, p. S73. Copyright 2012 by the International Federation of Gynecology and Obstetrics. Reprinted with permission (Copyright Clearance Center).

### Additional Background Information

**Infertility and Impaired Fecundity.** Infertility is the inability of a woman of childbearing age to successfully conceive and carry a viable pregnancy after twelve months of unprotected sexual intercourse (Alesandro, et. al., 2009; Bitler & Schmidt, 2006; Chandra et al., 2013; Evens, 2004; Hamilton & McManus, 2012; Macaluso, et. al., 2010; Yadav et al., 2014). Multiple organizations, such as the World Health Organization (WHO) and the American Society for Reproductive Medicine (ASRM) have declared infertility to be a disease (CDC, 2014b, p. 4). Infertility is often used as a generalized term; however, there are varying degrees and forms of infertility.

There are two degrees of infertility, primary and secondary. Based on the definition of primary infertility, miscarriages would be considered to be a form of primary infertility, as the pregnancy did not result in a live birth (WHO, 2014).

Secondary infertility occurs when a woman is physically incapable of conceiving or carrying a second pregnancy after a previous birth of a biological child (Resolve, 2014; Jensen, 2014) or after a prior failed pregnancy attempt or live birth resulting in additional failed pregnancies (WHO, 2014; Mascarenhas et al., 2013; Johns Hopkins Medicine, 2008).

Impaired fecundity is an additional form of infertility in which a woman can conceive, but may struggle to continue a pregnancy to term (Bitler & Schmidt, 2006; Chandra et al., 2013). Both infertility and impaired fecundity have the potential to pose similar adverse impacts on woman who wish to conceive a healthy, viable pregnancy (Chandra et al., 2013). It is important to note that the inability to successfully conceive may not only be from the woman, but may also be a concern with the male counterpart, or a combination of both partners (CDC, 2013). This dissertation focuses specifically on the experiences and perceptions of the woman partner.

**Potential Causes.** Various diseases, health conditions, and environmental factors have the ability to cause both primary and secondary infertility in addition to impaired fecundity. For women, the most common health conditions causing infertility is a hormonal or endocrine imbalance (Luciano 2013), such as thyroid disorders or an imbalance in the reproductive hormones follicle stimulating hormone or estrogen, fallopian tube occlusion, sexually transmitted infections, uterine fibroids, endometriosis, polycystic ovary syndrome (PCOS; CDC, 2013; Eisenberg & Brumbaugh, 2012).

Environmental factors potentially may play a role in a woman's ability to conceive and remain pregnant. The most common environmental factors include

smoking, excessive alcohol consumption, extreme weight gain, loss or being extremely over or underweight, as well as enduring excessive stress (CDC, 2013; Eisenberg & Brumbaugh, 2012).

**Statistics.** In the United States, over six percent of women of childbearing age are affected in some way by infertility (CDC, 2014; CDC, 2014c; Chandra et al., 2013; Chandra et al., 2014; Gupta, Mathur & Gupta, 2013; Jain & Hernstein, 2005; Macaluso, et al., 2010; Missmer et al., 2011). Some differences to note in the prevalence of infertility fall within ethnic backgrounds. The ethnicities that are most prevalent to be stricken with infertility stricken includes African-American (10.5%) and Hispanic (7%) women who have the highest rate of infertility, followed by white, non-Hispanic women (6.4%) (Missmer et al., 2011, p. 1943). The level of a woman's educational background also plays a role in the rate of infertility, stating that those women who have obtained a high school diploma or less are more likely to have a higher infertility rate (8.1% - 8.5%) than those with a college degree (5.6%) (Missmer et al., 2011). These women may or may not have suspected any medical concerns to seek medical assistance to screen, diagnose or treat their cause of infertility. Impaired fecundity affects an additional twelve percent of women of childbearing age who struggle to sustain a viable pregnancy (CDC, 2014; Chandra et al., 2013; Macaluso, et al., 2010).

**Stigmas of Infertility.** The act of carrying and having children is viewed not as a privilege, but as a right. When an individual or couple struggles with infertility stigmas that surface with the potential to create further concerns (Gupta et al., 2013). The inability to achieve parenthood can create concerns for an individual's wellbeing by

inflicting a sense of helplessness, causing depression, elevated levels of stress as well as marital problems (Culley, Hudson, & Norton, 2013). External social stigmas in communities may also exist as other community members may judge a couple's childlessness as being inferior to their ability to have a family to parent, perhaps concluding it is due to marital problems, financial hardship or other unrelated factors (Culley et al., 2013; Gupta et al., 2013; Missmer et al., 2011). Stigmas paired with the concern of other's reactions on the use of infertility assistance causes concerns for up to twenty-six percent of women who indicate having significant reservations or concerns of friends and family learning of their infertility treatment (Missmer et al., 2011).

### **Common Infertility Screenings and Treatment Options**

**Types of Screenings.** There are various types of screenings utilized to aid physicians in determining the possible underlying factor, or factors, causing a woman to suffer from infertility. Screenings are commonly completed by first conducting the most minimally invasive option(s) first unless concerns are raised that would suggest the need for a more invasive approach. Screenings begin with detailed health and family histories and physical assessment, which may or may not then lead to the completion of lab work or medical treatments.

**Health and Family History.** Health and family histories are completed with patients who present possible concerns of infertility as a non-invasive approach that may lead to a potential cause of infertility (Kuohung & Hornstein, 2014; Luciano, 2013). A health and family history screening covers topics such as the duration of time the woman has been trying to conceive, menstrual and ovulation history, if known, any prior surgical



or medical procedures that have been completed, sexual history, family history to determine if infertility may be due to a hereditary factor, and lifestyle choice information such as drinking and smoking tendencies and dietary habits (American Society for Reproductive Medicine, 2012; Kuohung & Hornstein, 2014).

***Physical Assessment.*** Physical assessments are conducted to help determine and identify any outward presenting factors that may be causing or contributing to a woman's infertility. During the physical assessment, there are various topics that are evaluated. The body mass index (BMI) is calculated from the patient's height and weight. BMI is used to determine if the woman is underweight, overweight or obese as any BMI outside of an ideal BMI may be a possible concern for infertility causes (Langley, 2014). Skin is checked for possible conditions that may suggest a thyroid or androgen concern, as well as a complete pelvic exam and possible ultrasound or x-rays to help rule out other possible diseases or conditions (American Society for Reproductive Medicine, 2012; Kuohung & Hornstein, 2014).

***Lab Tests.*** In addition to the previously discussed forms of screening, laboratory tests may be ordered by a physician to determine or rule out factors that are not physically visible within a woman suffering from infertility. The most common laboratory tests include those that require blood analysis, as well as urine testing, swab tests, and biopsies. The aggregate use of testing and screening for infertility causes has increased slightly from 1995 to 2010, from 4.8% to 5.3% respectively (Chandra et al., 2014).

***Blood analysis.*** Blood analysis is used for many types of infertility screens or

tests on a woman. Common reasons blood work is completed is to gain an understanding of estrogen, follicle stimulating hormone and thyroid hormone levels in addition to checking for concerns in patients who may be at risk for diabetes (American Society for Reproductive Medicine, 2012; Kuohung & Hornstein, 2014; Luciano, 2013).

***Urinalysis.*** Urinalysis is commonly used to can help gauge a woman's ovulation patterns, or lack thereof, which may be a primary factor in causing infertility in women who have irregular menstrual cycles (Kuohung & Hornstein, 2014). The common factor being evaluated within urinalysis is luteinizing hormone, which is the natural hormone that triggers ovulation (American Society for Reproductive Medicine, 2012). Urinalysis can be completed to determine if there is enough luteinizing hormone being produced to trigger ovulation, or if there may be an imbalance preventing ovulation.

***Sexually Transmitted Infection.*** Sexually transmitted infection screenings are also commonly completed to check for infections such as chlamydia that can create concerns and damage a woman's fallopian tubes, ultimately causing fertility concerns (Kuohung & Hornstein, 2014; Macaluso, et al., 2010).

***Biopsies.*** Laparoscopy may be required in situations where less invasive procedures or screenings are not conclusive. Through the use of laparoscopy, biopsies are obtained from a woman's uterus, cervix or vaginal cavities to complete further testing directly on the tissues. These tests can determine whether a woman has been ovulating, whether there is sufficient tissue structure, nourishment, and fluid to sustain an embryo, or also screen for concerns such as cancerous tissue cells (Gupta et al., 2013; Kuohung & Hornstein, 2014).

**Types of Treatments.** Of all women within the United States, over twelve percent have utilized infertility treatments at some point in their lifetime (Macaluso, et al., 2010). On average, of women who are evaluated for possible infertility concerns, half go on to receive some form of treatment for infertility (Kessler, Craig, Plosker, Reed & Quinn, 2013). For infertility treatments, the cost to patients, as stated by Wu, Odisho, Washington, Katz and Smith (2014), had a “median overall out-of-pocket expense was \$5,338” (p. 430).

**Medicine.** Depending on the infertility diagnosis determined by the physician, the treatment may require only medication be taken to correct a potential hormone imbalance, or treat diseases such as PCOS (CDC, 2013). Most medications prescribed for infertility stimulate ovulation in patients whose body may need assistance in restarting their menstrual cycle, regulating a hormone imbalance or are not able to naturally stimulate ovulation (CDC, 2013; U.S. Department of Health and Human Services, 2013b). Cost-wise, the average medicinal treatment of infertility ranges from \$200 to \$3,000 per menstrual cycle (Bitler & Schmidt, 2011). The use of medicinal treatment for infertility has increased slightly between 1995 and 2010 based on the NSFG, shifting from three percent to 3.8% respectively (Chandra et al., 2014). Medicine is the most common form of treatment used by women (Farland, Missmer, Rich-Edwards, Chavarro, Barbieri & Grodstein, 2014) who suffer from infertility.

**Surgery.** Some women’s infertility diagnosis may require that they undergo surgical measures to become pregnant. These treatments potentially incur average costs between \$10,000 and \$15,000 depending on the extent of surgery, amount of hospital

care and any needed follow-up care (Bitler & Schmidt, 2011). The common reasons requiring surgery include fallopian tube diseases and complications, endometriosis, uterine fibroids, polyps and scarring within the uterus (U.S. Department of Health and Human Services, 2013b). The use of surgical treatment has remained constant between the years of 1995 and 2010, with the percent of women in 1995 undergoing surgical treatment being 1.1%, as was the case in 2010 (Chandra et al., 2014).

*Assisted Reproductive Technologies.* Assisted Reproductive Technologies, commonly referred to as ART, is sought only once other less invasive and less expensive treatment options are unsuccessful (CDC, 2014a; U.S. Department of Health and Human Services, 2013b). ART is conducted by first removing eggs from the woman's ovaries surgically followed by then crossing them with the man's sperm externally with the final step being to place the fertilized eggs back into the woman's womb (CDC, 2013). Any form of conception assistance in which both a woman's egg(s) and a male's sperm is handled is classified as an ART procedure (CDC, 2014a; Chandra et al., 2014). The most common form of ART is In Vitro Fertilization (IVF), which allows the woman's eggs that were fertilized externally, to be placed back into the woman with hopes of the embryo implanting, resulting in a viable pregnancy (CDC, 2013; U.S. Department of Health and Human Services, 2013b). IVF is the most expensive treatment utilized for infertility, costing a couple an average of \$12,400 (Bitler & Schmidt, 2011; Macaluso, et al., 2010). However, some treatments cost upwards of \$200,000 (Bitler & Schmidt, 2011; Macaluso, et al., 2010). The number of ART procedures that have been completed has increased dramatically between 1995 and 2008, with 59,142 documented procedures in

1995, and 140,795 in 2008 (Chandra et al., 2014; Missmer et al., 2011).

Intrauterine Insemination (IUI) is another form of ART, in which the male partners sperm is inoculated directly into the woman's uterus during the woman's fertile window (CDC, 2013; U.S. Department of Health and Human Services, 2013c). The average cost associated with undergoing the assistance of IUI falls between \$10,000 and \$25,000 (Yu, Mumford, Royster, Segars, & Armstrong, 2014).

### **Types of Resources**

**Internet.** One of the most common approaches of women for finding infertility resources is through the internet (Missmer et al., 2011; Okamura, Bernstein & Fidler, 2002). Over forty percent of women have reported using the internet as a primary source of information for infertility and resources (Lundsberg, Pal, Garipey, Xu, Chu & Illuzzi, 2014). One major concern of public health professionals around the Internet being utilized as a primary medical resource is that the information is not always peer-reviewed and may be inaccurate or display false information (Okamura et al., 2002). Okamura et al. (2002) analyzed nearly 200 websites that provided infertility resource information and found that only 2% of those sites met the minimal standards for responsible print resources based on the Journal of the American Medical Association's (JAMA) rubric. These authors also found that of the sites evaluated, just over 50% were those of commercial companies of which over 70% failed to meet those minimal standards set in place by JAMA. Based on the results of Okamura et al. (2002) findings, it is conclusive that the most reliable resource for many individuals is their clinician, and that there is ample room to improve electronic resources for individuals.

**Physicians.** Seventy-five percent of women refer to their woman's health provider as their primary source of infertility and reproductive health information and thirty-five percent seeking this same medical advice from their primary care physician (Bennett et al., 2015; Lundsberg et al., 2014).

### **Availability and Accessibility of Resources – Rural vs. Urban Settings**

A survey conducted by Sherrod and Houser (2013) noted that when asked, nearly sixty-five percent of individuals indicate that everyone should have access to care necessary in the achievement of bearing a child. In some areas, resources such as an infertility clinic can be difficult for women to seek assistance at often due to a lengthy commute that may be required. Missmer et al. (2011) discovered, through a survey to help understand health care disparities with infertility, which women would travel anywhere from one mile, to two hundred miles to seek medical care and assistance. Sherrod (2004) has also found that disparities exist between rural and urban communities on the availability to receive infertility care, resulting in those within rural communities needing to travel much further, spend additional money and endure more stress than their urban counterparts.

Sherrod and Houser (2013) states that the relationship between infertility and rural living as “those who are infertile and living in rural areas already with limited access to care as a normal part of rural dwelling” (p. 116). This limited access to care in combination to primary care physicians becoming a common first resource for individuals who struggle to conceive can cause concern if those primary care physicians

are not familiar with infertility research, screening, treatment or care (Sherrod & Houser, 2013).

A concern of Lunde et al. (2013) with regards to rural care is a lack of alternative care or treatment options readily available. Lack of additional options was evident by their findings of a comparison of women in rural versus urban communities who had undergone sterilization (Lunde et al., 2013). Women in rural areas were found to be twice as likely to undergo sterilization procedures as a contraception method than those in urban areas (Lunde, et al., 2013). An additional concern of lack of alternative care in rural areas is the higher percent of regret felt after having undergone sterilization procedures than the urban counterpart (Lunde, et al., 2013).

### **Resource Utilization**

The number of women utilizing infertility services has declined between 1995 and 2010 from nearly twenty percent to seventeen percent respectively (Chandra et al., 2014). An even larger decrease was found in women who were readily aware of their current state of infertility, where, in 1995 fifty-six percent of women who knew of their struggle with infertility sought infertility services, but in 2010 that number drastically declined to only thirty-eight percent (Chandra et al., 2014).

The most common infertility service or treatment by women between the years of 2006 and 2010 include advice (6.5%), testing or screening for infertility (5.1%), miscarriage prevention measures (4.9%) and medication to assist in regulation of ovulation (4.0%) (CDC, 2014c; Chandra et al., 2014).

As will be discussed in a later section, some states have implemented insurance mandates regarding infertility service and treatment coverage. According to Bitler & Schmidt (2011), such mandates have been shown to increase the utilization of infertility treatments among women age 30 and above by over 30% more than to those who do not have insurance coverage for infertility treatments (Bitler & Schmidt, 2011). Bitler and Schmidt (2011) also note that the increase in utilization is found to be most common among women who are over the age of 30 and have a higher education level having attended at least some college education. These findings are also present in the research of Jain & Hornstein (2005), where it was found that women who had four years or more of college were the most likely to receive infertility assistance and treatment. According to Chandra et al. (2014), the women who are most likely to utilize infertility services are those that are married, non-Hispanic white individuals who are older and have a higher level of education than those who do not use the same services (Chandra et al., 2014).

### **Insurance**

Lack of insurance coverage for services and treatment has been a leading reason for disparities in the use of and non-use of infertility resources and services (Chandra et al., 2014). Within the United States, nearly fifteen percent of individuals did not have any form of health insurance coverage in 2012 (Cohen & Martinez, 2013), calculating to roughly eighty-five percent who did. Of the individuals who did obtain insurance coverage, sixty-four percent had private insurance coverage – high deductible health plans, flex spending accounts, health savings account, etc., - and sixteen percent had a



public form of coverage, or government Medicare or Medicaid coverage (Cohen & Martinez, 2013).

Of the available private insurance coverage options and carriers, only twenty-five percent include coverage for infertility treatments (Bitler & Schmidt, 2011; Schmidt, 2007), as the ability to conceive is often deemed by insurance companies as not being ‘medically necessary’ (Jain & Hornstein, 2005). Public insurance coverage such as Medicare or Medicaid accounts for nearly twenty percent of the insured population (Henry J. Kaiser Family Foundation, 2014). Typically, these individuals do not have infertility treatment coverage unless a state mandate or legislature exists which requires that the screenings and treatments be covered (United Healthcare, 2014).

**Mandates.** Due to the high costs associated with infertility treatments and lack of insurance providers covering the costs, 15 states within the United States have passed insurance mandates, imposing them as early as 1977 (American Society for Reproductive Medicine, 2014). These mandates require private insurance carriers to cover at least part of the cost of infertility treatment (American Society for Reproductive Medicine, 2014; Bitler & Schmidt, 2011). Even with the introduction of these state insurance mandates, over forty percent of women express concerns over the cost of undergoing infertility treatment (Missmer et al., 2011).

The impact of insurance mandates has been positive, showing an increase in the use of treatments such as IVF within the states who have mandates for coverage (Farland et al., 2014; Klatpongsan, Huckman & Hornstein, 2014). In the states with mandated infertility coverage, 16.6% of women undergo IVF, and only 9.9% of their counterparts

in states without mandated coverage (Farland et al., 2014). There are, however, still concerns that need to be addressed, even within the states with insurance mandates. For example, Missmer et al. (2011) found that in the state of Massachusetts, which has state laws mandating coverage for infertility services, nearly twenty-five percent of women surveyed had no, or only partial infertility coverage under their health insurance.

**Affordable Care Act.** As the Affordable Care Act was established to provide insurance coverage for essential health concerns to all American's (Devine, Stillman & DeCherney, 2014), questions and concerns exist on how it will affect infertility coverage. Under the Affordable Care Act, each state has been left to determine what is deemed as essential coverage. Furthermore, with states that have adopted insurance mandates, there may not be further action under the Affordable Care Act to advance the requirement of coverage of infertility services (Devine et al., 2014).

Concerns under the 2017 administration regarding the uncertainty of the Affordable Care Act existence includes the potential negative impact of existing medical coverages for infertility. The Center for Human Reproduction (2017) quotes specific concerns, "especially in states which mandate that private insurance companies cover IVF". Further concerns have arisen on potential effects on women's health care and extent of coverage for women's health (Hest, 2017).

### **Proposed Public Health Goals for Infertility**

In 2000, the United Nations set forth Millennium Development Goals with infertility being the fifth topic of focus (United Nations, 2014; Hammarberg & Kirkman, 2013). The focus points within the infertility goal include providing universal access to

reproductive health services (United Nations, 2014; Hammarberg & Kirkman, 2013), noting that the two areas that are lacking the most include that of family planning availability and assistance for reproductive health care (United Nations, 2014).

The National Institute of Child Health and Human Development (NICHD) has documented research goals on infertility (U.S. Department of Health and Human Services, 2013). These include evaluating causes of infertility, treatment methods of infertility, the economic impact of infertility and treatment options. In addition to evaluating infertility directly, the various health disparities that can lead to, contribute to or accompany infertility are also areas of interest for research (U.S. Department of Health and Human Services, 2013a). The CDC has set goals that coincide with many of those by NICHD, indicating their intent to promote prevention, detection and treatment of infertility and potential environmental or occupational threats that may be associated with infertility (CDC, 2014b, p. 3).

### **Need for New and Updated Resources**

Concerns regarding resources of infertility are greater than direct medical care for infertility itself. While coping with infertility couples and individuals may want to seek psychosocial support (Read, Carrier, Boucher, Whitley, Bond & Selkowitz, 2014). However, they often struggle to find readily available resources that would benefit them (Read et al., 2014). There also is the lack of understanding by many individuals on possible causes of infertility or sexual health in general (Lundsberg et al., 2014; Sherrod & Houser, 2013). Many women do not demonstrate an understanding of lifestyle factors that can have a large impact their fertility, such as obesity, being underweight, smoking

or sexually transmitted infections (Lundsberg, et al., 2014; Sherrod & Houser, 2013). Furthermore, many women report only visiting their gynecological health professional once a year, or less often, even when they have concerns regarding possible infertility (Lundsberg, et al., 2014). These concerns support the need to provide information necessary to adopt corrective behaviors for women who suffer from infertility due to factors that are treatable or preventable (Lundsberg, et al., 2014; Maculoso, Wright-Shnapp, Chandra, Johnson, Satterwhite, Pulver, Berman, Wang, Farr & Pollack, 2010).

### **Healthcare Needs of Rural Women**

Huttlinger, Schaller-Ayers, Lawson and Ayers (2003) found that individuals who live in rural communities feel those ailments that they may encounter are simply “a way of life” (p. 22) and that there are very few things they can do to alleviate the situation. The authors found that this type of approach to the lack of specialized care and easy access to medical assistance was a form of adaptation through belonging to a rural community (Hettlinger, et al., 2003). This adaptation can cause further concerns with regards to the ability, willingness and drive of women to seek infertility care within a rural community when the proper care is not readily available or known. Lee and Winters (2004) also note that those individuals who reside in rural settings are more apt to request or seek assistance from caregivers that they are more comfortable, or acquainted with. This sense of comfort is yet another factor that may impact the willingness of women to seek infertility care outside of their immediate area as well as seeking a second opinion.

Further concerns within a rural setting when seeking care for a disease such as infertility includes a potential or underlying fear of anonymity for women (Lee &

Winters, 2004) as they may fear that their inability to become pregnant may damage their reputation in some way if others were to find out. Based on the findings of Hettlinger, et al. (2003) and Lee & Winters (2004), there may be barriers for women within rural settings to first overcome the possible fear of being seen for infertility, but also having the proper resources available to gain the needed care. Even for those women who may have the means to obtain care outside of the immediate community, there will also be added stressors based on the familiarity and trust of working with a medical professional that is not an acquaintance, or community member (Lee & Winters, 2004).

### **Summary**

Most of the research that is readily available on the topic of infertility covers means and strategies of individuals and families coping with infertility, but not on the resources that may be available to them, specifically within rural settings. Many calls to action state that more information is needed on infertility, education of infertility and means of screening and treating its various causes (Read et al., 2014). Research must be completed to provide women within rural communities the means necessary to not only have the option available to gain assistance with infertility, to ensure they are comfortable and feel safe seeking assistance, (Hettlinger, et al., 2003; Lee & Winters, 2004) and understand the components of infertility through proper education on the topic (Lundsberg et al., 2014; Sherrod & Houser, 2013).

In this study, I explored the lived experiences and perceptions of women within rural communities about infertility services, information, and understanding. This insight was accomplished through gathering information on each participant on demographic and

socioeconomic characteristics in addition to undergoing interviews to discuss specific topics within infertility, its treatment, and available resources. In the following chapter, I provide a concise description of the methodology that was followed to complete the study.

### Chapter 3: Research Method

In this section, I cover information on the processes and procedures for the completed research study. Topics covered include the study purpose, research questions, participant inclusion requirements and recruitment procedures, ethical concerns and IRB needs, as well as data collection, coding, and data analysis measures. The purpose of this study was to evaluate the actual and perceived availability, quality and additional need for infertility resources within rural communities within the Upper Peninsula of Michigan. Information I obtained through interviews provided insight on how women of childbearing age, who may or may not be struggling with infertility while trying to conceive, gain information on infertility and how difficult it is to find resources, obtain services, as well as understand any readily available materials. An additional focus was placed on what the participants would like to see more information on within the topic of infertility.

#### **Research Design and Rationale**

##### **Research Questions**

Q1: What are common concerns among women in rural communities regarding the topic of infertility?

Q1a: How do community members feel these concerns can or should be addressed?

Q1b: How can infertility materials be created to address these concerns and be more effective?

Q2: What are the community members' perceptions of accessibility to infertility materials within their rural community?

Q2a: What are community member's perceptions of the information provided within available infertility resource materials?

Q2ai: What are community members' experiences with these materials?

Q2aii: How difficult has the community members' experiences been with seeking these materials?

Q2aiii: How well do community members understand the medical information presented in these materials?

Q2b: What additional information would community members' like to see made available within resource materials?

Q3: What impact does insurance coverage or type have on infertility resources?

Q3a: Is there an effect on availability?

Q3b: Is there an effect on quantity?

Q3c: Is there an effect on quality?

### **Central Concepts and Phenomena**

The central concepts of this research were to explore infertility resources in a remote or rural setting through descriptive phenomenology methods include the individuals, the environment, and the possible resources. *Individuals* within this study imply the participants who partook in interviews from within the rural setting, with the *environment* itself being the community. The resources included the local health care providers, health department, additional local resources and written or printed resources that may be available. Phenomena of the study included the evaluation of multiple



experiences observed by participants through their first-hand experience with resources, where applicable, as well as what they would like to see change or be improved within infertility resources.

### **Research Tradition and Framework**

The research tradition that I followed in this study was Heideggerian phenomenology. By following the Heideggerian phenomenology methodology and utilizing in-depth interviews, the focus was placed on the meaning of each individual's lived experience and perceptions (see Johansson et al., 2011; Reiners, 2012) of infertility resources within their community. Applying descriptive phenomenology to the evaluation of infertility resources on availability, community understanding, perceived value and quality of such resources based on lived experiences of community members provided a first-hand insight into individual's experiences while seeking infertility information (see HKIED, 2008; Stanford Encyclopedia of Philosophy, 2008; Reiners, 2012). Additionally, individual beliefs on the desire of additional information was gained through phenomenology by examining commonly expressed interests and concerns among participants. From Pascal's (2010) research, another valuable piece of Heideggerian's basis of phenomenology is that of a researcher's beliefs, experiences, and preconceptions that play an important role in conducting research, as Heidegger notions that it is impossible for a researcher to be completely unbiased and impartial to research (McConnell-Henry et al., 2009; Pascal, 2010).

### **Role of the Researcher**

I, being the researcher of this study, was involved as an observer. I did not inhabit the community of focus. Through conducting the interviews, I was the individual proposing questions to participants and facilitating the conversations while documenting the participants' responses with field notes and audio recordings (see Chenail, 2011).

Potential personal and professional relationships had the potential to surface due to my being a previous member of the rural community. The extent of any possible relationship with participants was of a friendly relation, or acquaintance as I had not held supervisory or instructor relations directly within the community or healthcare field.

### **Biases and Ethical Concerns**

It is important to address potentially biased concerns within this study which had potential to occur during participant recruitment, delivery and facilitation of the interview questions, as well as during the coding and evaluation of collected data (Pannucci & Wilkins, 2010). The specific bias of concern within participant recruitment is selection bias, defined as having an ideal selection of participants based on various factors that may impact the outcomes of the study (Bareinboim, Tian & Pear, 2014; Pannucci & Wilkins, 2010). I created the recruitment materials in a way that is easy to comprehend to not discourage participation of individuals who may have a difficult time understanding medical jargon will accomplish minimizing selection bias. Special consideration was also applied to the materials so that they did not deter any group of women based on age, ethnicity, race or socioeconomic and educational backgrounds. As no cohorts were required for this study to have participants placed in test or control groups, the selection

of participants only needed to follow the general inclusion requirements, regardless of any medical history, representation within the community or familiarity with me (Pannucci & Wilkins, 2010). The only known factor that could have caused concern of selection bias would have been the need for participants to be literate, both verbally and written in English. Inclusion requirements of participants can be found in the next section of this paper.

During the interview process, biases to be avoided include interviewer bias and recall bias of the participants (Pannucci & Wilkins, 2010). To help reduce the potential of interviewer bias, I read the questions and prompts as written on the interview questionnaires, so as to not lead any participants on answers (see Moss, 2014; Pannucci & Wilkins, 2010). The interview questions themselves were reviewed by myself and a fellow doctorate student researcher to ensure the intended outcome and the participants understand the intention of the question, to lead to the answers that can be coded for data analysis (Elo, Kääriäinen, Kanste, Pölkki, Utriainen, & Kyngäs, 2014). Recall bias became a concern for myself as the researcher due to the inability of participants to accurately remember and be able to verbalize events, experiences or understandings from their past (Hassan, 2013; Pannucci & Wilkins, 2010). The potential of recall bias was reduced through proper development and execution of the research questions, much like to reduce interviewer bias (Hassan, 2013; Pannucci & Wilkins, 2010).

Confounding concerns could have appeared within data analysis due to participants' socioeconomic standings and their ability to seek infertility services as necessary when not properly stated during the participant selection and interviews

(Pannucci & Wilkins, 2010). The concerns with confounding were minimized by obtaining a thorough background on participants, and recording all pertinent information on economic standing and health service consumption.

## **Methodology**

### **Population**

The targeted population for this research project was women of childbearing age 18 to 35, who have children, have recently conceived, were trying to conceive or plan to conceive children within their lifetime. As the researcher, I made an exception, and approved through additional IRB review (IRB approval number 04-25-16-0235787), including a participant of age 39 who had been struggling with infertility and treatments starting at age 33. In addition, the population was focused within rural communities. The population was not discriminated based on socioeconomic standing, race, ethnicity, or background.

### **Sampling Strategy**

Gathering participants for this study required nonrepresentative samples. More specifically, I used a mix of both convenience and purposive sampling. Convenience sampling allowed the recruitment of participants to be through a volunteer basis within the small rural communities. Purposive sampling allowed the participants to be recruited in areas which women would likely go to seek infertility services, prenatal services, preconception services or gynecological services.

Convenience sampling is used in infertility research projects as most of these studies requires gaining insight into a targeted population or sub-populations of those that

may be experiencing infertility (e.g., Akyuz, Sahiner, Seven & Bakir, 2014; Bennett et al., 2015). Purposive sampling is also common in infertility research through the use of medical and health professionals to recruit participants (e.g., Obeidat, Hamlan & Clark Callister, 2014). Using purposive sampling also ensured that the participants have a direct contribution to the topic of infertility (see Elo et al., 2014), rather than using a random sample in which the participants may not have any stake in infertility.

### **Participant Selection**

In this study, I based participant selection solely on the following factors: female, between the ages of 18 to 35, and residing within a rural community. The participants were not included or excluded based on the number of children they have currently, a lack of children they have currently, race, ethnicity, religion, socioeconomic standing or stage in their life in regard to wanting children. Each volunteer whom met the requirements to participant were included.

One additional participant, of age 39 (as previously noted), was included and approved through additional IRB review while being outside of the intended age range. This participant approached the researcher with interest in participating due to her struggle with infertility beginning at age 33, which was within the defined age range for the study. Participant criteria were evaluated based on self-reported information by the individual. Such information was gathered using a brief application questionnaire of the individual's demographic information provided prior to completing the interview process.

## **Participants**

In this study, I obtained participants through voluntary means of reaching out and contacting me via the email provided on recruitment documents. After a volunteer participant contacted me, the volunteer participant was sent a brief questionnaire to ensure they meet the inclusion requirements of the study. This questionnaire included questions relating to gender, age, race and ethnicity, socioeconomic factors, and any obstetric history. If the volunteer met the inclusion criteria and agreed to the terms of the research interview, I assigned the individual to a participant code. Documentation of the volunteer was also completed to acknowledge their understanding in the requirements, expectations and free-will of their involvement. Participants had the ability to reach out to me at any time if they had questions or concerns regarding the process.

I added one additional participant who was outside the defined criteria, which was approved through IRB. One participant interviewed, age 39, who fell out of the original target population of age 18-35 had been undergoing infertility testing, treatment and care for over 6 years at the time of her interview, starting at the age of 33, having just successfully delivered her first and only daughter 2 months prior. The inclusion of this participant provided additional details on experiences with infertility in a rural setting as well as ensured saturation via a larger sample size.

## **Sample Size**

The targeted number of participants for this research project was 12 to 15. Phenomenology generally requires anywhere from one to 25 participants dependent upon the research (Mason, 2010). However, as this research project covers a topic that has a

smaller level of understanding and research, obtaining a mid-range of participants ensures accurate and thorough analysis as well as saturation of the data (see Groenwald, 2004; Sandelowski, 1995; Starks & Trinidad, 2007). Saturation was reached through the inclusion of 12 participants through the use of long interviews as recommended by Creswell (see Groenwald, 2004).

### **In-Depth Interviews & Socioeconomic Factors**

The purpose of in-depth interviews is to identify and understand concerns or issues within infertility resource availability in rural communities (Guion, Diehl, & McDonald, 2013) through the participant's detailed responses. Open-ended questions allow for individual perceptions and experiences with infertility resources, screening, and treatments to be evaluated, discovering possible relationships within availability, value, quality, and desire of materials for infertility resources as well as allow for comparisons of use and accessibility based on insurance coverage (Guion et al., 2013; Phillips, Elander, & Montague, 2013; Soderberg, Lundgren, & Christensson, 2011). In addition to the initial in-depth interviews, demographic, socioeconomic and insurance coverage information was gathered using questionnaires for evaluating responses based on social and socioeconomic factors while gaining a better understanding of the community disposition.

### **Instrumentation**

Interview instrumentation that used consisted of open-ended, in-depth interviews with each participant. The interview questions were developed by myself, as there was not a previously established instrument that applied to this research project. Open-ended

questions allowed the participants to elaborate on their personal experiences and understandings of infertility as well as resources they may have sought, utilized, or had available within their community.

Demographic questionnaires were also used to collect the participants demographic and socioeconomic information for further analysis of experiences. As with the interview instrument, I developed the survey based on the specific information that was needed to address the research questions. The questionnaire had both structured, and unstructured sections for participants to complete.

During the interviews, audio recordings were completed to allow for transcription of the data after the meeting has concluded. Along with audio recordings of each interview, I completed field notes to emphasize participant's reactions and queues that occurred during the interviews.

The development of interview questions incorporated cognitive probes as a means of eliciting the types of responses that were intended (Collins, 2003). Various cognitive probes used include confidence judgment questions, to review how well the participant remembers, or how strongly they feel with regards to their response. Retrieval probes directed participants to be conscious about their answers and timing of events. Comprehension helped determine literacy and understanding of the interview questions as well as any materials and resources they had access to within the community. A final cognitive probe that was implemented was think-aloud probes, used to request elaboration on a response, or understanding of a question (Collins, 2003; Willis & Artino, 2013).



The validity of the interviews and questionnaires was established through the repeated use of verification with participant's responses. Verification allowed the researcher to check and confirm the participant's response to ensure that the information was valid and can lead the researcher to additional follow-up during the interview procedure rather than needing to gain clarification after the interview was concluded (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Additionally, the subsequent interviews and questionnaires have reliability and validity based on the population being appropriate to the information being sought (Morse, et al., 2002), as well as the information being retrieved based on lived experiences (Kuzmanic, 2009).

Interview recordings were transcribed verbatim, as heard on the audio recording. Any change in the participant's tone of voice or delayed response was noted for analysis in conjunction with field notes taken by the interviewer (Kuzmanic, 2009). A final means of reducing concerns of validity or trustworthiness of this research was through the comprehensive statement of processes and procedures to obtain the interview data and data analysis (Elo et al., 2014), allowing the study to be replicated.

### **Recruitment, Participation, Data Collection**

For each research question, information was gathered from both the initial questionnaire provided to each participant, as well as the interview questions. Questionnaires were provided for participants during the recruiting phase. The information provided by participants on the submitted questionnaire was verified at the beginning of the participant's scheduled interview and documented by myself.

Interviews were conducted and recorded by myself with the assistance of two audio recorders as well as field notes where applicable. Each participant was scheduled for one interview, lasting twenty-seven to fifty-seven minutes which allowed for sufficient time for responses and follow up or clarification if necessary. After the interview concluded I transcribed the audio recordings for documentation, coding and analysis purposes.

Provisions were also in place to recruit participants through the assistance of social media, and hospitals should there not be enough participants gathered through the displayed recruiting materials. Health providers would have been asked to discuss briefly the need for participants for the research study, providing information to patients who meet the inclusion criteria. Those who meet the criteria would have been provided the research information and my contact information to discuss participation should they be interested. The inclusion of health providers was not necessary at the recruiting stage.

### **Participant Debriefing**

Upon completion of each interview, I asked if they have questions or concerns regarding infertility, its screenings and treatment options as well as general infertility information as well as the study itself. Such information that would have been provided included the contact information for the Health Department, local hospitals, and OBGYN offices and the closest infertility clinic or center. No further information was requested of participants.

Participants did not have any required follow up to complete once they had concluded their interview with me. If the participants had questions, they were urged to let me know, even after the conclusion of the interview session.

### **Data Analysis Plan**

The data analysis framework followed for this research study is that of Ritchie and Spencer's, developed in the 1980s. This framework focuses on a case and theme approach to categorizing and evaluate data on an individual and community basis (Gale et al., 2013). Ritchie and Spencer's framework requires that data is collected and documented first, both through audio and written means, and then categorized followed by analysis. The output of data collection is completed within a matrix, allowing for quick review of data, but also to allow categorization by themes, questions, responses or participant. Within the framework, three levels of analysis were documented. These levels included thematic analysis, which covered the categorization and labeling of things, ideas and responses, such as an individual's attitude towards resources, and reasons for which they chose not to seek resources or care; typologies, which allowed classification of individuals based on backgrounds or other factors; and explanatory analysis, covering how and why participants feel or experienced the various topics within infertility resources and care (NatCen, 2012). Within this framework from Ritchie and Spencer, the contextual lens for this study focused on the individual's, or participants, ideas and feelings towards the experiences they have endured concerning infertility. The application of Ritchie and Spencer's framework to this lens required detailed information be documented from the interviews through transcription of audio recordings, as well as

field notes completed by myself. Coding was completed on various levels, including emotional responses, educational responses, requests, mental responses as well as types of verbal cues.

Ritchie and Spencer's framework has been successfully utilized within the healthcare field as a means of allowing careful research and evaluation of smaller data sets and coding categories. The smaller groups allow for additional detail to be reviewed, accounting for as much of a participant's response as possible. The smaller group works well with the research questions as many are tiered, needing detailed responses, and requiring elaboration from participants to accurately describe their experiences. Specifically, with regards to community members concerns with infertility resources, each participant had the same general response. However, they have different individual responses.

Transcription of the audio from the interviews was completed after the interviews were conducted along with a review of the written field notes taken during the interviews. The transcribed information was then organized by research question and response so that each question could be analyzed independently. Once items were coded, the data was analyzed for common responses or experiences as well as any themes associated with infertility resource use, availability or need.

The codes utilized varied upon the types and quantity of responses received for each question through the various interviews. Starting points or general nodes for analysis included emotional responses, educational responses or understandings, monetary responses or understandings, requests, mental responses, verbal cues as well as

internal and external obligation(s). Timeliness of use was also coded for those individuals who have sought infertility services. In order to gauge the perceived availability of resources, coding was completed to determine the level of difficulty that each participant portrayed in finding resource material as well as difficulty in seeking or utilizing the resources.

Demographic information collected was used to evaluate any commonalities of the coded interview responses based on factors such as education level, age, household income, or type of insurance coverage. It was not assumed that these factors may impact lived experiences, however, it provided insight into additional demographic groups that require more attention and resources with regards to fertility care.

For this research, discrepant cases were analyzed just like any other data, as within phenomenology, not every participant will have the same lived or perceived experiences. Information from any outliers was important to incorporate as a means of applying the small sample size to the larger community. Such outlier information was noted as such during the analysis and discussion sections clearly with a discussion of any discoveries or implications they may have.

Figure 1 shows how each research question was applied to the topics of interest as well as the relationship between the topics.

### **Issues of Trustworthiness**

The credibility of this project was established through verification and saturation. Verification of information and responses was completed throughout the recruitment and interview processes with each participant, ensuring the information provided is accurate

and honest. As previously indicated, questionnaire information was verified during each participant's interview. I also verified that each interview question along with any needed follow-up questions to confirm a thorough response was documented. The verification process also assisted in reducing recall bias of the participants, as they heard the information they provided repeated back to them for understanding.

Transferability of the information gained applies to that of rural communities outside of rural Michigan. With the sample population being interviewed, the gathered information is transferable to other small, rural communities, which may not have an abundant number of resources available for individuals battling infertility.

Ensuring dependability for this project required that the layout of the research methods, questionnaire and interview questions be included to assist in the reproducibility of the project in other rural areas to establish a need and understanding of infertility and available resources in that community. Throughout each interview, I documented any changes or alterations that occurred with interview questions or responses based on each participant's understanding or view of the prompt. Doing so aided in reducing any concern with the misunderstanding of questions, but also demonstrated how the use of verification assists in regaining focus and direction of the participants.

Documentation of each step of the interview process, response, verification, and coding strengthened the confirmability of this study. The use of verification served as a check of the responses given by the participants, ensuring that the understanding or comprehension of the response by myself was accurate to what the participant intended.

Reliability of the coding process was maintained through the use of only one individual conducting the coding process, that being myself. Having only myself involved in coding eliminated any difference in understanding or gauging of a particular code. Throughout the coding process, I compared data sets, which were given the same code to evaluate for consistency, especially for those being coded under the difficulty of seeking care, or timeliness, if the participant does not provide a chronological timeline of events.

### **Ethical Procedures**

Agreements to gain access to participants for interviewing were obtained by one of the local hospitals and subsequent women's health offices to display recruitment information. As the researcher, I hold NIH certification.

IRB approval was required to conduct interviews with participants. The approval needed to allow interviews to have audio recordings conducted throughout as well as a transcription of each interview. Approval was also gained for use of social media for recruitment purposes. IRB approval number obtained for this study is 04-25-16-0235787.

The materials used for recruitment were developed in a way that did not deter any individuals based on their background, race, ethnicity or socioeconomic factors. To ensure the recruitment materials were developed in this manner, the information was presented in a simple and easy to read format, without medical jargon being incorporated. Contact cards were made available for those who may be interested to take home and to request more information from me in the privacy of their homes.

Ethical concerns regarding data collection included participants opting out of the study after indicating their intent to participate, or withdrawal part way through an interview. Had an individual opted out of continuing to participate after expressing interest, any information that they provided would not have been included in the analysis, and, they would be noted as a respondent who did not participate. If a participant chose to withdraw their participation part way through an interview, or shortly after the interview has concluded, their involvement would have been noted, and so long as they provided permission, the information collected from questions answered would be incorporated, with those responses that are missing noted. Had the individual expressed their wish to not to have their information utilized, they would be noted as a respondent, but not included in the final analysis group. Regardless of the timing or circumstance of an individual's request to withdraw their participation, the same opportunity to ask questions or state concerns would be provided. Contact information would also be provided should they have additional questions or concerns regarding the project to follow up with me.

The data obtained through questionnaires as well as interviews was kept anonymous and confidential to protect each participant due to the potential concerns of living in a small community. No names or identifying characteristics are described in the research to ensure all responses are anonymous, and no information regarding one participant's interview responses or characteristics was discussed or disclosed to any other participant to ensure their information is confidential. To ensure that information is kept anonymous and confidential, questionnaires and interviews were notated as participant identification numbers, not by the individual's name.



Once the data was gathered, it was stored on my computer, under password protection. Any written documents such as field notes completed by the me were stored in a safe file box, locked by a key until they were scanned and stored electronically in the same file as the audio recordings on my computer. Once the written documentation was scanned, the paper documents were destroyed. Documentation will be destroyed five years upon completion of this research project unless requested otherwise by a participant. During the project as well as upon completion, I have been and will be the only individual whom will have access to the data.

### **Summary**

As a means of evaluating the perceived lived experiences and literacy of infertility resources within the rural community in Michigan, participants were voluntarily recruited through the use of study information being posted within the offices of a local hospital and its subsequent women's health office(s). IRB approval was required and obtained to recruit participants, conduct and record the interviews with each participant as well as obtain demographic and socioeconomic information. Additional information on the rules and regulations of posting recruitment material within the hospital or physician's offices was also reviewed to determine subsequent IRB approvals required for each site.

Those who wished to participate in the study completed a brief questionnaire, providing demographic and socioeconomic information to ensure they met the inclusion criteria, and for comparative analysis after completion of the individual interviews.

Throughout the interview process, verification techniques were used to ensure the information gathered is valid, reliable and true to the participants lived experience. Upon

completion of each interview, the participant had the option to review any field notes completed by myself for verification purposes as well as review transcriptions of the interview itself.

Debriefing for each participant was completed at the conclusion of each interview. Information provided to the participants included how to contact me should any questions or concerns arise.

Coding and analysis was completed manually by grouping research question responses together. General starting nodes for the coding process have been established as being an emotional, educational, or monetary response or understanding; internal or external obligation; timeliness of seeking assistance, as well as the level of difficulty in finding and understanding resources. After completion of coding data, the results were analyzed for common themes, characteristics, concerns or needs of the sample. Such findings will be outlined in the results section of this study.

## Chapter 4: Results

In Chapter 4, I focus on the results of the study. In this chapter, I also describe the participants, the interview process, data collection and analysis as well as the overall results identified through the coding process. The purpose of this study was to evaluate the lived and perceived experiences of women of child bearing age within rural Michigan in regard to the topic of infertility, more specifically their access to care, knowledge of care, knowledge of the disease, and access to resources or resource materials. I collected data through open-ended interviews were completed to allow for descriptive analysis of those experiences. The interviews were designed to address the following research questions, as outlined initially in Chapter 1:

Q1: What are common concerns among women in rural communities regarding the topic of infertility?

Q1a: How do community members feel these concerns can or should be addressed?

Q1b: How can infertility materials be created to address these concerns and be more effective?

Q2: What are the community members' perceptions of accessibility to infertility materials within their rural community?

Q2a: What are community member's perceptions of the information provided in available infertility resource materials?

Q2ai: What are community members' experiences with these materials?

Q2aai: How difficult has the community members' experiences been with

seeking these materials?

Q2aiii: How well do community members understand the medical information presented in these materials?

Q2b: What additional information would community members' like to see made available within resource materials?

Q3: What impact does insurance coverage or type have on infertility resources?

Q3a: Is there an effect on availability?

Q3b: Is there an effect on quantity?

Q3c: Is there an effect on quality?

### **Setting**

During the interview process, all participants completed their respective interview within the comfort of their own home. While the majority of participants, eight of the 12, had children, four had to complete the interview with their children present, causing mild distraction at times. Two other participants completed the interview while also completing various household chores, such as cooking, and tending to animals. In any situation where the participant was inadvertently distracted from the interview itself, there was no hesitation on their part to ask that a question be repeated or clarified prior to providing their response. I completed all interviews within the same office setting, and no distractions present.

## Demographics

Through the recruitment process, I obtained a total of 12 participants, ranging from age 24 to 39. Of the 12, 11 were married, with one currently dating. The time each spent with their significant other ranged from 6 months to 10.5 years. Eight of the participants had children at the time of their interview, with ages starting at 7 months, up to 10.5 years. Of those with children, seven families had biological children, from either both the mother and father (five families), or only biologically the significant other (two families, where the children were biologically the male's offspring). One family had a child produced from an adopted egg, but the spouse's sperm.

When I asked participants if they intended to have children, or more children, of those who currently have children, five stated they intend to have more, where two indicated that they had no intentions of having additional children, and one not being sure. Of those participants without children, three indicated that they intend to have children, whereas one had no interest. For the participants who do intend to have children or more children, three were expecting at the time of their interview, one was actively trying to become pregnant, with two others stating that they would like to give birth within 1 to 2 years, and another two indicating they would like to have children in 2 to 3 years.

Of the 12 participants, six declared having some form of challenges with pregnancy or conception of varying degrees, including miscarriage(s), preeclampsia, placenta previa, endocrine (thyroid) disorders, having infertility diagnosis or undeclared diagnosis as well as the male partner having low sperm count and motility and formation

concerns. I also asked participants about health insurance coverage. All 12 participants had insurance at the time of their interview, with 10 having private insurance through an employer and two having public insurance through the state. Ten participants were not familiar with their insurance with regards to infertility coverage and the other two knowing that testing was covered, but not actual fertility treatments, or that care was not covered unless deemed medically necessary. Only two participants had received some form of pregnancy resource from their insurance provider – both of whom were covered by public insurance.

I collected some other demographic information. Employment was obtained by nine of the participants, spanning from administrative duties, to nursing, education and environmental positions. The remaining three remained in the home to care for children. Financially, 10 participants stated that their family was content with their current income. The annual income for each family ranged from \$26,000 to \$160,000 (two with less than \$50,000, five within \$50,000-\$70,000, two between \$70,000-100,000 and three over \$100,000). Eleven participants owned their own home, with only one renting at the time of the interviews.

I also collected information on education level. There was a wide range of levels of education. The education level of all participants was beyond a high school diploma, with two having attended only some college, one earning an associate degree, seven obtaining their bachelor degree and two others continuing to complete a master degree.

When I asked what their satisfaction level was within their community, as a whole, on a scale of 0 (*no satisfaction*) to 10, all participants answered between six and

nine. When asked about their satisfaction with regards to healthcare or infertility care in the community, the responses fell within a wider range, from one to nine, with most responses falling under four (eight respondents).

I also considered any potential or known hazards and negative exposures regarding health of participants, with five not being aware of any, three indicating a possibility (hospital risks of two nurses, and possible lead paint exposure), and four knowing a possible hazardous exposure such as herbicides and pesticides, extended radon exposure and black mold. Participants were also asked if they have an immediate health condition that may lead to or contribute to infertility with four indicating yes (celiac disease, PCOS, endocrine imbalance and low iron), two indicating a possibility (having only one ovary, having high anxiety and stress), and six indicating they did not.

I also asked participants further if they do suffer from infertility, with five indicating they do not, four stating they do, two being under the assumption and one was not sure. Eight participants indicated they have not undergone treatments for fertility concerns, with four having been through some form of treatment (thyroid treatment, PCOS, embryo transfer, IUI).

For health care, most participants travelled between 5 and 30 minutes (up to 20 miles), with three traveling longer than 60 minutes (over two hundred miles). The wait time for participants to be seen by a care provider (typically a family/primary care physician or OBGYN) was 1 to 2 weeks, however for specialists (infertility or endocrinologist) the wait time was 2 or more months.

## **Data Collection**

All 12 participants allowed the interviews to be recorded. Of which, there were no participants who asked to end an interview preemptively, skip a question, or to have any information disregarded from the study, or withdraw their participation completely. The interviews were completed via phone with the participants residing within their own home with transcription being completed within one week of completion. Interviews were scheduled between July 17, 2016 and August 25, 2016, with at most two being completed in one day. The duration of interviews varied between 27 and 57 minutes.

I recorded interviews on both a computer-based audio recording program and an external audio recording device upon participant approval. Upon the recordings beginning the participants were asked to once again confirm their approval for recording to occur. No variations in data collection were experienced outside of the expected interview length as they were projected to last up to an hour and a half. All interviews were transcribed as planned, reviewed by participants for errors (to which none were expressed) and used for coding and analysis. There were no unusual circumstances which were encountered during the data collection process.

## **Data Analysis**

### **Coding Process**

In order to analyze the collected interview data, I completed detailed transcriptions of each recorded interview session. Once those transcriptions were complete, each was printed out for manual notation. On each printed interview, all research questions were noted in the left margin of the page. The next step included



reviewing each transcript and paraphrasing the participant's response to determine key topics and ideas that was portrayed. These notes were written in the right margin. By paraphrasing each participants response to interview questions and combining the dismantled transcripts by interview question it helped to keep the responses confidential so as the researcher was not able to recall who the participant was or how the conversation continued. Upon completion of all notes, the transcripts were then clipped by interview question and gathered in envelopes, categorized by interview question so that all twelve responses to one question were accessible together.

I then used the individual interview question response groups to make a list of all responses to the individual questions on one page. Those note pages specific to each interview question were then used to complete open coding of responses into nodes. The nodes used varied slightly across interview questions, with the most frequent including educational responses, sympathetic or empathetic responses, stereotypes, awareness and literacy. After all responses were coded and combined into respective nodes, those classified responses were then evaluated further to determine an underlying common concern, idea or experience through focused coding. As most of the presented research questions were comprised of multiple interview questions, those determined underlying concerns, ideas or experiences were then reviewed within each specific research question to determine a final themed analysis for that given question through the process of axial coding.

The coding process of each interview question and ultimately each research question followed the same process as indicated previously. First, I transcribed the

interview, interview questions noted in the left margins, and paraphrased responses noted in the right margins. Then, I dismantled the interviews by interview question, each interview question compiled together and wrote out to review all responses at once. Third, I determined key topics or themes within the responses to determine nodes, and further evaluated the nodes to determine the underlying theme of responses for each interview question. Finally, all subsequent interview questions that applied to individual research questions were evaluated to find the underlying theme of responses and experiences to the applicable overarching research question.

### **Codes, Categories and Themes**

Throughout the coding process, there were codes, nodes, categories and themes that were both independent within each research question as well as those that applied across multiple questions. Nodes which became common across research questions include education or knowledge – of participants, physicians or opportunities available within the community –, sympathetic or empathetic responses and personality traits – of participants, family and friends of participants, of physicians and community members –, awareness, or the lack thereof – within the community, by physicians and among participants –, literacy levels, and stereotypes – both implied or understood by participants and community members, and experienced by participants. Others, with regard to resources, included availability, accessibility, topics covered, formatting or type of the resource and the means in which it is presented. Within the infertility literacy research questions, common coded nodes included the degree to which each participant

was able to provide a definition, categorized as detailed definitions, general definitions, minimal definitions, vague definitions, or inaccurate definitions.

I coded other responses as stated by the participant, such as when indicating their familiarity with a topic, insurance coverage or experience. These responses include “not sure”, “don’t know”, “no idea”, “not familiar”, “no clue”, “not aware”, and “only if medically necessary”. Upon completing axial coding, it was apparent that there were a few common themes that emerged. These themes included a need and expressed desire of more educational opportunities, substantially more trustworthy resource materials made available, a greater need for more experienced physicians with regards to infertility, more options and treatments made available within the community and a need for financial resources or insurance coverage for the possible care associated with infertility treatment. All codes, categories and themes by research question can be found later in this chapter.

### **Discrepant Cases**

Across all research and interview questions there were very few discrepant cases or responses. In situations where there was a discrepant or outlying response it was still factored into the analysis during the coding process. In some situations, an outlier was the only response outside of the majority, and was therefore not specifically accounted for within the final axial coding, as it was not a significant piece of an overarching theme. Any of the discrepant cases and responses will be discussed further within the results section.

### **Evidence of Trustworthiness**

The credibility of this research study was established through verification of information and responses and saturation. Verification was achieved throughout the research study process, starting with recruiting and ending with data collection and transcription. During the recruiting process applicants were asked to complete a brief questionnaire to determine eligibility. Those questionnaire responses were verified during the interview process when participants were verbally asked similar questions. Throughout the interview process if there was any question or hesitation of a participant's response, clarification was asked so that the participant could further elaborate to provide a clear and concise understanding by the researcher. Upon completion of the interview, all transcripts were transcribed word for word by the researcher and were then sent to the applicable participant to review for accuracy. At this stage of the process, no changes to or concerns within the transcriptions were requested or stated by participants.

Transferability of the study holds to that which was discussed in chapter 3. The data gathered and analyzed is transferable to other small, rural communities as there were no characteristics among participants or experiences specific to those that the participant lived in. The only exception may be in rural communities in states that have insurance mandates for infertility coverage, as the impact of insurance coverage may be different or non-existent as it was found to be a factor within these participants.

Dependability has been achieved through the thorough documentation of the research methods, recruiting materials, eligibility questionnaire, and interview questions to ensure reproducibility of the research. This ensures the ability for similar data to be

collected and analyzed within other rural communities should it be necessary to gain further understanding within the community. Participant misunderstandings were minimized through rephrasing or elaborating on a question when necessary, and such alterations were documented within the interview transcriptions.

Confirmability was achieved through the thorough documentation of each stage of the interview process, verification process and coding. Verification by each participant of the gathered data ensured that the responses being analyzed were accurate and were what the participant intended.

## **Results**

Each research question was analyzed independently as well as collaboratively. This section will outline the analysis and results of each research question individually and as a research project overall.

### **Research Question 1**

The first research question, “What are common concerns among women in rural communities regarding the topic of infertility” was evaluated based upon four interview questions, detailed in Table 2. Each interview question was reviewed independently at first, and then together to result in an inclusive theme or finding.

Table 2

#### *Research Question 1 Coding Progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
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	<u>1-1</u> What do you feel are common misconceptions/misperceptions of infertility?	Education Sympathy/Empathy Stereotypes Awareness Tact Literacy	Education /Literacy	
Q1	<u>1-2</u> Do you feel there are differences in health care options for women who may struggle with infertility in rural communities?	Yes <ul style="list-style-type: none"> <li>• Available options</li> <li>• Reason for disparities</li> <li>• Consequences of fewer options</li> </ul>	Fewer Resources	Lack of/need for increased education/literacy and resources
	<u>1-3</u> What concerns do you have with regards to infertility?	Education Awareness Stereotypes Literacy Financial Resources Other	Education /Literacy Resources	
	<u>1-4</u> What would prevent you from seeking infertility assistance?	Cost/Finances Travel Time Other	Lack of Resources	

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**Interview Question 1-1.** Interview question 1-1 focused on participant’s experiences with misconceptions or misperceptions of infertility within their community. Many of the responses were categorized as falling into the nodes outlined in Table 2.

Educational responses included infertility being “complicated” and more prevalent than perceived, being something that is difficult to fix, people incorrectly self-diagnosing, and having the misunderstanding of assuming that infertility means that someone cannot have kids ever within their lifetime.

Sympathetic or empathetic responses included participant’s stating that they have friends or family who have struggled with infertility, subsequently witnessing its effects,

stating it is a “heroing experience”, or that individuals may often lack sympathy or empathy, and not be able to understand the impact infertility can have on people.

Stereotypes that emerged included “it only happens to older women”, “can’t happen to me”, infertility only being a woman’s issue, if someone is of a higher status, they won’t suffer from infertility, and if you suffer from infertility, you will never have kids.

Awareness, or lack of awareness, responses included there being a lack of advertisement of the issue, the topic of infertility not being discussed, or being “hush-hush” and not publicized, causing it to be a form of taboo.

Tact, the lack thereof, was also a category found within responses to this interview question. Participant’s stated they’ve heard “just adopt”, or “just let it go” in situations where individuals are infertile. Also, experiencing people not taking the topic seriously and refusing to discuss the topic as a concern.

Participants, noting that the term infertility itself is often used broadly, and perhaps incorrectly, also discussed the literacy of infertility as a common misconception or misperception.

Responses to these nodes were further evaluated into broader themes, resulting in education and literacy being the stem of many misconceptions and misperceptions experienced by participants. The coding map seen in Figure 4 provides a visualization of those relationships below.

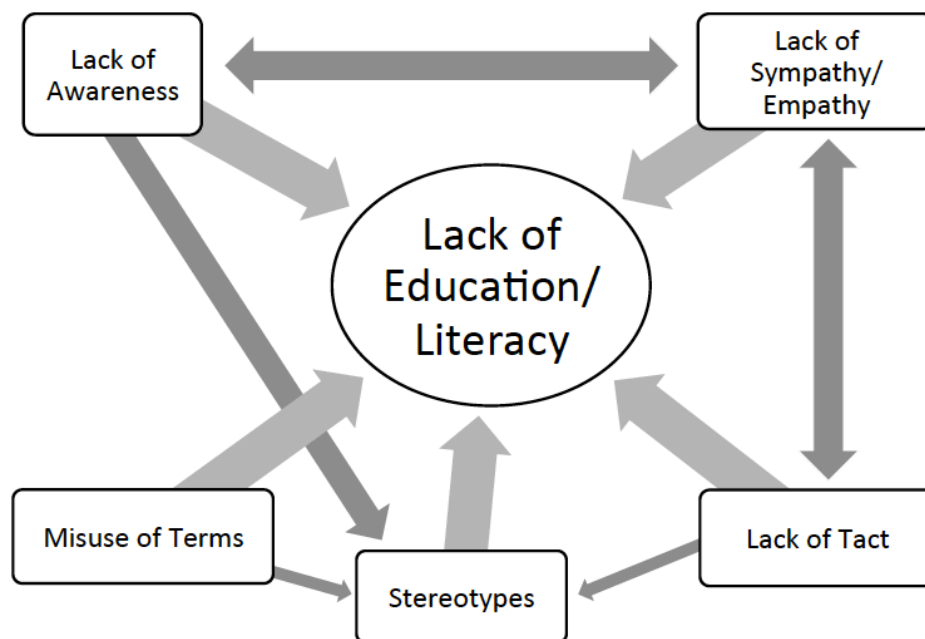


Figure 4 Interview Question 1-1 response coding map

**Interview Question 1-2.** Interview question 1-2 looked at participants' opinions on whether they felt there were differences in the health care options that are available for women in rural communities for infertility care. All participants unanimously agreed that there are differences between rural and urban infertility care options, with the responses being categorized into available options, reasons for rural disparities, and consequences of having fewer options, as seen in Table 2.

The available options indicated by participants include OB-GYN's, family practitioners or getting referrals to specialists, outside of their rural community.

The rural disparity node was categorized from responses given of fewer providers being available, limited specialties of physicians which cater to the communities need,



infertility care is more expensive to have rurally, and there being more options in urban areas due to the higher populations and ultimately more consumers.

Consequences of having fewer options in the rural communities were stated as having to travel for a specialist – the closest being approximately four hours away, one way – also resulting in the need for additional time and money to gain access to care, or that care for infertility in their area is more expensive, if available.

The core of these three nodes was summarized down to ultimately having fewer infertility resources within rural communities.

**Interview Question 1-3.** Interview question 1-3 focused on specific concerns that each participant has with regards to infertility, such as screenings, detection, available treatments or education. This question was initially coded into seen nodes: education, awareness, stereotypes, literacy, financial, resources and others. Table 2 outlines the nodes and coding of interview question 1-3.

Educational responses include individuals having a lack of understanding or general knowledge of infertility, needing more education regarding infertility within the community, and a lack of infertility knowledge on behalf of the local physicians.

Concerns surrounding awareness of infertility included a lack of being informed, as well as the lack of awareness and understanding within the community surrounding the topic.

Stereotypes discussed included infertility meaning that one will never be able to conceive naturally, those who suffer from infertility feeling embarrassed, and assuming that infertility is “someone’s fault”.

Infertility literacy was a concern similar to education, with a lack of understanding and knowledge of both physicians and community members, but also referring to the use of internet serving as the main resource used, which can be problematic.

The financial concerns from participant's responses included a lack of insurance coverage for infertility treatments or measures, as well as other costs such as travel.

The resources node covers a broad range of responses, including the time available to spend with practitioners during office visits – to discuss concerns, questions, etc. – lack of resources available for infertility testing and screening, lack of treatment options, being referred elsewhere for care, using the internet for infertility information, as well as a lack of guidance or support from providers on what is needed to be accomplished for next steps.

The final node, others, included statements of “suffering in silence”, the topic of infertility being too “hush-hush” or taboo, needing to make time for travel to seek care, and concerns of undergoing treatments or side effects of medications.

Summarizing this interview question further resulted in education and literacy as a major concern, much like the result of interview question 1-1, as well as resources, again, much like the result of interview question 1-2. Figure 5 provides a visual for the

relationships among interview question 1-3.

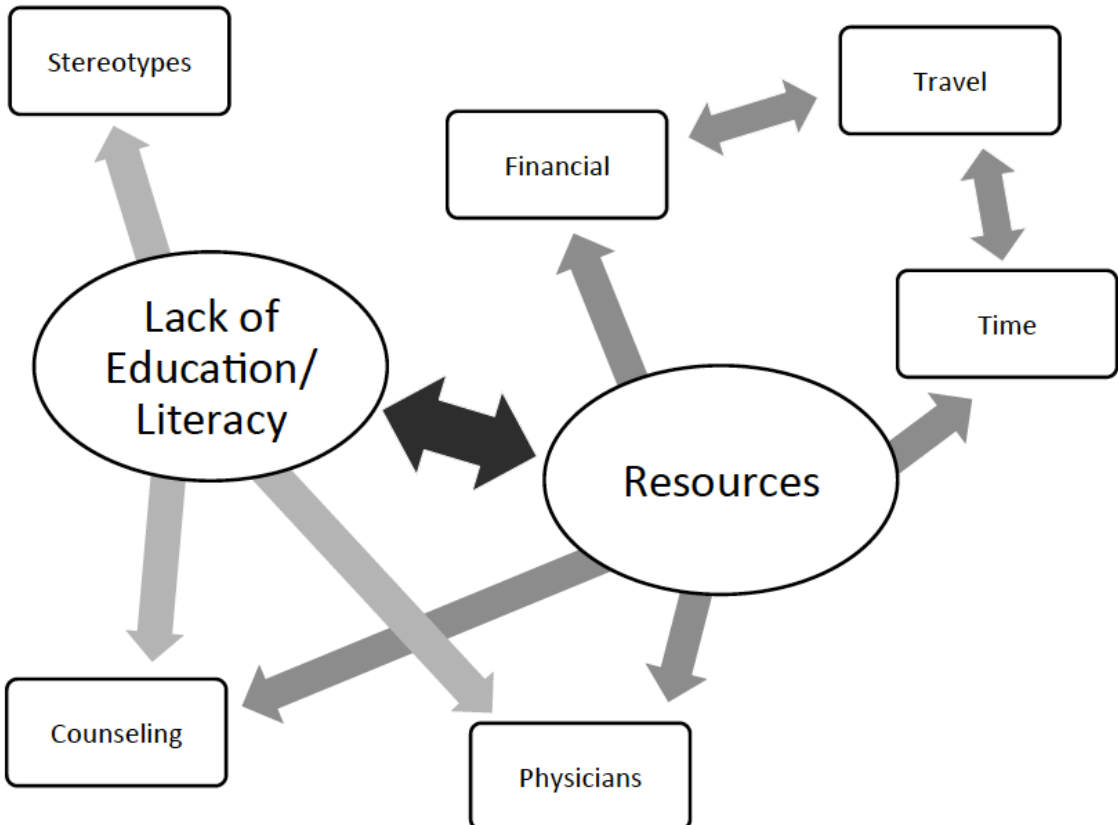


Figure 5 Interview Question 1-3 response coding map

**Interview Question 1-4.** Interview question 1-4 looked at what, if anything would prevent the participant from seeking infertility assistance if it was needed. These responses were categorized into financial, travel, resources or awareness, time and other nodes as demonstrated in Table 2.

Financial responses covered the cost of treatment – the total amount as well as how to afford it – and the lack of insurance coverage for infertility treatments.

Travel concerns included the time necessary to make the travel – taking time from work or being able to correlate schedules – as well as the distance traveled, and ultimately not knowing where the best destination is to travel to for care.

Resource or awareness responses included there being a lack of resources where the participant wouldn't feel comfortable knowing where to start or where to go for care.

Time, again, being a concern or barrier with getting time away from work and the duration needed for infertility care.

The responses categorized as other include feeling embarrassed, knowing the likely pain of treatments, having to take medications, drugs or shots and not knowing the possible side effects of those treatments, as well as indication that there likely would be nothing that would prevent the participant from seeking the care necessary.

Further analyzing of the responses from interview question 1-4 resulted in the final theme being a lack of resources as the major contributor to participants ultimately not seeking care. Figure 6 provides a coding map of the relationship of responses to a lack of resource.

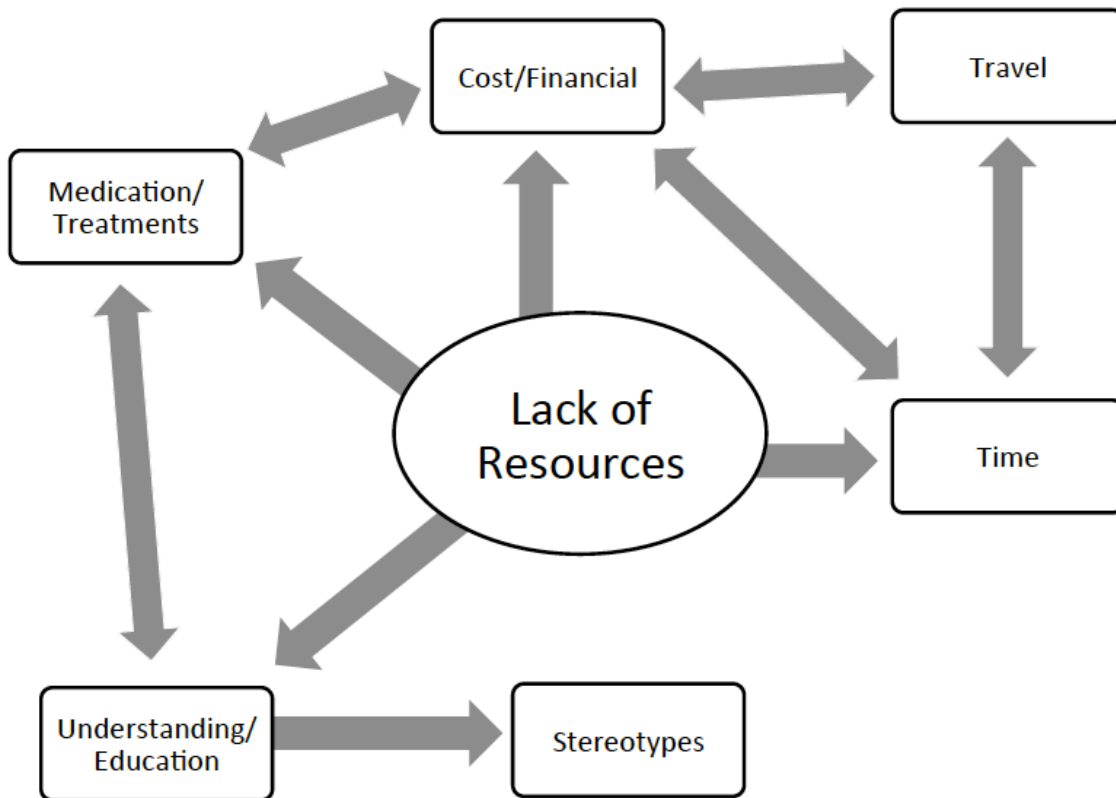


Figure 6 Interview Question 1-4 response coding map

**Conclusion.** Taking into consideration the resulting themes of interview questions 1-1 (education and literacy), 1-2 (fewer resources), 1-3 (education and literacy, resources) and 1-4 (lack of resources), as seen in Table 2, the overarching theme found within research question 1 is a lack of, or need for increased education and health literacy of infertility and an increased need for resources.

**Research Question 1a**

Research question 1a, “How do community members feel these concerns can or should be addressed” looked further into research question 1. This question was addressed through two interview questions, as outlined in Table 3. Each interview

question was evaluated independently and collaboratively to determine the common theme of responses within research question 1a.

Table 3

*Research Question 1a coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
Q1a	<u>1a-1</u> If you could contribute to helping resolve these concerns, what would you do?	Education Sympathy/empathy Awareness Information topics Services Other	Increase awareness	Increase awareness
	<u>1a-2</u> What do you feel would be beneficial to help reduce or address these concerns within your community?	Education Awareness Resources Providers/offices Insurance	Increase providers (knowledge/resources)	

**Interview Question 1a-1.** Interview question 1a-1 evaluated what each participant feels that they themselves could do to contribute towards resolving their concerns stated previously within research question 1. The responses provided were initially categorized into six nodes, education, sympathy and empathy, awareness, information topics, services and other, as noted within Table 2.

Responses grouped into the education node included wanting to increase the available education opportunities on infertility within the community, implementing a health expo that incorporated infertility, increasing provider knowledge, and determining a need base for infertility care within the community.

Sympathetic and empathetic responses included offering support groups and going through a development and advertisement process for those groups.

Increasing awareness across the board with regards to infertility appeared to be important to participants, stating that they would like to see an increased amount of general information provided, information on available options and treatments within the community, where to go within the community to seek assistance and who to talk to, and an awareness of what can potentially cause infertility with how to go about getting tested.

The important topics that participants would make known include what to expect with infertility, resources such as where to go for assistance, next steps, specialists within or near their community and support groups, along with general information such as options, tests available, treatments and causes.

Services that participants would make available were traveling specialists whom would come to their community to see patients, increasing infertility services at the local health department and hospitals, offering one-on-one meetings with someone from the health department, implementing support groups or a small clinic, and having more printed resources within physician's offices.

The other topic covered was with regards to increasing the amount of infertility coverage from insurance companies, at least to be able to undergo the proper testing to determine the cause of infertility.

Further analyzing these six nodes, the overall theme for this interview question was a need for increasing awareness within the community. Figure 7 provides a visualization of the relationship among participant responses for interview question 1a-1.

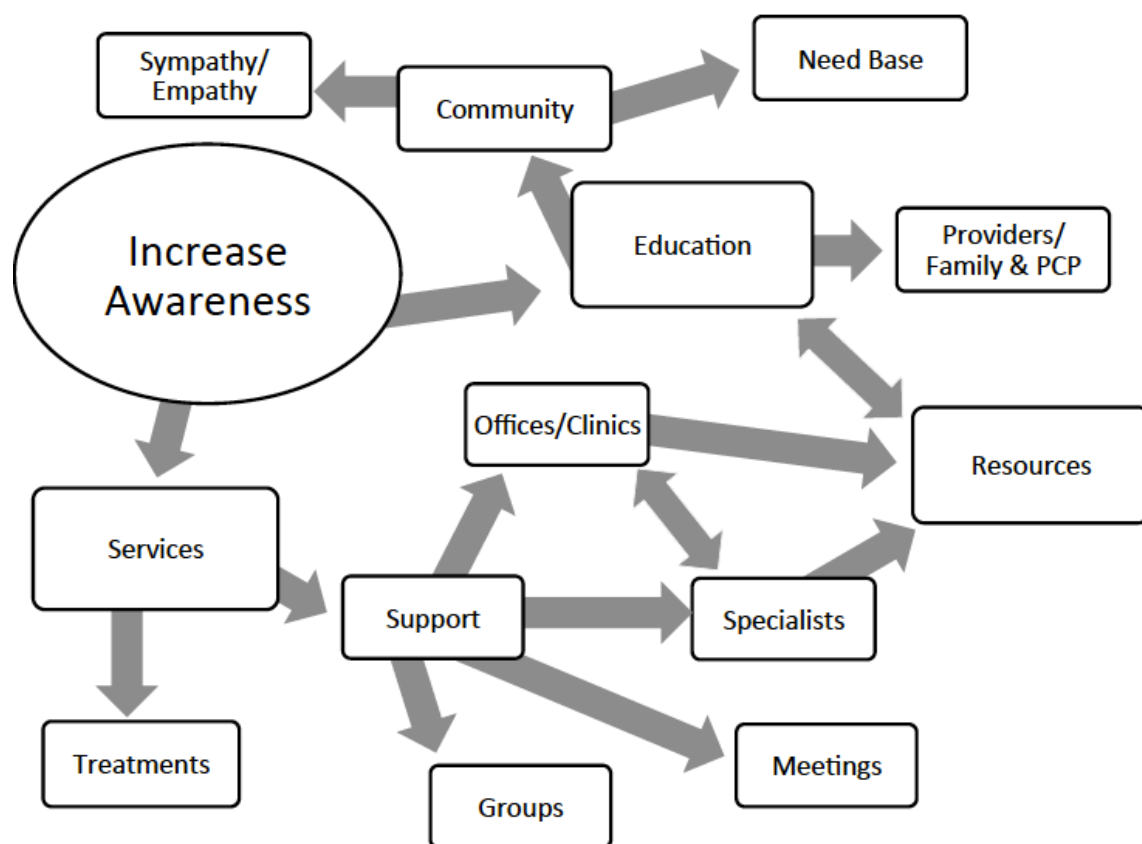


Figure 7 Interview Question 1a-1 response code map

**Interview Question 1a-2.** Interview question 1a-2 asked participants what they think would help reduce the concerns within their community. This question was coded into five nodes initially, as outlined in Table 2. Those nodes include education, awareness, resources, providers or doctor's offices, and insurance.

Educational responses included a general increase in education with regards to infertility within the community, as well as offering classes for those who do struggle with infertility.

Increasing general awareness within the community through the implementation of meetings and educational opportunities was also discussed.



Making more resources, in general, available was important to participants.

Resources that were easily accessible, such as online, that included general infertility information, options available within the community, support groups, clinics and expos.

For providers and doctor's offices, the participants stated that opening a center or clinic within the community would be beneficial. It was also stressed that providers should be more open with regards to the topic of infertility, possibly discussing the topic during annual visits and having an office point of contact for infertility.

Insurance coverage for fertility testing and treatments was also discussed with participants voicing a need for policy reform and mandates implemented for infertility coverage within the state of Michigan.

Analyzing the nodes further it was found that interview question 1a-2 demonstrated the importance of a need for more knowledgeable providers and provider resources within the rural communities. Figure 8 shows a visual representation of the thematic relationships.

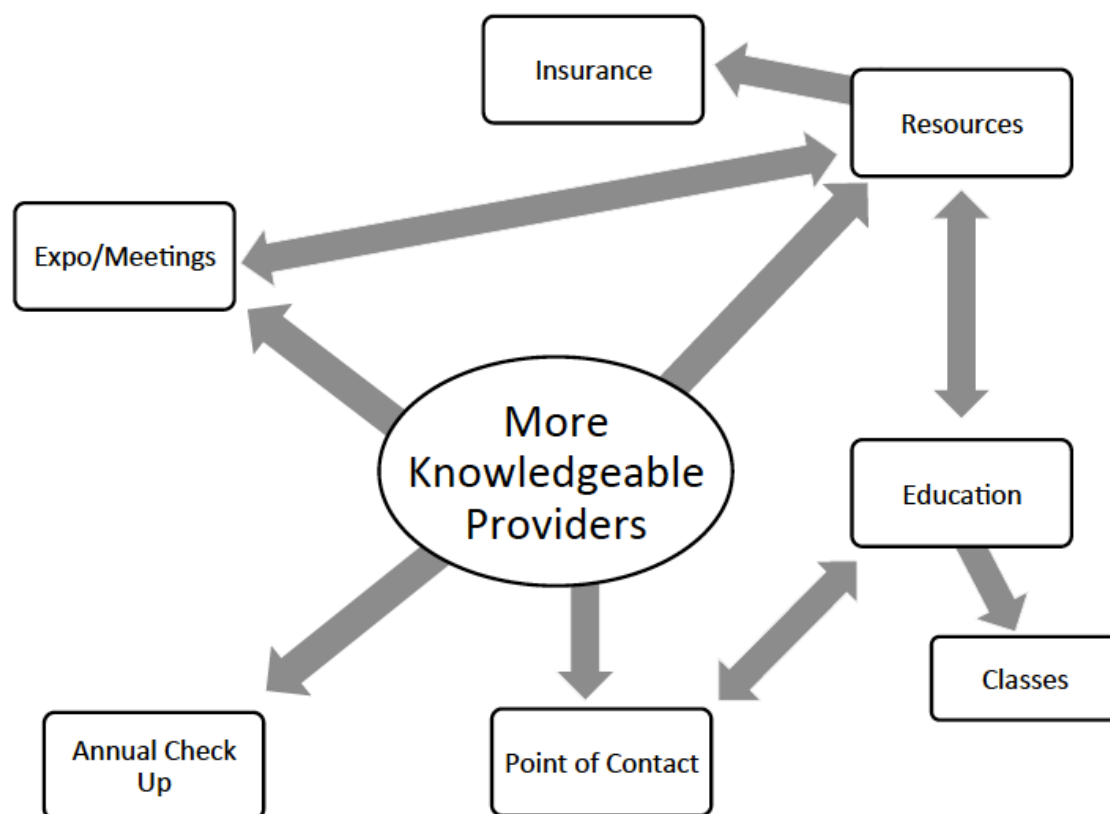


Figure 8 Interview Question 1a-2 response code map

**Conclusion.** Upon evaluating interview questions 1a-1 and 1a-2, research question 1a was found to have an overall theme of a need for increased awareness. This increased awareness on infertility is needed within communities as a whole, including at the individual community member level, physicians and through providing resources within the community.

### Research Question 1b

Research question 1b focused on how infertility materials be created to address the concerns discussed by participants, and be more effective. Two interview questions were used to explore this research question, as outlined in Table 4.

Table 4

*Research Question 1b coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
Q1b	<u>1b-1</u> What new/updated information should be included in infertility resources?	General/background Information Options Updated information Resource type	Updated/relevant Information General/FAQ Community specific	Various formats  Relevant to the community
	<u>1b-2</u> What type or format of resource do you feel would be most rewarding/used by community members?	Printed resources Person lead Online/web based	Printed Person Online	Continually updated

**Interview Question 1b.** Interview question 1b focused on what information or topics participant's felt should be included in infertility resources. The reported topics were initially pared down into 4 nodes, general or background information, options, updated information, and resource type as outlined in Table 3.

Responses for general or background information included providing information on possible causes or triggers of infertility, a general background on the reproductive process, definitions of common terms and infertility itself, statistics or measures both specific to the community as well as overall, and as one participant stated, something along the lines of "what to expect when you're not expecting" for those who have been trying to conceive, but have not been successful.

Within the options node, responses included providing information on the available screening and tests available locally, what treatments are available along with

the steps for treatment and any procedures or medications that may be needed or are common, along with information on providers, specialists and clinics.

Another important factor for participants was just the act of having updated and accurate information provided, stressing that having new and updated information, stats and outcomes for various procedures would be important in addition to information on what available infertility practices and new procedures may exist for treatment.

Focusing on the type of resource, participants touched on various formats, which will be addressed in interview question 1b-2.

A thorough review of interview question 1b-1 found that the most important aspects of an infertility resource includes that the information be updated regularly and is relevant, community specific and provides a general understanding of the topic of infertility.

**Interview Question 1b-2.** Interview question 1b-2 further looked into what type or format of resources they felt would be the most beneficial for the members of their community. In addition to the direct responses to this interview question, those responses from interview question 1b-1 which addressed a resource format were included within this analysis. Table 3 outlines that this interview question was coded into three categories, printed resources, person lead, and online or web based.

Printed resources or materials were important to participants because they served as a take home item, which could be referenced at a later time. Specific formats of print materials discussed included pamphlets, brochures, and handouts, which could be made readily available in doctor's offices.

Person lead resources included person-to-person meetings, or one-on-one's, classes, led by physicians or another knowledgeable healthcare provider, support groups, which could provide clarification for some individuals on the processes they may be going through, as well as learning other's experiences that have gone through the same situations.

The third category of resource that was discussed during interviews was online or web based resources. Participants discussed online materials and websites as being new age, easily accessible and can be of lower cost than printed materials. They further discussed these forms of resources, stating they should be interactive and uplifting, with one participant taking it a step further and suggesting an app.

Within interview question 1b-2, these three categories continued after the initial round of coding as they each showed an independently valuable role among participants responses.

**Conclusion.** Based on the responses to both interview questions 1b-1 and 1b-2, research question 1b found that participants wanted to see infertility materials available in various formats, as different people will be drawn to different types of resources, but agreed that the information presented needs to be relevant to their community and constantly updated as processes, procedures and options change.

## **Research Question 2**

Research question 2 looked at "What are the community members' perceptions of accessibility to infertility materials within their rural community?". This question was evaluated through the use of six interview questions, outlined in Table 5.

Table 5

*Research Question 2 coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
Q2	<u>2-1</u> Off the top of your head, how many sources of infertility materials would you say is available within your community?	None Physicians Locations Resource	Family physicians Clinics/hospitals OBGYNs None	
	<u>2-2*</u> How easy do you feel it is to access those resources?	Resources rating Physicians rating	Actual printed resources = very difficult Physicians (as starting point/first step) = moderate	
	<u>2-3</u> How many do you feel there should be available?	Types Locations "More" "Couple" Sufficient as-is	"Multiple" "More" "At least a couple"	Outside of primary/family /OBGYN physicians or use of internet, very difficult – there are no written materials or specialists (need more, make more prevalent)
	<u>2-4</u> Are you aware of infertility resources in neighboring communities?	Not aware Locations Distance	Majority = not aware	
	<u>2-5</u> Do you feel there are fewer infertility resources within your community compared to others?	Yes! Similar Possibly Depends More	Depends – close by is similar or possibly more, but further out (2+hrs), fewer	
	<u>2-6</u> What do you think would be the most common forms or types of information and resources sought for infertility?	Resource Type Topics	Resource type – Specialist/physician; online resources Topics – General information; next steps; options	

\*Participant's asked to rate based on a 0-10 scale, 0 being impossible and 10 being very easy.

**Interview Question 2-1.** Interview question 2-1 asked participants how many infertility resources are available within their community. These responses fell into one of four nodes, none, or no resources known, physicians, locations, and resource.

Half of the participants (six) indicated that they were not aware of any resources available within the community for infertility.

Physicians were indicated as a form of resource for infertility, which could be OB-GYN's, family physicians, women's clinics or clinics and local hospitals.

Locations discussed, in addition to doctor's offices and hospitals, include the health department, Planned Parenthood, or specialists outside of the community where people are often referred to for infertility care.

Resources that participants listed include being outsourced by referral, being provided general pregnancy resources, as well as one participant being provided a miscarriage pamphlet while in the emergency room.

As these four nodes were important factors within participant's responses, they were not pared down further within analysis of the interview question.

**Interview Question 2-2.** Interview question 2-2 asked participants to rate their experience with the ease of access to infertility resources within their community. This was completed on a scale of 0 to 10, with 0 being impossible to access, and 10 being very easy to access. This data was initially evaluated based on rating given (0, 1, 4, 5, 6, 7, and 10), and then by the type of resource (physicians or resources in general).

Within the physician ratings, common topics or concerns reported included being referred out to a specialist (ratings given of 0 and 6), the wait time to see a physician (ratings of 4 for a specialist, and 7 for family physician), physicians serving as a starting point (ratings of 5, 6, and 10) but having a lack of infertility knowledge and willing to refer to a specialist (rating of 6).

Resource ratings were centered around three aspects, availability (rated as a 1), trustworthiness (rated as a 1) and needing to request the materials (rating of 10). Participants discussed concerns with materials not being made readily available, with those that are easily accessible online carrying a concern of trustworthiness as it can be difficult for individuals to know whether to trust a site or not. One participant stated that requesting materials is easy, as you can simply call your providers office or the local health department for information.

**Interview Question 2-3.** Interview question 2-3 asked participants how many resource materials they feel should be readily available within their community. These responses were categorized both quantitatively as “more”, “a couple”, or “sufficient as-is” and qualitatively into the types or locations of resources.

The specific types of resources that participants discussed included having someone within the community, or at the community level, that can be approached, specialists, more general providers with infertility knowledge, trustworthy websites, having a center or office that provides testing and treatments, as well as classes and pamphlets that are presented in hospitals, clinics and health departments.

Key locations that participants stated they would like to see such resources included hospitals, doctor’s offices or clinics, the health department, and within an infertility center.

Participants who quantified their response were coded into “more”, wanting more resources, in general, or stating that multiple resources would be important. Those



classified as “a couple” stated “at least a couple” or “one or two” resources. One individual felt that the number available was sufficient as a starting point for resources.

As stated by one participant, “multiple [resources] has a greater chance of reaching more people”. The focus found of this interview question is really having at least some resources, whether it be “more”, “a couple” or “multiple”.

**Interview Question 2-4.** Interview question 2-4 explores participant’s familiarity with infertility resources in neighboring communities. Responses to this question were classified into three nodes, not aware, locations, and distance away.

Of the twelve participants, seven were not aware of any infertility resources within neighboring communities.

Locations were commonly referenced as an infertility resource within neighboring communities. Such locations include health departments, doctor’s offices (family and primary care) and hospitals, OB-GYN offices as well as adoption clinics or centers.

Some participants elaborated further on how far resources in neighboring areas, specifically for infertility care, are from them. These distances were stated as being one to two hours away, and four or more hours one way.

Reviewing the interview question further, the common theme in regard to available infertility resources within neighboring communities was that the majority of participants were not aware of any resources specific to infertility care, outside of the two participants who elaborated further with distances travelled to seek assistance.

**Interview Question 2-5.** Interview question 2-5 asked participants if they felt there were fewer infertility resources within their immediate community compared to

other communities. The responses were categorized into five nodes. These nodes included yes, similar, possibly, depends and more.

Two participants strongly stated that yes there were definitely fewer infertility resources within their immediate rural community.

Those participants who stated the resources were similar in their community as compared to others clarified further that they have similar resources to those communities that are close by, within a one-hour proximity, stated simply that they are the same or pretty even in comparison.

Two participants felt that their community possibly had fewer resources.

For the participants who indicated that it may depend, they further explained that they felt like their community may have the same or more infertility resources locally, however, far fewer than those communities who were two or more hours further out.

Some participants also felt that their community had more infertility resources than immediate surrounding communities, clarifying within a one-hour radius.

Taking into consideration the broad perceptions gained by participants for this interview question, the final coding for interview question 2-5 focused on their community possibly having more resources than those close by, but not communities further out, following that of those who stated it “depends”.

**Interview Question 2-6.** Interview question 2-6 asked participants what they felt the most common information and resources sought for infertility would be within their community. Responses were categorized into two nodes, the type of resource, and topics searched.

The types of resources that participants felt would be the most commonly sought within their community included physicians, whether trying to find a specialist, or making appointments with their family or primary care provider, printed copies of materials such as pamphlets or brochures and online or web based materials.

Perceived common topics that participants felt community members would seek included first and foremost general infertility information, reviewing options and treatments that are available, diagnosis or testing measures, possible underlying causes, signs and symptoms, “why can’t I get pregnant”, referral or specialist information, prevalence or statistics on infertility, likely causing a feeling of “I’m not alone”, miscarriage(s), self-help such as what one can do differently, and “not getting pregnant”.

Evaluating these two nodes further, interview question 2-6 was found to have two major themes, one with regards to the infertility resource type where the common perceptions centered around specialists or physicians and the use of online materials, and the topics covered narrowed down to general information regarding infertility, next steps for seeking assistance or care and available options.

**Conclusion.** Taking into consideration the interview questions within research question 2, it was found that the community members’ perceptions of infertility resource accessibility in their own communities is very difficult outside of seeking assistance from their primary, family or OB-GYN physicians or resorting to the use of the internet. None of the participants were able to clearly distinguish that any written materials or infertility specialists were available within their rural community, or if they are available were not aware of them.

## Research Question 2a

Research question 2a sought to evaluate participants' perceptions of information provided within any available infertility resource materials they were familiar with. Table 6 provides a visualization of the coding progression based on the applicable interview questions, through the various stages of coding.

Table 6

### *Research Question 2a coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
Q2a	<u>2a-1</u> Are you aware of any infertility resources available to you within your community?	No/none Healthcare provider Other	Majority = not aware Physicians	Physicians: good in general, but lack with regards to infertility; could be more accessible and transparent
	<u>2a-2</u> What types of infertility resources are available to you within your community?	Providers Locations None/not Sure Others	Physicians/doctor's offices	Print materials: very limited – poor or nonexistent; only specific illnesses/diseases available

**Interview Question 2a-1.** Interview question 2a-1 looked at whether participants were aware with any readily available infertility resources within their community. The responses were categorized into three nodes, no or none, healthcare provider and other.

The responses included within the no or none node included simply stating that they were not aware of any, that there were none that they were aware of, or that they had not seen any available.

Healthcare provider responses included physicians, doctor's offices, being referred to a specialist or clinics.

Those that fell within the other category included participant's being aware of pamphlets on specific conditions, such as PCOS or miscarriage, or pamphlets that were not directly about infertility, but may have touched on infertility as a symptom to a disease or condition.

The overall theme within interview question 2a-1 was that the majority of participants were not aware of infertility resources within their community, outside of physicians being considered a reference.

**Interview Question 2a-2.** Interview question 2a-2 served as a follow up to interview question 2a-1, asking what types of resources are available within the community on infertility. This question was categorized into four nodes initially, with providers, locations, others and none or not sure.

Providers that were expressed as an infertility resource include physicians or doctors in general, and primary care physicians.

Locations for resources provided were the doctors' offices and clinics as well as the local adoption clinic.

Two participants stated that there were none, or that they were unsure of any type of resource within their community.

The other responses included doctor appointments, as well as documents or pamphlets on specific conditions, again not directly infertility related.

Taking all of the response themes into consideration, it was determined that the major type of resource within the participants community was physician's offices where

participants felt some minimal information could be obtained through handouts but also using the physicians themselves are a resource for infertility information.

**Conclusion.** Axial coding for research question 2a found that there were two major types of resources to be considered, the physicians and print materials. The perception of physicians is that they are a good resource in general, however, they lack with regards to infertility experience and knowledge. Some participants even noted that they felt physicians could be more easily accessible and transparent with patients. Print materials were reportedly very limited, poor at best, but seemingly non-existent with only specific diseases or conditions made readily available, of which infertility was not a central focus.

### Research Question 2ai

Research question 2ai looked even further into participant's experiences with infertility resources within their community, which were discussed in research question 2a. Table 7 provides a breakdown of the interview questions and coding progression of the gathered data.

Table 7

#### *Research Question 2ai coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
Q2ai	2ai-1** For each type of infertility resource you have encountered or experienced, please rate them	Healthcare provider <ul style="list-style-type: none"> <li>• Nurse midwife</li> <li>• Specialist</li> <li>• Family provider</li> <li>• Physicians</li> </ul> Written materials	Written materials – very poor Physicians/provider – varies based on physician; family physician rated higher than specialists	Very limited/basic – only specific illnesses or diseases are provided/available when applicable

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<p><u>2ai-2</u> What do you like/appreciate from the materials?</p>	<p>Physicians</p> <ul style="list-style-type: none"> <li>• Emotional</li> <li>• Sympathy/empathy</li> <li>• Knowledge</li> <li>• Personality traits</li> </ul> <p>Materials/handouts Other</p>	<p>Physicians were caring, sympathetic, understanding, knowledgeable, listened and discussed Handouts</p>
<p><u>2ai-3</u> What did you least like/appreciate from the materials?</p>	<p>Physicians</p> <ul style="list-style-type: none"> <li>• Accessibility/availability</li> <li>• Knowledge</li> </ul> <p>Resources</p> <ul style="list-style-type: none"> <li>• Handouts/materials</li> <li>• Information provided</li> </ul> <p>Other</p>	<p>Physicians – lack of accessibility, lack of infertility knowledge, lack of transparency Resources – none provided; lack of information included</p>
<p><u>2ai-4</u> How do you feel these can be improved to elevate your experience?</p>	<p>Knowledge/education Resources Services Sympathy/empathy</p>	<p>Education – more education on infertility; provide more resources Resources – handouts made readily available Services – offer screening/testing; follow up with patients; decrease wait times</p>

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\*\*Participants asked to rate based on a 0-10 scale, 0 being a horrible experience and 10 being an amazing experience.

**Interview Question 2ai-1.** Interview question 2ai-1 asked participants to rank their experience with any infertility resources based on a 0 to 10 scale, where 0 was a horrible experience, 5 being a so-so experience and 10 being an amazing experience. Responses to this prompt were categorized into two nodes based on resource type of either a healthcare provider or a written material.

Healthcare provider experiences for participants, in general, were reported to be with a nurse midwife, which rated as an 8, infertility specialist, who rated as a 4, family

providers who were ranked as both a 4 and 7, and general physicians, who ranked between a 1 and 9 (actual reported ratings 1, 4, 5, 5, 6, 7, 7, 7, 8, 9). Most of the participants did not specifically see their healthcare provider with regards to infertility care to determine the rating provided. Participants considered physicians, in general, to be a resource and evaluated their overall experiences as such.

Written materials were ranked poorly, with only a miscarriage pamphlet being discussed, and was rated as a 2 for the participants experience.

Interview question 2ai-1 was further evaluated into more general themes, with written materials being found to have poor experiences within the participants rural community, and with regards to physicians, the experiences varied greatly based on specific providers. It was, however, found that family care physicians as a whole rated higher than infertility specialists patient experiences.

**Interview Question 2ai-2.** Interview question 2ai-2 focused on what participants liked or appreciated the most from the resource(s) previously discussed. These responses were categorized into three nodes of physicians, materials or handouts and other, with physicians being further broken down based on response types of emotional, sympathetic or empathetic, knowledge and personality traits.

Looking within the physician's resources, emotional responses included participants feeling as their provider was caring, having a positive demeanor, and being kind and welcoming. Participant's also noted their physician's being open to discussion, providing reassurance that "you're not alone" with regards to struggling with infertility, as well as their physician having a genuine interest in the participant having a child.



Similar responses were categorized into the sympathy and empathy node, where participants indicated that their physicians were compassionate, personable, sympathetic and caring in nature.

Many participants also noted physician knowledge within positive experiences. They stated that physicians were helpful and provided explanations and options when applicable, and answered any questions or concerns they may have had.

Some participants noted personality traits of their physicians as being something they appreciated during their interactions. The personality traits mentioned include the physician being confident, having a helpful nature and having good bedside care.

With regards to printed materials or handouts, participants noted that they appreciated being able to take home pregnancy handouts after an appointment, which could be referenced at a later time.

Other topics participants appreciated of resources they've experienced included during visits with physicians included learning how to increase chances to obtain pregnancy, as well as being able to appreciate the overall quality of the resources that are available within the community.

Final review of interview question 2ai-2 found that participants appreciated the few handouts that were provided as a means of going back to reference information at a later time, but also that their physicians were caring, sympathetic, understanding of a patient's situation, knowledgeable and open to listen and discuss situations, questions and concerns.

**Interview Question 2ai-3.** Interview question 2ai-3 asked participants what they

liked or appreciated least in the same experiences as discussed in the previous interview questions related to research question 2ai. The responses, again, were categorized similarly to those of interview question 2ai-2, with physicians, resources and other being the main nodes.

Physician related responses were further broken down into accessibility and availability, and knowledge. Characteristics of experiences that participants expressed within the accessibility and availability node included an overall need of physicians to be more readily and easily accessible by patients, the wait time to see a physician being long, the length of time allotted for appointments being too short or feeling rushed. Some participants stated a general dislike of their physician.

Knowledge of physicians was a dislike for many participants as well, some indicating a lack of general infertility knowledge and lack of knowledge of treating infertility, not being given an explanation or cause for being infertile, a lack of transparency when working with patients, and one participant indicating their particular physician tends to assume what is best for her, rather than asking and discussing it.

With regards to resource materials specifically, participants responses appeared to focus around the handout or material itself, and the information provided within. The handouts or materials themselves were of concern due to the lack of materials available or provided where participants voiced a desire to be given some kind of take home information.

Focusing on the information provided within resources, outside of there being the lack of information provided in general, one participant stated that rather than being

provided any information, she was informed that “pretty much this is your only option” to her situation where no justification or discussion was continued on what other options may exist.

There was only one response classified within the other node, with the participant indicating that although she likes her physician, there was one situation where an illness was left to progress further than it should have.

Focused coding of interview question 2ai-3 found that of physicians and resources, main concerns were a lack of accessibility, infertility knowledge and transparency of physicians, and the absence of resource materials available.

**Interview Question 2ai-4.** Interview question 2ai-4 asked participants to identify ways in which changes could be made or implemented to improve these experiences. Coding the initial responses resulted in four nodes of knowledge and education, resources, services, and sympathy and empathy.

Participant’s ideas for positively changing their experiences that fell within the knowledge or education node included a general increase in the understanding of infertility within both the community and among healthcare providers, possibly denoting one physician to have a focus or special interest within infertility, and having additional research completed within the community on the topic of infertility.

Responses related to resources included providing more information or resources in general with regards to infertility, creating new and updated resources, providing take home information on what to expect, how to prevent, who to contact and next steps when it comes to finding out you are suffering with infertility.

Services that were suggested to be implemented included having basic or general testing and screenings available to anyone who would wish to have them completed, implementing a follow up process with physicians either by phone or email, bring in additional OB-GYN providers to help reduce wait times to be seen and having those physician offices stick to scheduled appointment times, and developing a way for patients to work with the appointment scheduler to determine the length of appointment that may be needed to discuss concerns and establish a potential need for testing or screenings.

Sympathetic and empathetic suggestions included keeping patient's informed of any delays for appointments, possibly rescheduling if necessary, physicians being more transparent in their approach and information being provided and practicing to be more compassionate towards patients.

Evaluating these four nodes further, three themes emerged for proposed improvements by participants. These included education based, through implementing more infertility education and providing more community resources, resource based where more handouts are made available and provided by physicians, and services offered being increased in regards to infertility screening and testing, as well as patient centered services in physician's offices by providing follow ups and decreasing appointment wait times.

**Conclusion.** The four interview questions used to address research question 2ai were further reviewed as a whole, resulting in the common theme with regards to experiences with resources being very basic or limited, especially with written materials or handouts, which only depict specific illnesses, diseases or conditions that do not cover

infertility, unless noted as a side effect. The experiences with physicians was also very limited, concerns expressed with the wait times, lack of follow up and lack of knowledge regarding infertility.

### Research Question 2aii

Research question 2aii looked at how difficult it was for participants to find the infertility resources within their community. To evaluate this, three interview questions were asked with the responses analyzed as seen in Table 8.

Table 8

#### *Research Question 2aii coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
	<u>2aii-1***</u> Please rate the ease of access of the infertility materials	General Internet Community	Internet is easy Within community is difficult (outside of making doctor appointment)	
Q2aii	<u>2aii-2</u> Please explain your experience with finding these resources/materials	Online Physicians Not sure where to start	Online – easy to search, but not always trustworthy Physicians – serve as a good starting point	Extremely difficult outside of using the internet  The internet isn't always trustworthy or accurate, depending on source used or referenced
	<u>2aii-3</u> How would you improve the ease of access of these materials?	Physicians Resources Websites No changes Other	Physicians – increase knowledge of current practitioners; bring in specialist(s) Resources – increase availability, provide trustworthy web resource	

\*\*\* Participants asked to rate based on a 0-10 scale, with 0 being impossible and 10 being

extremely easy

**Interview Question 2aii-1.** Interview question 2aii-1 asked participants to rate their experience with regards to ease of access to infertility materials on a scale of 0 to 10, with 0 being impossible, and 10 being extremely easy. Responses were initially categorized into three nodes based on resource type, of internet, community and a general group.

In general, participants rated their ease of access poorly, between a 2 and 4, with one participant stating, “thank god for the internet” as they had to turn to the internet to find information. One participant indicated that in general it is “pretty easy” to find information.

Ease of access to internet resources on infertility were rated high by participants, scoring between 8 and 9.

Within the community specifically responses surrounded physicians. Participant’s ratings varied greatly with the ease of access to physicians, some indicating that it is “easy to make a doctor appointment, but otherwise difficult”.

Taking into account all of the responses, the final theme determined for interview question 2aii-1 was that the ease of access of resources and information via the internet is very easy, however, if looking directly within the community it is extremely difficult, outside of scheduling an appointment with an OB-GYN, or primary or family care provider

**Interview Question 2aii-2.** Interview question 2aii-2 asked participants to further explain their experience with finding infertility resources. Responses were grouped based on the type of resource sought, which was online or physicians. One participant indicated

that they were not even sure where to start to find infertility resources.

Most participants referenced going online to find information and resources, some stating they would look for research on the topic or begin their searches based off of materials provided from a physician. Concerns were voiced regarding the trustworthiness of online resources, while yet another individual said they felt comfortable being able to determine credible sources online. Many participants stated using the internet to find infertility specialists or clinics that may be close enough to travel to for assistance.

With regards to physicians, participants stated their process was simply calling their physicians office, whether it be family or primary provider, or OB-GYN, to make an appointment.

Overall it was found that online searching for resources is an easy way to find information, however, can be difficult to determine if the information found is trustworthy, whereas physicians are typically easily accessible and serve as a good starting point, but often don't have vast infertility knowledge.

**Interview Question 2a-3.** Interview question 2a-3 then asked participants how they would improve the ease of access to infertility materials within their community. These responses were initially coded into five categories including physicians, resources, websites, no changes, and other.

Responses categorized into the physician's node included those that were regarding access to physicians in the community, including family or primary care physicians, OB-GYN's and specialists. Such responses included offering more options of

physician specialties, having a knowledgeable contact whom focuses on infertility, having physician offices be more proactive in their approach to infertility concerns by allowing patients to complete labs prior to their appointment as well as having a nurse from the office call ahead of the scheduled appointment to begin discussing concerns to provide a starting point for the physician during the appointment.

The resource node consisted of ideas relating to resource materials specifically, such as providing a wider range of printed materials on infertility topics, implementing educational opportunities within the community or holding support groups and open forums on infertility.

A few participants also discussed websites, where they would like to see more online resources made available to the community. Such implementations include having one main website, or hub, with information and providing trustworthy links to external resources, and developing an advocacy site for infertility.

There were two outlying responses within this question, one participant whom stated that they did not feel any changes were necessary, and another with a non resource specific suggestion to ensure internet access to everyone within the community, as not everyone had that access.

Final analysis of interview question 2a-3 found that physicians and resources each had common themes of ideas for improving access. Participant's ideas with regards to physicians were to increase the infertility knowledgebase of current practitioners as well as bringing in a specialist. Resources were suggested to be improved by increasing



availability overall for infertility resources and materials, as well as providing access to trustworthy web resources.

**Conclusion.** Evaluating participant’s experience with finding infertility resources, based on the three previous interview questions discussed, found that in the participants’ rural communities it is extremely difficult to access infertility resources outside of relying on the internet. With referring to the internet there was concerns of the information trustworthiness and accuracy where participants would like to see improvements implemented in identifying trustworthy web resources, but also greatly improving the basis of printed materials on infertility.

### **Research Question 2aiii**

Research Question 2aiii was to evaluate the participants literacy of common infertility terms. Each of the following seven interview questions asked participants to define such terms. Results can be found in Table 9 below. Each of the interview questions was evaluated on how detailed and accurate the responses were to the correct definitions.

Table 9

#### *Research Question 2aiii coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
Q2aiii	<u>2aiii-1</u> Can you please define infertility for me?	Detailed definition General definition Minimal definition	All able to provide at least a minimal definition	Outside of infertility and IVF, not understood well
	<u>2aiii-2a</u> Please define AI – artificial insemination	General definition Minimal definition Vague definition Inaccurate definition	Majority could not accurately define AI	

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<u>2aiii-2b</u> Please define IUI – intrauterine insemination	Detailed definition General definition Minimal definition Inaccurate definition	Some could, some could not define IUI
<u>2aiii-2c</u> Please define ART – assisted reproductive technologies	Detailed definition Minimal definition Vague definition Inaccurate definition	Most either couldn't, or barely could define ART
<u>2aiii-2d</u> Please define IVF- in vitro fertilization	Detailed definition General definition Vague definition Inaccurate definition	Most understood IVF
<u>2aiii-2e</u> Please define primary vs. secondary infertility	Accurate definition Partially accurate definition Inaccurate definition	Most could not define primary vs. secondary
<u>2aiii-2f</u> Please define impaired fecundity	Not sure Don't know No idea Not familiar No clue	None could define

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**Interview Question 2aiii-1.** Interview question 2aiii-1 asked participants to define infertility in their own words. Key points that were looked for within responses include a time frame (1 year or longer of not conceiving naturally for women age 35 and older, or 6 months for those younger), being able to conceive and carry a pregnancy naturally, having unprotected intercourse or actively trying to conceive, not being able to achieve pregnancy, not being able to have kids, or indicating a medical condition impacting conception. Each participants response was evaluated based on these key points and categorized into one of four types of definitions.

The first, and most accurate, definition classification is detailed definition, which required that three or more key points discussed previously were stated accurately. The second definition classification is a general definition where the participant was able to accurately provide two key points. A minimal definition required only one key point to be provided, and an inaccurate definition was one in which the participant could not accurately define infertility.

Of the four definition classifications, three participants provided accurate detailed definitions of infertility, six provided general definitions, and three were able to provide a minimal definition. There were no inaccurate definitions provided, as all participants were able to successfully provide at least a minimal definition. The breakdown of definitions can be seen in Table 10 below.

Table 10

*'Infertility' definition response classifications*

Definition classification – <i>Criteria</i>	Participant responses
Detailed definition – <i>provided 3 or more key points</i>	<p>“...unable to obtain a pregnancy, um, I believe it is within a year, of just normal intercourse.”</p> <p>“...having difficulty getting pregnant with having tried for more than a year.”</p> <p>“...difficulty getting pregnant after a year if you’re actively attempting to conceive – I have also seen six months.”</p>

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General definition – <i>provided 2 key points</i>	<p>“...struggling to or not being able to get pregnant, or have kids at all”</p> <p>“...the inability to achieve pregnancy after one year of trying”</p> <p>“...difficulties with getting pregnant, or staying pregnant, generally something that’s medical that causes it.”</p> <p>“...inability to conceive on your own terms, after a certain amount of time.”</p> <p>“...unability* to have children, or the difficulties in having children, and like with what’s associated with it within your body.”</p> <p>“...somebody who has been having chronic difficulty conceiving, and chronic being more than six months.”</p> <p style="text-align: center;"><i>*participant word choice</i></p>
Minimal definition – <i>provided 1 key point</i>	<p>“...not being able to get pregnant. Like, unable to get pregnant”</p> <p>“...not being able to bare children, not being fertile. Not being able to have children”</p> <p>“...the inability to conceive and then carry through a viable pregnancy”</p>
Inaccurate definition – <i>no response; off topic or incorrect response</i>	- None -

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Evaluating all of the responses to defining infertility it was determined that all participants at least have a general understanding of, and are able to dictate that understanding of infertility. This is regardless of direct experience with infertility or any socioeconomic factors.

**Interview Question 2aiii-2a.** Interview question 2aiii-2a asked participants to define Artificial Insemination (AI). These responses were categorized similarly to how those to interview question 2aiii-1 were. The key points that were looked for include semen being collected or inserted, the uterus, fertile window or ovulation window, and being an alternative name for Intrauterine Insemination (IUI).

An accurate, detailed definition required that three or more key points were provided. Providing two key points resulted in a general definition classification, where

one key point was placed into a minimal definition category. Two other classifications were used with one being a vague or catch-all type definition where the participant may have somewhat provided a key point or general idea of artificial insemination, and an inaccurate definition.

None of the participants were able to successfully provide a detailed definition of AI. Only two participants were able to provide a general definition, with another two providing a minimal definition. There was one response classified as a vague definition, but the majority, being seven, provided an inaccurate definition. Table 11 provides a breakdown of the response types and quoted definitions from participants.

Table 11

*Artificial Insemination definition response classifications*

Definition classification – <i>Criteria</i>	Participant responses
Detailed definition – <i>provided 3 or more key points</i>	- None -
General definition – <i>provided 2 key points</i>	“...when a female gets a male’s sperm inserted into her uterus for conception, or into her fallopian tubes.” “...taking the sperm from a male donor, and donating it into the female.”
Minimal definition – <i>provided 1 key point</i>	“...where they place, um, materials to help conceive in a woman, into her uterus.” “...having a doctor fertilize the females egg with maybe like a syringe or a needle.”
Vague definition – <i>somewhat provides a key point or general idea</i>	“...that would be when the doctors go in and try to get you pregnant.”

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<p>Inaccurate definition – <i>no response/don't know, off topic response</i></p>	<p>“...not familiar.”</p> <p>“...collection of the egg and the sperm and putting them together in a lab setting, and then transferring the embryo.”</p> <p>“...semen injected into the vagina, so no, you know, procedure where it's actually going through your cervix”</p> <p>“...going and having it done medically – having the egg and sperm implanted medically together, or fertilized egg I should say.”</p> <p>“...where the doctors would take the sperm and um, you know, put it with the egg, and put it back in the woman.”</p> <p>“...it's just where they take a sample and they – I don't know if it's where they mix it and then they, um, insert it and hope it connects, I guess.”</p> <p>“...the act of you've collected eggs from the woman and sperm from the man and then going through the process of putting those in via the doctor.”</p>
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There were some items noted while evaluating the responses to defining AI. It appeared that some of the participants were either embarrassed by, not familiar with or simply not comfortable using accurate terminology for topics such as semen, sperm and uterus, using words or phrases such as “materials to help conceive”, and “sample”.

After classifying each response, it was found that the majority of participants could not accurately define artificial insemination when asked to provide their definition.

**Interview Question 2aiii-2b.** Interview Question 2aiii-2b asked participants to define Intrauterine Insemination, or IUI. Responses were categorized into one of five possible classifications of definitions dependent upon how many key points were included. The key points sought for IUI include semen being collected and/or inserted, uterus, fertile window or ovulation and being the same as AI.

The five possible definition classifications include detailed definitions, where participants were able to include three or more key points, a general definition, requiring two key points, minimal definition where only one key point was provided, a vague

definition which somewhat provides a key point or generalization and an inaccurate definition, which includes no response, responses of not knowing, or an off-topic response.

Only two participants provided a detailed definition of IUI. A total of five were able to provide a general definition, two of whom identified IUI as being the same as AI. One participant provided a minimal definition, with the remaining four not being able to provide an accurate definition. Table 12 provides a breakdown of the participants responses by definition classification.

Table 12

*Intrauterine Insemination definition response classification*

Definition classification – <i>Criteria</i>	Participant responses
Detailed definition – <i>provided 3 or more key points</i>	<p>“...in that procedure they do work to improve the sperm quality or select the best sperm and then that is injected through your cervix and into your uterus directly.”</p> <p>“...they take sperm at the time of ovulation and they inject into the woman’s cervix so that hopefully there is a better chance of getting pregnant.”</p>
General definition – <i>provided 2 key points</i>	<p>“That’s when the doctor collects your husband or your partners sperm and it’s injected into your uterus.”</p> <p>“Insemination of the sperm into her uterus.”</p> <p>“Same as AI”</p> <p>“Same kind of idea as the AI”</p> <p>“...would take the sperm and put it into the uterus for the egg to be fertilized.”</p>
Minimal definition – <i>provided 1 key point</i>	<p>“...where they place the sperm in there, that’s not fertilized...just with the sperm where the egg isn’t fertilized.”</p>
Vague definition – <i>somewhat provides a key point or general idea</i>	- None -

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Inaccurate definition – <i>no response/don't know, off topic response</i>	<p>“...don't know”</p> <p>“...don't know how it works”</p> <p>“...an artificial way of implantation. A provider implanting into a woman's uterus.”</p> <p>“no idea”</p>
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Further analyzing the definition classifications, it was determined that there was a fairly even split of those participants who could and those who could not provide a definition for IUI. Of those who were able to provide a definition, most were able to provide at least a general understanding if not full comprehension of the procedure.

**Interview Question 2aiii-2c.** Interview question 2aiii-2c evaluated participant's ability to accurately provide a definition or understanding of Assisted Reproductive Technologies, or ART. These responses were, again, categorized into one of five classifications of definitions based on key points, which include the egg and sperm being removed, collected or handles and being externally fertilized, implantation of a fertilized egg and external conception assistance.

To be classified as a detailed definition, a participant must provide three or more key points within their response. Providing two key points would result in a general definition classification whereas only providing one key point would result in a minimal definition classification. Vague definitions were those that somewhat provides a key point or a general idea of the topic. Inaccurate responses include those who were not familiar with the topic and unable to provide a definition as well as any off-topic responses.



There was only one participant who was able to provide a detailed definition of ART with the majority providing a very vague (4) or minimal (2) definition. A total of five participants were not able to provide any definition of ART. Table 13 below breaks down the participants responses based on their assigned definition classifications.

Table 13

*Assisted Reproductive Technologies definition response classification*

Definition classification – <i>Criteria</i>	Participant responses
Detailed definition – <i>provided 3 or more key points</i>	“...catch-all term for, um, the various treatments where they’re actually fertilizing the egg outside of the body.”
General definition – <i>provided 2 key points</i>	- None -
Minimal definition – <i>provided 1 key point</i>	“...that refers to a collection of treatment options, with IUI and IVF” “...anything that is used to enhance, um, being able to get pregnant.”
Vague definition – <i>somewhat provides a key point or general idea</i>	“...maybe technology that would help or assist you in being able to become pregnant.” “...maybe technology that is out there to help couples get pregnant and stay pregnant.” “...the equipment that is used and the medicine used to help the process of getting a woman pregnant.” “...anything that would help with the issue of infertility, any of the artificial assistance.”
Inaccurate definition – <i>no response/don’t know, off topic response</i>	“no.” “Not sure.” “Don’t know.” “Don’t know.” “Never heard of it”

Upon further analyzing the classified responses it was found that any accurate definitions were very minimal with participants only being able to provide a general idea of the topic, otherwise unable to define.

One phenomenon to note with some of the vague definitions was that it appeared participants may have wagered a guess as to what the topic was, beginning their responses with "...maybe".

**Interview Question 2a-2d.** Interview question 2a-2d evaluated participants familiarity with In Vitro Fertilization, commonly referred to as IVF. The provided definitions were categorized into one of five classifications based on key points covered within that definition. Key points for IVF include the egg and sperm being collected, external fertilization of the egg and fertilized eggs being inserted into the uterus with hopes for implantation to occur.

Detailed definitions require that participants provided three or more key points or details of IVF. General definitions are those that successfully provided two key points. Responses classified as minimal definitions provided one key point whereas a vague definition response somewhat provided a key point or the general idea of IVF. Inaccurate responses include those of no response, the participant being unfamiliar with the topic or an off-topic response being provided.

Classifying participant's responses found that four individuals were able to provide a detailed definition, as well as another four providing a general definition of IVF. Only one participant vaguely defined the topic, and three were unable to provide an accurate definition. Table 14 provides the breakdown of participant definitions based on classification.

Table 14

*In Vitro Fertilization definition response classification*

Definition classification – <i>Criteria</i>	Participant responses
Detailed definition – <i>provided 3 or more key points</i>	<p>“...they collect the woman’s eggs and they collect the man’s sperm and they put the two together in a laboratory setting and transfer that embryo.”</p> <p>“They take a woman’s egg, and a man’s sperm in a petri dish and they get the egg pregnant, and they put it back in the woman and into her uterus.”</p> <p>“...where the egg is fertilized in the lab, and the best eggs are selected and implanted after they are fertilized.”</p> <p>“...they would take the egg and the sperm and put them together and hopefully create a healthy embryo and put it back in the woman.”</p>
General definition – <i>provided 2 key points</i>	<p>“...when the egg is fertilized already and then those are then placed in the uterus, or somewhere, I would assume the uterus.”</p> <p>“...I think that’s where they take an egg out, and then they take the sample and they put it together and put it back in, I think.”</p> <p>“...when they fertilize the egg outside of the body and implant the egg into the female.”</p> <p>“...implant the already fertilized egg into the uterus.”</p>
Minimal definition – <i>provided 1 key point</i>	- None -
Vague definition – <i>somewhat provides a key point or general idea</i>	“...using, um, medicines and tools to kind of place the products of conception.”
Inaccurate definition – <i>no response/don’t know, off topic response</i>	<p>“nope”</p> <p>“...I feel that would be the same as artificial, maybe.”</p> <p>“...I’ve never heard of it.”</p>

After classifying each of the participants definitions it was found that the majority of participants have at least a general idea of IVF and were able to articulate their understanding.

**Interview Question 2aiii-2e.** Interview question 2aiii-2e looked at the ability of

participants to accurately define the difference(s) between primary and secondary infertility. The provided definitions were categorized into one of three definition classifications. The three classifications include accurate definition, where the participant was able to provide accurate definitions and understanding of both primary and secondary infertility, partially accurate definition in which the participant was able to provide an accurate definition or understanding of one of the two types of infertility, or a general response to both primary and secondary infertility, and inaccurate definition where the participant was not able to provide a general understanding of either type of infertility.

To determine the classification type of each response, key points for both primary and secondary infertility were referenced. The key points of primary infertility include being unable to get pregnant after one year, unable to carry a pregnancy to term, resulting in a live birth. For secondary infertility, key points included being physically incapable of conceiving or carrying a second or subsequent pregnancy after the birth of a biological child, having additional failed pregnancies after a failed prior pregnancy attempt or live birth.

Only one participant was able to provide an accurate definition of both primary and secondary infertility or its differences. There were three partially accurate responses, noting that of these three responses, two participants were able to accurately depict the topic of primary infertility, but struggled with defining or providing an idea for secondary infertility. The majority of participants (8) were not able to provide any degree of accuracy within their definitions of primary or secondary infertility, with most of them

not being familiar with either term. Table 15 provides a breakdown of the response classifications for primary versus secondary infertility definitions.

Table 15

*Primary versus Secondary infertility definition response classification*

Definition classification – <i>Criteria</i>	Participant responses
<i>Accurate definition – provides accurate definitions or understanding of both primary and secondary infertility</i>	“Primary infertility would be, you’ve never been pregnant, and secondary would be that you’ve been pregnant and perhaps have a child, and then after that you were infertile.”
<i>Partially accurate definition – provides accurate definition or understanding of one type of infertility, or general response to both</i>	<p>“Primary infertility would be to get pregnant the first time, to try to get pregnant, and then secondary infertility would be after a healthy live birth, and then having difficulty and having infertility issues after having a live birth.”</p> <p>“...primary infertility is you cannot conceive at all, and secondary would I believe include miscarriages, or things like that, where the pregnancy is not viable.”</p> <p>“Not being able to at all, whereas the other one might be being able to but it’s just more difficult.”</p>
<i>Inaccurate definition – does not know; does not provide a general understanding of either type of infertility</i>	<p>“...haven’t heard.”</p> <p>“...primary usually means that’s the main problem, secondary means there is a different problem that is causing the infertility.”</p> <p>“don’t know the difference.”</p> <p>“not sure on the difference.”</p> <p>“I don’t know the difference.”</p> <p>“...have heard the terms, but not sure what the difference is.”</p> <p>“...don’t know the difference.”</p> <p>“...primary infertility is an issue with, directly with the female or the male, like the egg or sperm, and just not being able to get pregnant in that sense, and maybe secondary is being able to like not having an issue with the egg or sperm but maybe not being able to carry it.”</p>

Further evaluation of the responses to primary versus secondary infertility concluded that the majority of participants are not able to provide an accurate definition or general idea of either degree of infertility. Most participants either were not at all

familiar with primary or secondary infertility, or had only heard the terms before but were unable to put them into context.

**Interview Question 2aiii-2f.** Interview question 2aiii-2f was the final definition inquiry of participants, asking each to define impaired fecundity. Of the twelve participants, only one indicated they had heard the term previously, however, like all of the others, was not able to provide a definition. Responses obtained included “not sure” (2), “don’t know” (6), “no idea” (2), “not familiar” (1) and “no clue” (1).

**Conclusion.** The seven interview questions making up research question 2aiii set out to evaluate the participant’s understanding, or literacy, of the topic of infertility, or infertility information that may be available. Based on the focused coding within each of the seven interview questions, as outlined in Table 8, further axial coding found that outside of the direct topic of infertility or IVF, participants did not understand various common infertility topics well, if at all.

### **Research Question 2b**

Research question 2b looked at what information community members would like to see within resources, and what those resources would look like. To explore this topic, participant’s responses were obtained from three interview questions. Table 16 provides a breakdown of interview questions and coding themes.

Table 16

#### *Research Question 2b coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
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	<u>2b-1</u>				
	What types of resources would you like to see made available on the topic of infertility?	Resource format Resource topics	Format <ul style="list-style-type: none"> <li>• Web</li> <li>• Print</li> <li>• Meeting/group</li> </ul> Topics <ul style="list-style-type: none"> <li>• Next steps</li> <li>• Options</li> <li>• General info</li> </ul> Resources <ul style="list-style-type: none"> <li>• More</li> <li>• Readily available</li> <li>• General improvement</li> </ul> Providers <ul style="list-style-type: none"> <li>• More; specialist(s)</li> <li>• Community point of contact or researcher</li> </ul>		
Q2b	<u>2b-2</u>	Resources Providers		General information, resource information, options and steps/plan	
	What changes would you like to be made to the resources that are available?				
	<u>2b-3</u>	General/FAQ Definitions/terms Options/treatments Steps to take Clinics/specialist information Community resources Signs/symptoms Insurance information Assistance programs/alternative options Other	General information Options/treatments Steps Specialist/clinic information		
	What are the topics you feel need to be covered on infertility resources?				

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**Interview Question 2b-1.** Interview question 2b-1 asked participants what type of resources they would like to see be made available within their community on the topic of infertility. The gathered responses represented both resource formats as well as specific resource topics, noted as the open coding phase shown in Table 15.

The formats discussed for infertility resources included the internet or web based materials, printed materials in pamphlet or brochure form or packets, support groups or

meetings made available and having a clinic or center within the community with infertility specialists. The most common types being the printed materials having five responses and internet or web based materials tying with having groups or meetings with three responses each.

Resource topics that participants discussed included next steps or a plan for treatment, available treatments and options, possible causes of infertility, contact information or referrals for who to seek assistance from, general information on infertility, FAQ's, signs and symptoms of infertility, how to improve chances of conception and definitions of common infertility terms. The most common topics participants discussed included general information and available treatment options, with five mentions for each, as well as having a plan outline and FAQs available, again, each with three responses.

**Interview Question 2b-2.** Interview question 2b-2 looked at what changes participants felt needed to be made to any infertility resources that are already available to them in their rural community. There were two distinct types of resources that participants provided improvement tips for that were found during open coding – resource materials and providers.

Focused coding found specific response with regard to resources including having easier access to the materials, a general, all around improvement to the resources, and making more resources readily available within the community. For providers, responses included designating someone as a 'researcher' for infertility in the community, having more specialists, or a specialist available without needing to travel out of town for care,



offering additional training to nurses and support staff, and having additional educational opportunities within the community to increase knowledge.

**Interview Question 2b-3.** Interview question 2b-3 asked participants what topics they felt need to be covered or included in infertility resources. This question provided a broad range of responses during open coding, including a desire for general information or infertility FAQs, definitions of infertility vocabulary or terms commonly used, available treatment options, a plan or steps to take, clinic and specialist information, signs, symptoms and causes of infertility, insurance information, assistance programs if and where applicable as well as infertility concerns specific to men and women. These responses were similar to those provided in interview question 2b-1 but more expansive. The most common responses were those regarding general information or FAQs, available treatment options, steps to take and clinic or specialist information.

**Conclusion.** Axial coding of research question 2b found that the most important or desired information that the participants would like to see made available within infertility resource materials is general infertility information, or FAQs, resource information such as specialists or clinics to gain care, as well as what available options for treatment and care are and what steps to take for a treatment or care plan.

### **Research Question 3**

Research question 3 sought to determine if there was an impact on infertility resources within the rural communities based on insurance coverage. Four interview questions were asked to analyze the potential impact experienced by participants which were then coded and analyzed as outlined in Table 17.

Table 17

*Research Question 3 coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
	<u>3-1</u> Do you know how much coverage your insurance has in regards to infertility?	Not sure – 5 Only if medically necessary – 3 Tests covered – 1 Office visits – 1 None – 1 Some – 1	Note sure Only if medically necessary Tests covered Office visits None Some	
	<u>3-2</u> What infertility treatments are covered under your insurance?	Not sure – 5 Office visits – Medications – 1 Only if Medically Necessary – 2	Not sure Office visits Medicine Only if medically necessary	Impacts what is chosen to do/completed
Q3	<u>3-3</u> How much does your insurance cover for infertility treatments or screening?	Not Sure – 8 None – 1 Testing – 1 Only if medically necessary – 2	Not sure None Testing Only if medically necessary	Whether any option is pursued Affordability
	<u>3-4</u> If you have undergone, or will be undergoing infertility treatments, how do you plan to pay for the cost?	Payment plan Loan/finance Savings HAS Grants/financial resources Hope insurance covers Not sure Wouldn't pursue	Savings Loan/finance Payment plan	

**Interview Question 3-1.** Interview question 3-1 asked participants if they were aware of how much coverage their insurance covers with regards to infertility. Responses regarding coverage varied greatly, with five participants stating that they weren't sure what, if any, infertility coverage they had under their insurance, one stating that they were not aware of any coverage of costs, yet another indicating that they would assume

there to be some coverage. Five participants were familiar with what would be covered, three of which stating that costs would only be covered through insurance if the treatment was deemed “medically necessary”, one knowing that testing or screening measures would be covered, and another knowing office visits would be covered.

**Interview Question 3-2.** Interview question 3-2 looked at whether there were specific infertility treatments covered by the participant’s insurance. The majority of participants were not sure of any specific treatments that would be covered by their insurance. Similar to responses to interview question 3-1, those that were familiar with what would specifically be covered, included office visits of physicians or specialists, and treatments deemed “medical necessary”. Additional known treatments covered by some participants’ insurance included medications.

**Interview Question 3-3.** Interview question 3-3 asked how much coverage for infertility treatments or screening that their insurance provider covers. When discussing the coverage amounts allowed by insurance providers, most participants were not sure of whether there was or was not a limit for infertility coverage. Two participants indicated that if treatments and screenings were needed for medical purposes outside of simply conceiving, the costs would be covered. One other participant noted that testing would be covered in full, and one final participant stating that there would be no infertility costs covered under her insurance.

**Interview Question 3-4.** Interview question 3-4 focused on participants plan for covering infertility costs, had or should they undergo treatments. As most participants weren’t aware of insurance coverage, or their insurance lacks infertility coverage, the

responses varied greatly on a plan for covering the costs associated with infertility care. One participant stated that they “would try everything before giving up” regardless of what was necessary to be done to cover costs, whereas another participant stated that they wouldn’t pursue infertility treatments if not covered by their insurance, and would either save the money that would be placed towards care, or choose to adopt. The majority of participants stated they would work with the care provider on a payment plan if it were an option or utilize their savings (personal or health). A small number of participants went so far as to state that they would look at taking out a loan or financing the costs to conceive biologically. There was one participant of whom had just completed infertility treatments, and stated that she and her husband dealt with the costs as they came up, and unfortunately had to opt out of some treatments due to the costs associated. Focused coding for this interview question found the top three responses to be classified into using savings accounts, financing the costs or completing payment plans with the care providers.

**Conclusion.** Axial coding of the four interview questions within research question 3 found that the extent to which insurance coverage covers infertility costs has a large impact on what tests and treatments may be chosen to follow or complete, or whether an option is pursued at all. Additionally, the level of insurance coverage has an impact on the affordability of care for individuals, where lower insurance coverage may cause the care to be out of an individual’s affordability range.

### Research Question 3a

Research question 3a sought to explore if there is an effect on infertility resource availability or access within rural communities. This research question was evaluated based off of two interview questions as shown within Table 18 below.

Table 18

#### *Research Question 3a coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
Q3a	3a-1 Are there specific guidelines set in place for your insurance to cover infertility treatments?	Referral required for specialist- 4 Not sure - 2 Not aware – 2 Nothing covered – 1 Only specific docs covered – 1 Depends on insurance coding – 1 No requirements - 1	Referral required Not sure/not aware Nothing covered No requirements Only specific docs	Limits use or extent of use - affordability
	3a-2 In what ways do you feel your insurance coverage, or lack thereof, has or would impact the availability of infertility care?	Location impacted Use impacted Increase stress Increased conception time	Location • Lack of specialists covered • Private vs. non profit Use – can't pay out of pocket or afford	

**Interview Question 3a-1.** Interview question 3a-1 asked participants if they were aware of any specific guidelines that were required to be met in order for infertility care to be covered, such as obtaining a second opinion prior to receiving treatment. The majority of participants answered in regard to general care, having not explored infertility care at the time of their interview. Four participants stated that their insurance provider requires a referral in order to seek care from a specialist, in general. Two participants

were not sure whether there were guidelines in place or not. Two more participants were under the assumption that there were no guidelines in place in order for care to be covered. One participant stated that there was no infertility coverage, therefore no guidelines to follow to request care coverage. Another participant stated there were no guidelines, that they were able to proceed with scheduling appointments as they would with general care. Two other participants provided further detailed responses, with one stating that there were only specific specialists that would be covered for infertility, and another indicating that the potential coverage of infertility care would be dependent upon the way their care was coded for billing to their insurance.

Focused coding of these responses was able to narrow down the classifications some into the following categories: referral required, not sure or not aware of any guidelines, no coverage provided, no requirements for coverage to be obtained, and only having specific doctors covered.

**Interview Question 3a-2.** Interview question 3a-2 asked participants in what ways they personally felt that their insurance coverage, or the lack of, has or would impact the availability of infertility care for them within a rural community. Responses to this question were initially coded into four nodes during open coding, including the location of care being impacted, the use of care being impacted, increased levels of stress experienced, and an increased time to successful conception.

With regards to the location of care being impacted by a lack of insurance coverage for infertility, participants stated concerns of the lack of specialist coverage where they would have to seek care under their primary provider or pay out of pocket.

Additional discussions of private for-profit versus non-profit facilities surfaced. The responses regarding the use of care or treatments included the inability to pay out of pocket, ultimately resulting in the participant not pursuing certain options or resources, limiting the options readily available to them. An increase in stress was a concern for some participants due to financial concerns as well as strains on their relationship with their significant other with the possibility of high cost for infertility care. The concern regarding an increase in the time to conception was also voiced, “what can we pay for right now...it just kind of dragged on” by one participant who had chosen to pay for care as it came up, which required that they chose to opt out of some treatment options due to staggering costs.

Focused coding of interview question 3a-2 found that both location (lack of specialists covered and whether seeking care from a for- or non-profit agency) and use (ultimately based upon being able to afford to pay out of pocket) of care would be impacted for individuals within rural community’s due to a lack of insurance coverage for infertility care.

**Conclusion.** Axial coding of research question 3a found that the lack of insurance coverage for infertility care would greatly impact the availability of care for individuals in a rural community by limiting the use or extent of use of various treatment options or methods due to many of such treatments having high costs, causing an affordability concern when needing to pay out of pocket. This phenomenon would then play into a ‘supply and demand’ situation, where the lack of insurance coverage would cause individuals to not seek options, resulting in those options not being offered within the

community due to a low, or no, basis of need of such options.

### Research Question 3b

Research question 3b set out to evaluate if there is an effect on the quantity of infertility care based on insurance coverage. This question was evaluated through one interview question. The coding progression for research question 3b can be found in Table 19.

Table 19

#### *Research Question 3b coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
Q3b	<sup>3b</sup> Does your insurance limit the number of office or specialist visits, tests, treatments, or other infertility measurements?	No limits – 1 Not aware of limits – 3 Thinks there are limits – 1 Not sure – 6	Not sure/aware None Some	Most aren't sure or aware of limits

**Interview Question 3b.** Interview question 3b asked participants if their insurance limits the number of office or specialist visits, testing, treatments or any other infertility measures. Half of the participants were not sure if limits existed with regards to infertility treatment coverages. With regards to general insurance coverages, one participant stated that their insurance does not have limits, three additional stating that they were not aware of there being any limits for care, and only one indicating that they believe there to be limits for care. There was one participant who was not sure of how to answer the question directly.

**Conclusion.** Most participants were not readily aware of their insurance provider



placing limits on the amount of treatments or rounds of care – whether it be directly related to infertility treatments or general medical care.

### **Research Question 3c**

Research question 3c evaluated if insurance coverage has an impact on the quality of infertility care within rural communities. One interview question was used to evaluate the potential impact on quality of care. The progression of coding participants' responses can be found in Table 20.

Table 20

#### *Research Question 3c coding progression*

Research question	Interview question	Open coding: Nodes	Focused coding	Axial coding
	3c			
Q3c	In what ways do you feel your insurance coverage, or lack thereof, has impacted the quality of care you've received, or possibly would receive for infertility measures?	No impact/remain same - 3 Impact on treatment plan/type – 6 Yes – 2	No impact Process impacted Yes – impact	Yes – there would be an impact on what is or isn't done and how it is done

**Interview Question 3c.** Interview question 3c asked participants in what ways they felt their insurance coverage, or lack thereof, had or would impact the quality of care they received or potentially would receive in regard to infertility. The majority of participants stated that they feel there would definitely be an impact on the quality of care received for infertility based on a lack of insurance coverage for such care. Concerns were expressed with regards to the route or plan followed being impacted, such as needing to postpone treatments or not pursuing specific options that may be the most successful. Treatment types were also stated to be potentially impacted in regard to the

quality of care. Participants discussed possibly not being able to obtain proper screening or testing measures, as well as not being able to afford a higher quality of care due to high out of pocket costs. One participant stated "...as far as the quality of care, sometimes you go the cheap route just because insurance will cover so much...as far as quality goes, you may choose a lesser option because it's cheaper."

Only three participants felt there would be no impact in the quality of care based on the amount of insurance coverage that would be applied to infertility treatments.

**Conclusion.** Axial coding for research question 3c found that participants felt strongly that there would be an impact on the quality of care received based on insurance (lack of) coverage. As previously quoted, the financial burden placed on individuals for infertility care may force them to choose a lesser option to be able to afford a smaller cost out of pocket.

### **Summary**

Chapter four provided a break down and evaluation of the descriptive, open-ended interviews conducted with twelve participants in regard to the literacy and experiences of infertility resources in rural settings. Each research question was broken down into one or more interview questions which were carefully categorized into nodes through open coding, further classified within focused coding and evaluated further during axial coding across all pertinent interview questions under each research question. In total, thirteen research questions were evaluated based upon participants' responses to forty-one interview questions. In total, 440 minutes of recorded interviews were analyzed, resulting in the findings summarized below.

**Research Question 1**

Research question 1 asks “What are common concerns among women in rural communities regarding the topic of infertility?”. Careful review of participants responses to four different interview questions, outlined in Table 2, found that the overarching theme was that there was concern with the lack of, or need for more educational opportunities on infertility. This increased need for education in rural communities includes improving health literacy of infertility as well as increasing the number of resources readily available.

**Research Question 1a.** As a follow up to research question 1, research question 1a set out to evaluate “How do community members feel these concerns can or should be addressed?”. Two interview questions were asked to evaluate participants thoughts on addressing their concerns as outlined in Table 3. The overwhelming response was for a need to increase awareness of infertility across the community. This increase of awareness not only was implied towards community members, but also to physicians, whom participants felt did not have an adequate knowledgebase of infertility.

**Research Question 1b.** Further evaluating the concerns of participants, research question 1b asked “How can infertility materials be created to address these concerns and be more effective?”. Two interview questions were posed to address this research question as detailed in Table 4. Participant’s expressed the need to present infertility materials in various formats due to people being drawn to different types of resources. All participants, however, agreed that the information portrayed in such resources should be relevant to their immediate community and continuously be updated as changes in

processes, procedures and available options change.

### **Research Question 2**

Research question 2 looked at “What are the community members’ perceptions of accessibility to infertility materials within their rural community?”. This research question was comprised of six interview questions, as seen in Table 5. Based on participant responses it was found that the community members’ perceptions of infertility resource accessibility in their own community is extremely difficult unless they wish to simply seek assistance from their physician, be it primary, family or OB-GYN, or through the use of the internet. Not one participant was able to indicate that written materials exist on the topic of infertility in their community, or that there was an infertility specialist available to community members.

**Research Question 2a.** Research question 2a evaluated “What are community member’s perceptions of the information provided within available infertility resource materials?”. To evaluate this research question, participants were asked two interview questions, outlined in Table 6. Based upon the responses to those two interview questions there are two types of infertility resources available within the rural community or referenced – physicians and printed materials. Participants perceived physicians to be a good general resource for infertility, however, lacking with regard to infertility experience and knowledge. The perception of printed materials was limited with participants expressing that in most cases, such resources are non-existent and only available in regard to specific conditions such as miscarriage or PCOS where infertility is not the main focus, merely a side effect or possible contributing factor.

**Research Question 2ai.** Research question 2ai evaluated “What are community members’ experiences with these materials?”. To answer this, four interview questions were examined. Table 7 provides a breakdown of these questions. Analysis of the participant’s responses found that experiences with resources were very basic or limited as written materials were only available on specific topics – illnesses, diseases or conditions – that did not cover infertility. Experiences with physicians as a resource was also limited, as participants expressed concerns with wait times for appointments, a lack of follow up after an appointment and a general lack of infertility knowledge of the provider.

**Research Question 2aii.** Research question 2aii asked “How difficult has the community members’ experiences been with seeking these materials?”, referring to those same resources referenced in the three prior research questions. To evaluate those lived experiences, three interview questions, as outlined in Table 8, were discussed. Evaluating those responses found that, outside of utilizing the internet as an infertility resource, it is extremely difficult for members within rural communities to access infertility information. There were concerns expressed by participants with using the internet as a primary resource for infertility information, including the trustworthiness and accuracy of the information presented. Participants voiced their desire to see improvements with internet resources where trustworthy sites are clearly identified or referenced, but that they would also like to see printed materials made available.

**Research Question 2aiii.** Research question 2aiii explored “How well do community members understand the medical information presented in these materials?”.

To evaluate this research question, seven interview questions were asked of participants to define common infertility terms as listed in Table 9. Upon analyzing participants responses to those seven interview questions it was found that outside of defining infertility itself or IVF, participants did not understand the infertility topics or terms very well, if even at all.

**Research Question 2b.** Research question 2b looked at “What additional information would community members’ like to see made available within resource materials?”. This research question was explored through three interview questions displayed in Table 16. The most common information that participants expressed they would like to see included in materials is general infertility information, such as FAQs and definitions, available or close specialist information to receive infertility treatments as well as what current available options for treatment are along with the steps for obtaining those treatments.

### **Research Question 3**

Research question 3 was the first question to explore insurance impact, evaluating “What impact does insurance coverage or type have on infertility resources?”. To answer this, four interview questions were asked and can be found in Table 17. Evaluation of those interview questions found that the extent to which insurance covers infertility costs has a large impact on what tests and treatments may be chosen by individuals to undergo, or whether an option is pursued at all. Participants also discussed the level of insurance coverage having an impact on the affordability of infertility care, with lower insurance coverages causing infertility care to be out of an individual’s ability to cover the costs.

**Research Question 3a.** Research question 3a evaluated insurance coverage impact further, asking “Is there an effect on availability?” for infertility resources. Two interview questions were used to obtain participants views and can be seen in Table 18. Participants responses found that a lack of insurance coverage of infertility care has a great impact on the availability of care for those individuals within rural settings. This impact of availability is seen through a limit in the use or extent of use of treatments options due to the high costs and concerns of paying out of pocket. This phenomenon would then play into a ‘supply and demand’ situation, where the lack of insurance coverage would cause individuals to not seek options, resulting in those options not being offered within the community due to a low, or no, basis of need.

**Research Question 3b.** Research question 3b further evaluated insurance impact. This research question asked, “Is there an effect on quantity?” of infertility resources. One interview question was used and the coding process outlined in Table 19. Most participants were not aware of whether or not their insurance provider had a limit for the amount of treatments or care covered.

**Research Question 3c.** Research question 3c explored “Is there an effect on quality?” of infertility resources due to a lack of insurance coverage. To evaluate this, one interview question was asked and analyzed as outlined in Table 20. Responses of participants indicated that they felt very strongly that there would be an impact on the quality of care received for infertility due to a lack of insurance coverage. This would be due to the financial burden of the treatment costs being placed on the individual directly, often times this would result in the individual choosing a lesser option, or no treatment

option, to be able to afford a smaller out of pocket cost. In chapter 5 I will discuss these research findings along with applicable implications and recommendations within public health.



## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

The purpose of this study was to evaluate the lived experiences of participants with regards to infertility comprehension, resources and care within rural settings, including perceived availability, quality, and additional need for infertility resources. Open-ended interviews allowed me to obtain descriptive data to evaluate women's experiences with access to infertility care, knowledge of such care, knowledge of the topic, as well as any known available access to resources and materials on infertility.

The nature of this completed study was qualitative to gain descriptive information and insight of participants on infertility resources and materials within their rural communities. This allowed me to gain insight also includes feedback on what the participants feel is most important to implement within their community to improve the awareness and understanding of infertility.

There were 12 participants who were all women, between the ages of 24 and 39. These women may or may not have had a known infertility concern, suspected infertility problem, or who may or may not plan to conceive children within their lifetime. This range of participants contributed to gaining feedback from a mix of individuals who were both more likely and not very likely to have an understanding of infertility, providing a more representative spectrum of data for analysis.

The need for this research has been documented previously, as researchers have identified gaps in public health concerning infertility with regards to access of proper infertility care within rural communities (e.g., Lunde, Rankin, Harwood & Chavez, 2013;

Missmer, Seifer & Jain, 2011; Sherrod & Houser, 2013), the utilization of available infertility resources (e.g., Chandra, Copen & Stephen, 2014), the lack of available educational materials (e.g., Sherrod & Houser, 2013), and a lack an individual's understanding of infertility and its potential causes (e.g., CDC, 2012a). Rural health disparities also directly impact infertility care and can be compounded by documented insurance coverage inequalities for infertility services, which contribute to a lack of specialized resources available to rural communities (Jain & Hornstein, 2005; Ruggiero et al., 2011; Sherrod & Houser, 2013).

As stated by Sherrod (2004), “Studies, which look at the needs and perspective of infertile rural residents from their lived experiences, can assist health care providers to better meet their needs” (p. 82). This completed study will provide practitioners within the rural community with feedback of what has been experienced by community members, as well as provide information on what improvements participants have suggested.

### **Interpretation of the Findings**

#### **Confirm Knowledge**

The findings of this study confirmed various aspects of infertility research that has previously been discussed in Chapter 2. Such topics include types of care or resources, literacy, stigmas and mental health as well as the impact of insurance coverage for infertility care. In Chapter 2, I discussed the types or formats of care that women typically use or seek out for infertility care, with the most common being their primary care physicians or OB/GYN. This completed study confirms Sherrod's (2004) findings

that care for infertility within rural community's general falls upon primary care physician's due to the lack of infertility clinics or specialists available as well as the findings of Bennett et al. (2015) and Lundsberg et al. (2014), stating that OB/GYN's were referenced by 75-77% of participants, and Sherrod and Houser (2013) finding doctors being reported as a resource by over 50% of their participants.

Regarding infertility resources, this study reinforced Ruggerio et al.'s (2011) conclusion that rural health disparities lead individuals to utilize the internet as a main source of information for health-related topics. These results were similar to Bennett, et al. (2015), in that the Internet was a top resource of infertility patients, as well as Missmer et al. (2011) and Okamura, Bernstein, and Fidler (2010) who found that the Internet was one of the first types of a resource women struggling with infertility utilize.

In the completed study, I found that participants had to resort to the Internet for information on infertility due to the lack of resources or information immediately available within their rural communities. Some participants also voiced concerns regarding not being able to always trust the information presented through internet resources. This distrust also confirmed Zulman et al.'s (2011) and Okamura et al.'s (2010) findings, which were previously discussed.

Further concerns of participants being able to locate and use any infertility resources in their rural communities confirmed Read et al.'s (2014) conclusion which conveyed a difficulty in being able to find resources local to participants on infertility. Bennett et al. (2015), Lundsberg et al. (2014), as well as Sherrod and Houser (2013) all discussed the inability of individuals to understand infertility and possible causes. I found

that, outside of a general definition of infertility itself, participants did not comprehend common terminology, treatments, or topics of infertility.

Concerns of stigmas, or perceived stigmas, and increased stress was also confirmed upon completion of this study. Culley, Hudson, and Norton (2013), Gupta et al., (2013), and Missmer et al. (2011) all indicated that depression, financial strain, marital problems and increased stress can be a result of individuals not achieving parenthood, which was discussed by a couple participants who have known fertility concerns and have experience seeking care for infertility. Similarly, a couple participants discussed how the topic of infertility in their communities is too “hush-hush”, where there is a perceived negative connotation associated with the topic. This was a finding of Lee and Winters (2004), indicating that underlying fear or potential anonymity often coincides with infertility concerns in women.

A final confirmation of this completed study was that a lack of insurance had an affect on services and treatments of infertility. Chandra et al. (2014) indicated that the lack of insurance coverage for infertility services and treatments is a main factor in the use or nonuse of infertility resources and services. Upon analyzing the participants responses, this was confirmed on multiple occasions. There were several accounts of participants indicating that they would either opt out of some treatments or services, or need to utilize an alternative based on financial investments if or when their health insurance would not cover the costs.

**Disconfirm Knowledge**

There are some findings of this study that did not conform to those of previously completed published work regarding infertility. Differences were seen in some of the common forms of sources for infertility information as well as aspects of access to care. Bennett et al. (2015) found that both friends and family members of individuals were used as resources on infertility information, however, neither family or friends were discussed by any participants during interviews. Huttlinger, Schaller-Ayers, Lawson, and Ayers (2003) found that individuals from rural communities often find being confined in a rural setting as “a way of life” (p. 22), where they essentially lack access to care and approach specialized care outside of their community. Contrary to those findings, I found that many participants had either travelled or intended to travel to seek the necessary care for infertility.

**Extend Knowledge**

As discussed previously, Sherrod (2004) recommended the need for advancement of health care, education, and research on the topic of infertility, with particular consideration for the availability and access to health care within rural communities. This completed study further explored a potential need for additional education and a need for more health care options with regards to infertility in rural areas. Sherrod also expressed a need for further research to gain “a better understanding of the impact of infertility for those who live in rural areas” with qualitative research studies providing “the fullest understanding of this phenomenon of infertility and rurality” (p. 82).

Missmer et al. (2011) discovered, through a survey to help understand health care disparities with infertility, that women would travel anywhere from 1 mile, to 200 miles to seek medical care and assistance. This was discussed by many participants in my study as they described their need to travel for infertility care. One participant indicated she traveled 700 miles, one way, to receive infertility treatments.

A topic that was of great concern by participants in this study was insurance coverage for infertility treatments. As discussed in the literature review, of the available private insurance coverage options and carriers, only 25% tended to include coverage for infertility treatments (Bitler & Schmidt, 2011; Schmidt, 2007). One reason may be that the ability to conceive is often not deemed by insurance companies as being *medically necessary* (Jain & Hornstein, 2005). Many of the participants within this completed study stated that treatments for infertility are only completed if deemed medically necessary and are not covered if the only concern or complication is fertility. In addition, a common response to resources participants would like to see made available regarding infertility is insurance coverage, so that those who do struggle with infertility are allowed the opportunity to receive some degree of care in the attempt to conceive their own biological children.

The United Nations Millennium Development Goal aimed to provide universal access to reproductive health services (United Nations, 2014; Hammarberg & Kirkman, 2013), noting that the two areas that are lacking the most include that of family planning availability and assistance for reproductive health care. My research extends this knowledge further, providing information on what kind of assistance and planning

availability that participants within rural communities would like to see made available, or strive to find. Included in the type of resources or support discussed by participants was psychological or psychosocial support, as Read, Carrier, Boucher, Whitley, Bond, and Selkowitz (2014) found. Participants elaborated on the type of support they would like to see made available, stating that support groups and access to one-on-one meetings with an infertility specialist, office or contact would be desired.

### **Limitations of the Study**

Limitations to trustworthiness that occurred during the execution of this study includes the lack of a previously used or published interview transcript or questionnaire as well as conducting interviews over the phone rather than in person. The use of a non-published interview questionnaire or transcript can take away from the dependability or confirmability of the study if the same interview questions are not narrated as written, should the study be replicated. The additional limitation in the design for data collection was the need for completing interviews via telephone. Utilizing telephone interviews inhibits the ability to obtain field notes of the participant's physical appearance and body language to be included in analysis with the interview transcript. It is also possible that a participant's tone of voice was incorrectly evaluated due to a lack of physical observation of the participant during interviews.

Transferability limitations of the study includes the phenomena of infertility being an under-researched topic, as there is a great need for additional research on the topic of infertility. Additionally, the outcomes of this particular study in regard to items such as the concerns and need for resources may not directly correlate with other health

phenomena such as diabetes, where the scope and background may be extremely different.

Concerning dependability, a limitation is that each rural community can have differing outcomes. Although there is a standard definition of a rural community or rural setting the individuals and resources that make up that rural community will vary, ultimately varying the possible number and accessibility of infertility resources from one rural community to the next. This was apparent during data analysis where the distance required for travel varied dependent upon the community's geographical location and distance to the nearest urban area.

Potential biases that may have surfaced in this study include during recruitment, with selection bias, during the interview process with both interviewer bias and recall bias, as well as through confounding variables. During the recruitment phase, selection bias was a potential concern if the inclusion and exclusion criteria had not been closely followed. Within the data collection during interviews, two possible biases may have arisen – the interviewer bias, and recall bias. Interviewer bias may occur from unintentional non-verbal cues as well as through the reading of the interview questions if not done consistently from interview to interview. This bias was reduced significantly if not completely through strictly reading the interview questions as written during each interview. The recall bias is dependent upon the participants to have a clear memory of past experiences, and if there is doubt, there is a possibility of having skewed data for analysis. Recall bias did not appear to be a concern as participants were not hesitant with responses regarding experiences, only those with providing definitions or terms.



Confounding did not present a concern with data collection or analysis as all participants willingly answered all questions and provided the necessary background information.

As a means of addressing the previously stated limitations, the recruitment materials were created in a way that clearly presented the inclusion criteria, and were welcoming to women of all backgrounds and statuses. During the interview, questions were read clearly and as written on the interview transcript so as to ensure the same delivery during each interview. In situations where a participant was unsure of how to answer a question, I asked follow-up questions to prompt the participant to elaborate on their given response, or allowed the participant to ask for clarification of a topic should the participant not be familiar. In these situations, I then further defined the question carefully so as not to try and direct the participant to an answer. Any unsure responses were noted as such so that the data point would be appropriately analyzed.

### **Recommendations**

Recommendations for further research include both stand alone and comparative studies of both rural and urban communities. Completing an identical study to this one, but in an urban setting, would provide additional data to evaluate and explore potential differences in care and resources between the rural and urban populations. Likewise, completing similar studies in different states with both rural and urban communities may provide information on any possible differences across or between states, to include those which have insurance mandates for infertility coverage. In addition to these individual studies, completing studies that evaluate urban and rural, or state to state communities at the same time would provide a better comparison of participants experiences.

Completing studies focused on a need base within communities, both rural and urban and within states with and without insurance mandates, is important. This information would be able to provide healthcare workers (e.g., health departments, doctors' offices and hospitals) with information on the types of resources and materials that community members would like to see made available. In turn, that gathered information would allow stakeholders to evaluate the available health care options and to adjust offerings as seen fit to best serve the community members.

### **Implications**

#### **Positive Social Change**

Social change implications of this research addresses three levels, including societal, community and individuals by providing new insights into lived experiences of those who live within rural communities who may be struggling with infertility. Additional implications for social change stem from gaining an understanding of the perceived difficulties and disparities within the rural setting with regards to receiving proper infertility care as well as providing information on what those individuals in the rural community may be looking for in future infertility resources.

#### **Individual**

Positive social change implications specific to those at the individual level from the completion of this research include a few standpoints. First, promoting empowerment of the individuals as this study provided community members with the ability to voice their concerns regarding available resources, or the lack thereof, along with what any wants and needs were voiced.

This study also enforces a ‘you are not alone’ viewpoint of infertility, where those within rural communities can be assured that struggles with infertility are likely more prevalent than they think. This notion can bring about healthy discussions and opportunities surrounding the topic in a means of reducing associated stigmas of those who struggle with their fertility.

The findings of this study may also promote the need for additional resources to be provided within the community, and potentially the distribution of additional resources or materials within health agencies for community members use and reference.

### **Organizational**

The social change implications of this research at the organization level impacts healthcare providers and workers. The findings of the study provide those healthcare providers with an understanding of their patients underlying concerns regarding infertility, which can impact the patient-physician relationship, promoting potential topics to be covered and discussions to have at annual visits.

This study also provides the community stakeholders in public health and health care with a basis of knowledge of where the members within their community stand in the understanding of infertility, concerns of or with infertility, and the perception of availability of resources and care. This outcome can help the stakeholders improve the visualization of the resources that are available as well as have an understanding of what should be focused on for their community specifically, providing a better experience for women who struggle to conceive. A final organizational social change implication is the ability to provide health care providers and health organizations with information

regarding what specific topics and specific concerns members of their community have to help determine additional education focuses or opportunities that should be taken for provider training to improve patient care.

### **Societal/Policy**

Societal and policy related social change implications of this study include evaluating the need for further insurance mandates or increased coverage options for those who suffer from infertility. Also, evaluating and structuring care guidelines for infertility. Establishing the need for continual and improved training for family and primary practice physicians or continuing education opportunities to help serve individuals more completely.

Social change implications also include the delivery and use of infertility – or other health topic – resources. Internet or web based resources were commonly discussed by participants indicating a need for more trustworthy and easily accessed materials. Developing an infertility resource that is web based will create the easy access sought by community members but also provide an avenue for increasing awareness of the topic. Additionally, the use of internet or web based resources can be expanded to include other illnesses, diseases or health topics that are pertinent to the community.

### **Methodological/Theoretical/Empirical**

Additional implications of this study include providing tools for replication (interview questions and protocol, coding analysis) within other rural areas, along with the ability to alter the protocol to conduct within urban areas as well. Larger scale studies could also be conducted based off of the provided protocol to gain a broader

understanding of participants across multiple communities and evaluate an overarching evaluation of women with relation to infertility concerns.

### **Recommendations for Practice**

Recommendations for practice based on the findings of this study span multiple professions, from physicians to educators to public health professionals and to policy makers. For physicians specifically, increasing the practical awareness of infertility and understanding of underlying causes can greatly impact their reputation as well as patient care satisfaction, ultimately improving their practice. Additionally, providing physicians and health care providers with the understanding of concern for women with regards to infertility can promote an increase in openness as well as sympathy or empathy when discussing infertility.

Involving more policy makers in infertility research would provide another front of action and assistance for public health practitioners in combating infertility as a public health concern. This involvement would be able to impact existing policy as well as promote additional policies to be put in place in regard to infertility care, screening, insurance coverage and options available regardless of rurality or urbanity.

A grave need for increased education and resources materials on infertility was also established from the findings of this research. The increase in education should be implemented at all levels, including the community level where individuals can attend meetings or classes and find materials at local health care facilities, and the practitioner level with physicians and applicable nurses or aids undergoing some infertility care training. Resources should be made available at the community, state, regional and

national level to provide individuals with information ranging from basic infertility topics, to specialists, procedures offered and top locations to receive infertility care.

### **Conclusion**

Evaluating the gathered data from this research study has been able to validate concerns, hypothesis and goals relating to infertility in rural areas including screening and treatment, available resources and concerns with insurance coverage or lack thereof. The findings of this study follow closely to those of Sherrod and Houser (2013) where it was determined that research on educational material to understand the various causes of infertility, available resources and information on treatment options should be a public health focus. Recommendations from this completed study encourages further research and evaluation of ways to improve care and knowledge of infertility in those rural areas as well as gather comparative data for urban communities. Those recommendations that can immediately be implemented include increasing the education and awareness regarding infertility within the community, including health care providers, community members and stakeholders.

A few participants voiced their appreciation for covering the topic of infertility in rural areas, with one stating “I think this is awesome that you are covering this because so many people struggle with [infertility] – it makes me sad. It’s great you’re researching this!” and another “I thank you! I mean obviously this topic needs to be spread out in the open a lot more, dealing with both insurance information and the offices getting information distributed and disbursed to the community, it’s definitely needed, so, great topic!”. These participant quotes parallel one of Greil, Slauson-Blevins, Tiemery,

McQuillan and Shreffler, stating, “Fewer than 50% of women who meet the medical/behavioral criteria for infertility receive medical services.” (2016, p. 133). These concerns of a lack of voice for those struggling with infertility as well as the ability to receive the medical treatments necessary to conceive need further attention. This study supports the CDC’s declaration of infertility being a public health concern and the need for the topic to be a priority.

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Dr. S.

Sent from my iPhone

> On Jan 14, 2016, at 10:26 AM, Amber Dessellier <amber.dessellier@waldenu.edu> wrote:

>

> Hi Dr. Sherrod & Dr. Houser,

>

> I am writing to you both in hopes of gaining your permission to use Table 2, Who to Seek Help From in my dissertation literature review. I would be using the table to demonstrate and reinforce who women are most likely to seek assistance from with regard to fertility/infertility concerns. My dissertation topic is on the literacy of, availability of and use/experiences of infertility resources within rural communities. I would not be intending to continue research off of or alter the table in anyway.

>

> I thank you very much for your time,

> Amber Dessellier

>

> Walden University

> PhD Public Health - Community Health Education

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**Author:** Kirsten I. Black, Ian S. Fraser

**Publication:** International Journal of Gynecology & Obstetrics

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## Appendix B: Interview Questions

Insert appendix here. Appendices are ordered with letters rather than numbers. If there is but one appendix, label it Appendix, followed by the title, with no letter designation.

### **Research Questions and Applicable Interview Questions**

**Q1: What are common concerns among women in rural communities regarding the topic of infertility?**

- What do you feel are common misconceptions/misperceptions of infertility?
- Do you feel there are differences in health care options for women who may struggle with infertility in rural communities?
- What concerns do you have with regards to infertility? (screenings, treatment, detection, general understanding/education...)
- What would prevent you from seeking infertility assistance?

**Q1a: How do community members feel these concerns can or should be addressed?**

- If you could contribute to helping resolve these concerns, what would you do?
- What do you feel would be beneficial to help reduce or address these concerns within your community?

**Q1b: How can infertility materials be created to address these concerns and be more effective?**

- What new/updated information should be included in infertility resources?
- What type or format of resource do you feel would be most rewarding/used by

community members? (internet, brochure, pamphlet, etc)

**Q2: What are the community members' perceptions of accessibility to infertility materials within their rural community?**

- Off the top of your head, how many sources of infertility materials would you say is available within your community?
- How easy do you feel it is to access those resources? (scale of 0-10, with 0 being impossible, and 10 being very easy).
- How many do you feel there should be available?
- Are you aware of infertility resources in neighboring communities?
- Do you feel there are fewer infertility resources within your community compared to others?
- What do you think would be the most common forms or types of information and resources sought for infertility?

**Q2a: What are community member's perceptions of the information provided within available infertility resource materials?**

- Are you aware of any (or the?) infertility resources available to you within your community?
- What types of infertility resources are available to you within your community?

**Q2ai: What are community members' experiences with these materials?**

- For each type of infertility resource you have encountered or experienced, please rate them on a scale of 0-10, with 0 being a horrible experience, 5 being a so-so experience, and 10 being an amazing experience.
- What did you like/appreciate from the materials?
- What did you least like/appreciate from the materials?
- How do you feel these can be improved to elevate your experience?

**Q2aii: How difficult has the community members' experiences been with seeking these materials?**

- On a scale of 0 to 10, with 0 being impossible, and 10 being extremely easy, please rate the ease of access of the infertility materials.
- Please explain your experience with finding these resources/materials.
- How would you improve the ease of access of these materials?

**Q2aiii: How well do community members understand the medical information presented in these materials?**

- Can you, please, define infertility for me?
- I am going to read off a few abbreviations and terms – please tell me if you are familiar with them, and provide a definition for those you know of: (AI – Artificial Insemination; IUI – Intrauterine Insemination; ART – Assisted Reproductive Technologies; IVF – In Vitro fertilization; Primary infertility; Secondary infertility; impaired fecundity; )



**Q2b: What additional information would community members' like to see made available within resource materials?**

- What types of resources would you like to see made available to you(r community) on the topic of infertility?
- What changes would you like to be made to the resources that are available to you(r community) already?
- What are the topics you feel need to be covered on infertility in resources?

**Q3: What impact does insurance coverage or type have on infertility resources?**

- Do you know how much coverage your insurance has with regards to infertility?
- What infertility treatments are covered under your insurance?
- How much does your insurance cover for infertility treatments/screening? (i.e. 20%, up to \$10,000, etc).
- If you have undergone, or will be undergoing infertility treatments, how do you plan to pay for the costs?

**Q3a: Is there an effect on availability?**

- Are there specific guidelines set in place for your insurance to cover infertility treatments? For example, do you need to seek a second opinion, seek care through a specialist or other parameters?
- In what ways do you feel your insurance coverage, or lack thereof, has or would impact the availability of infertility care?

**Q3b: Is there an effect on quantity?**

- Does your insurance limit the number of office or specialist visits, tests, treatments, number of rounds of treatments or other infertility measures?

**Q3c: Is there an effect on quality?**

- In what ways do you feel your insurance coverage, or lack thereof, has impacted the quality of care you've received, or possibly would receive for infertility measures?

**Demographic & Socioeconomic Questions**

- I know this can be a touchy/controversial subject, but if you don't mind me asking, how old are you?
- Are you married?/How would you classify your marital status: married, single, "taken", domestic partner, divorced, widowed, other
- How long have you been married/with your significant other?
- Do you (and your husband/spouse/significant other) have any children? How many?  
Ages?
  - All biological? Adopted?
  - With the same spouse/significant other?
- Do you intend to have children at some point during your life? (for those without children)
  - Within the next year? 3 years? 5 years? 10 years? Other?
- Any challenges with any pregnancies? Or known fertility issues?

- Do you currently have health insurance coverage?
  - Public or private? (Covered by the state?) If Private – through employer or self?
    - Private insurance is provided through an employer or union, or may be purchased directly by an individual from an insurance company (United States Census Bureau, 2015).
    - Public insurance is insurance that is provided by a government agency, such as Medicare, Medicaid, Tricare or other state or Indian health plans (United States Census Bureau, 2015).
- Do you know if your insurance cover infertility costs, such as but not limited to screenings, testing, treatment or modes of artificial conception (ART, IVF, AI, etc)?
- Has your insurance provider been able to provide resources or advice on infertility?
- Are you currently employed? What would you say your current level of employment is: internship, entry level (0-2yr exp), intermediate (2-5yr exp)/tenured/experienced/seasoned, senior (5-8yr exp), lead (>8yr exp), management, upper management, etc.
  - Length of time for employment with this position/company; full time/part time/per diem, etc
- Household income/salary:
- Do you feel you are at a good place financially?
- Highest level of education completed/degree awarded (GPA a plus!):
- Are you aware of any possible exposures you may have had to toxic substances or poor air/water quality within your home, work or community?
- Do you rent/own? Size of dwelling?

- How would you rate your overall level of enjoyment and satisfaction with your community? 0-10 scale
- How would you rate your satisfaction with available offerings with regard to healthcare/infertility?
- Are you aware of having any health conditions that may lead to concerns with fertility?
- Have you been informed that you do, or may suffer from infertility? Or has infertility been ruled out completely?
  - (for those who know they struggle with infertility): Have you discovered the cause or contributing factors of your infertility? Have you been undergoing treatments?
- If you have sought assistance from a healthcare provider with infertility concerns, how far did you travel? How long was the wait period to get into see the provider? What type of provider did you seek? (i.e. specialist, ob/gyn, pa)