

2019

Patient-provider communication during high-risk pregnancy: Considerations for theory and praxis

Laura Jackman
Iowa State University

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Patient-provider communication during high-risk pregnancy: Considerations for theory and praxis

by

Laura Jane Jackman

A dissertation submitted to the graduate faculty
in partial fulfillment of the requirements for the degree of
DOCTOR OF PHILOSOPHY

Major: Rhetoric and Professional Communication

Program of Study Committee:
Stacy Tye-Williams, Major Professor
Tina A. Coffelt
Margaret R. LaWare
Kelly G. Odenweller
Dara M. Wald

The student author, whose presentation of the scholarship herein was approved by the program of study committee, is solely responsible for the content of this dissertation. The Graduate College will ensure this dissertation is globally accessible and will not permit alterations after a degree is conferred.

Iowa State University
Ames, Iowa
2019

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DEDICATION

This dissertation is dedicated to the women who participated in this study. I am honored that you have chosen to entrust me with your stories, and I am touched beyond words to have learned about the precious babies you have sheltered in your womb. Thank you for your bravery in being vulnerable and sharing your experiences with me.

I would also like to dedicate this dissertation to my parents, John and Katherine Jackman, who instilled a love of learning and work ethic in me. Words are not enough to express my love for you.

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ACKNOWLEDGMENTS

I would like to thank my committee chair, Dr. Stacy Tye-Willians, and my committee members, Dr. Tina Coffelt, Dr. Margaret LaWare, Dr. Kelly Odenweller, and Dr. Dara Wald, for their guidance and support throughout the course of this research. Your support, feedback, and exhortations to improve my work are foundational to my success.

In addition, I would also like to thank my friends, colleagues, the department faculty and staff for making my time at Iowa State University an experience full of growth. I want to also offer my appreciation to those who were willing to participate in my study, without whom, this dissertation would not have been possible. I am extremely grateful to the healthcare providers and patients who shared their experiences with me.

My friends and family have been a bedrock of support throughout this experience—thank you! I could not have done this without you. And lastly, to Matthew, thank you for being my cheerleader, therapist, chef, housekeeper, and all-around rock star. Thank you for encouraging me when I wanted to quit, and for providing me with perspective when I was overwhelmed. You mean the world to me.

ABSTRACT

The overall purpose of this study was to explore the ways in which patients and providers communicate with each other about high-risk pregnancy. The first research question I posed was how do patients communicate with providers about high-risk pregnancies? The second research question I addressed was how do providers communicate about high-risk pregnancy with patients? In order to answer these questions I conducted semi-structured interviews with two types of participants: women who experienced high-risk pregnancy, and healthcare providers practicing high-risk pregnancy care. I interviewed 32 patients which yielded 347 pages of single-spaced text. Additionally, I interviewed 6 providers which yielded 74 pages of single-spaced text.

A thematic analysis of the interview data resulted in several key findings. First, patients desired to establish positive and trusting relationships with their providers during high-risk pregnancy. Patients wanted to feel cared for and listened to throughout their high-risk pregnancy. Second, research findings identified the need for ongoing, formalized communication training for high-risk pregnancy providers. This type of training could include general communication skills when working with all patients, as well as more complex skills for interacting with high-risk pregnancy patients. Lastly, patients and providers both reported the desire to exert control throughout high-risk pregnancy. Patients expressed wanting to have input regarding care decisions, while providers desired patient compliance. These findings have implications at the organizational, provider, and individual patient levels. Additionally, this study revealed theoretical and practical implications and areas of future research which would contribute even further to understanding the complexities of patient-provider communication about high-risk

pregnancy. Communication-based interventions may help to improve health outcomes centered around high-risk pregnancy in the United States.

CHAPTER 1. INTRODUCTION

Risk and pregnancy are inseparable, put another way “There is no such thing as a healthy pregnancy...the best you can hope for is a low-risk pregnancy” (Rothman, 2014). Encountering risk throughout the maternity process is reality for the approximately 6,000,000 women experiencing pregnancy in the United States each year (CDC, 2017). Of those women, approximately 500,000 experience complications (e.g. premature birth, birth defects, gestational diabetes, and death of mother or infant) related to high-risk pregnancy (NIH, 2017). In the United States, approximately 97% of women experiencing pregnancy seek guidance from a healthcare provider (Lee, Ayers, & Holden, 2012; Scamell & Alaszewski, 2012). To contextualize these figures, approximately six million women experience pregnancy in the United States each year, and over 5,820,000 of them interact with providers within healthcare organizations. Theoretical thinking and research about such interactions between pregnant women and healthcare providers have been both underexplored and misunderstood despite repeated calls from communication scholars to extend work in this area (Coxon, Scamell, & Alaszewski, 2012; Rothman, 2014; Coxon, 2016).

While researchers have investigated communication between patients and providers (Shoebridge, 2015), no published studies exist which examine patient-provider communication regarding pregnancy and risk. Current research emphasizes medical management of risk during pregnancy (Lindhart, Rubak, Mogensen, Lamont, & Joergensen, 2013), including the diagnosis of high-risk pregnancy and patient compliance (Kupperman, Little, Harris, Kukla, & Kupperman, 2009; Tabatabaei, Moakhar, Pour, Mallashahi, & Zaboli, 2015). To further complicate matters, research on communication of high-risk pregnancy topics has only addressed issues from the perspective of providers (Grohmann et al, 2013; Hillemeier et al, 2014). To date,

the investigation of pregnancy risk communication from the perspective of patients remains under-researched. This study will explore the ways in which patients and healthcare providers communicate during high-risk pregnancy. Specifically, I explore interactions from both the patient and the provider perspectives in order to understand the experiences of both parties and to also inform recommendations for patient-provider communication about high-risk pregnancy in the future. In the remainder of this introduction, I contextualize pregnancy and childbirth trends within the United States, as well as problematize present research and current practices and preview the body of my dissertation.

Contextualization of Pregnancy and Related Terms

Background information about pregnancy is necessary to contextualize this study; this contextualization first must begin with the concept of what a pregnancy “is”. According to the American College of Obstetricians and Gynecologists (2013), the establishment of a pregnancy takes several days, and is completed when a fertilized egg is implanted in the uterine lining, which typically begins five days after fertilization and can take up to 18 days. The act of fertilization alone does not guarantee a pregnancy, as one-third to one-half of all fertilized eggs do not fully implant (American College of Obstetricians and Gynecologists, 2013). While a woman is pregnant, the maturity of the fetus is referred to as the gestational age, which is based on the first day of the last menstrual period (American Academy of Pediatrics, 2004). For example, one might say that a fetus is at 18 weeks of gestation. The estimated gestational age of a fetus is really a “best guess” scenario, as one cannot truly determine the exact date of implantation (American Academy of Pediatrics, 2004). The term *perinatal* refers to the entire time period surrounding pre-conception, conception, pregnancy, and childbirth; *antenatal* exclusively describes the period between implantation and childbirth; *neonatal* applies to the

period immediately following birth up to two weeks (American College of Obstetricians and Gynecologists, 2013).

Nearly five million births occur in the United States each year, although the total number of pregnancies is difficult to determine (Martin et al, 2015). This reporting difficulty is due to unknown frequencies of terminated pregnancies (including abortions and spontaneous abortions, also known as miscarriages). According to the Centers for Disease Control (2017), nearly 700,000 legal abortions are performed annually in the United States. Additionally, it is estimated that at least 10-25% of all pregnancies end in miscarriage (Goldman, 2016). Miscarriages are most common in the first twelve weeks of pregnancy, and are attributable to a variety of factors such as infection, genetic or physical abnormalities, and possible lifestyle factors (such as drug or alcohol use) of the mothers (Goldman, 2016; Martin et al, 2015). The underlying cause of most miscarriages is unknown. When one accounts for legal abortions, live births, and the rates of miscarriage, there are approximately six million pregnancies per year in the United States. Of those pregnancies, approximately 500,000 women experience medical complications due to high-risk pregnancy.

Defining High-Risk Pregnancy

As discussed in the beginning of this chapter, the concept of risk is inherently tied to pregnancy. Healthcare professionals have become so focused on risk and potential negative outcomes during pregnancy that a “normal” pregnancy is considered so because there is an absence of danger to the mother and fetus (Scamell & Alaszewski, 2012). Medical surveillance of pregnancy has increased in frequency and intensity, and women classified as having high-risk pregnancies undergo even more intense medical monitoring and intervention (Lee, Ayers, & Holden, 2012). Healthcare practitioners generally define high-risk pregnancy as one in which

there is increased risk to the mother and/or fetus at any point during pregnancy or delivery (ACOG, 2012; NIH 2017). Most notably, the National Institutes of Health (2017), explains that high-risk pregnancy, “Is one that threatens the health or life of the mother and her fetus” (p. 1). Broad classifications of risk during pregnancy include pre-existing conditions (e.g. diabetes, high blood pressure), being overweight or obese, multiple births (i.e. twins or triplets), and age factors (e.g. being a teenage or over age 35). It is important to note that the category of risk itself is not a negative outcome, it simply increases the likelihood that women who are considered to be in these categories of risk experience the increasing likelihood of poor outcomes such as pregnancy loss, birth defects, preeclampsia, cesarean birth, and fetal death (ACOG, 2012; NIH, 2017). Next, I discuss how the medical management of pregnancy and childbirth established the dominant birthing paradigm in the United States.

Historicizing Maternity Care

Monitoring pregnancy and childbirth in hospital settings gained popularity in the early 20th century and represented a shift in expertise from lay persons to physicians-as-experts (Barker, 1996; Seigel, 2014; Owens, 2015). In these times, prenatal care and childbirth were typically situated within a maternal system of midwives and family members. This changed once pregnancy became a medical diagnosis and was placed on the spectrum of disease, which occurred during the 1940s (Barker, 1998, WHO, 2019). Table 1 (below) presents an overview of pregnancy-related diagnostic codes, referred to within healthcare systems as ICD codes. It is important to note that ICD codes are published by the World Health Organization (WHO) and are identified as International Classification of Diseases (ICD); therefore, attaching ICD codes to

patients in their medical record completes the diagnosis/disease identification (WHO, 2019).

These codes are entered into a patient's medical record for the purposes of health tracking and billing.

Table 1. ICD-10 codes for various stages of pregnancy (CMS, 2015).

| Description | ICD-10 Codes |
|--|----------------|
| Pregnancy, first | Z34.00 |
| Pregnancy, first, obstetrical care | Z34.00 |
| Pregnancy, GI problems | O26.899, R19.8 |
| Pregnancy, high-risk | O09.90 |
| Pregnancy, high-risk, assisted reproductive technology | O09.819 |
| Pregnancy, high-risk, maternal age 35+ multigravida | O09.529 |
| Pregnancy, high-risk, maternal age 35+ primigravida | O09.519 |
| Pregnancy, high-risk, maternal age <16 multigravida | O09.629 |
| Pregnancy, high-risk, maternal age <16 primigravida | O09.619 |
| Pregnancy, high-risk, obstetrical care insufficient | O09.30 |
| Pregnancy, illegitimate | Z64.0 |
| Pregnancy, incidental | Z33.1 |
| Pregnancy, molar | O02.0 |

During the 1920s-1940s, biomedical rhetoric was employed to turn pregnant women into “patients” with a “disease,” rather than embracing pregnancy as a natural process (Barker, 1998). Midwives and those with folk medicine knowledge were literally written out of the pregnancy manual, “The educated woman reformer who is herself a mother comes to be replaced by the

scientifically trained male doctor” (Barker, 1998, p. 1073). Such restructuring of the maternal healthcare system gave physicians a monopoly over perinatal care. One of the earliest proponents of prenatal care and prenatal hospital wards, J.W. Ballantyne, believed that the health of most pregnant mothers was at risk and should be monitored (Seigel, 2014). Through the process of pregnancy medicalization and pathology in the early 20th century, “The pregnant woman herself seems to have dropped out of the picture except as her body serves as a conduit and site of scientific study for treating the fetus” (Seigel, 2014, p. 38). The medicalization of pregnancy has moved the pregnant woman from a home setting into one of hospitals and healthcare provider offices, and also established the patriarchal reign over pregnancy and childbirth (Owens, 2015; Seigel, 2013). In the early 1900s, approximately five percent of pregnant women would have visited a physician for prenatal care, while in the 1990s 95% of pregnant women received routine prenatal care from a physician (MacDorman, Mathews, & Declercq, 2014).

Problematizing Pregnancy in the United States

If pregnancy and childbirth are medical conditions requiring care and intervention, it is reasonable to conclude that the increase in prenatal contact with physicians and healthcare providers (such as nurse practitioners or physician assistants) should result in optimal pregnancy outcomes. Surprisingly, the United States has the highest maternal mortality rates among developed nations (Robeznieks, 2015). The United States’ maternal mortality rate is 28 per 100,000 births, which is the highest frequency of first-world nations (Agrawal, 2015). The amount of technology and monitoring in pregnancy and childbirth have increased exponentially in the last 30 years, yet alarmingly “Pregnancy-related deaths in the U.S. have risen from 7.2 per

100,000 live births in 1987 to 17.8 in 2009 and 2011” (Robeznieks, 2015, p. 1). Figure 1, below, provides a visual representation of the continued rise of maternal mortality rates in the United States.



Figure 1. Increased maternal mortality rates from 1987-2014 (CDC, 2018).

The causes of the increase in maternal mortality are currently unknown, but are believed to be multifactorial (CDC, 2018). Likely factors reported by the CDC (2018) include increased infection and sepsis rates, improved identification and reporting of maternal deaths, increased influenza rates, and increased rates of chronic conditions such as high blood pressure and diabetes. In rankings released by the Central Intelligence Agency (2011), out of 184 countries, the United States is in position 136 for maternal mortality, with identical rates to Iran and

Hungary. The CIA monitors both maternal and infant mortality rates as an indicator of the overall health of a country; i.e., the lower the maternal/infant mortality rate, the healthier the country. The United States is in the 138th position (out of 184) in comparison with other countries for rates of maternal mortality, and although it is not the focus of this dissertation, it is worth noting that the maternal mortality rate of black women is nearly four times as high as for white women (Seigel, 2014; CDC, 2018). CDC-reported maternal mortality rates for women in the United States from 2011-2014 were 12.4 deaths per 100,000 live births for white women, and 40.0 deaths per 100,000 live births for black women (CDC, 2018). Given these statistics, “A black woman is 22 percent more likely to die from heart disease than a white woman, 71 percent more likely to perish from cervical cancer, but 243 percent more likely to die from pregnancy- or childbirth-related causes” (Martin, 2017, p. 3). Although the exact causes of increased maternal mortality rates are unknown, it is reasonable to conclude that racial disparity issues play a key role. Indeed, racial disparity may be one of the unknown factors (per the CDC) influencing the considerably higher maternal mortality rate in the United States when compared with other developed countries. Maternal mortality rates are rising in the United States while falling in numerous first-world nations; this is visually depicted in Figure 2 below.

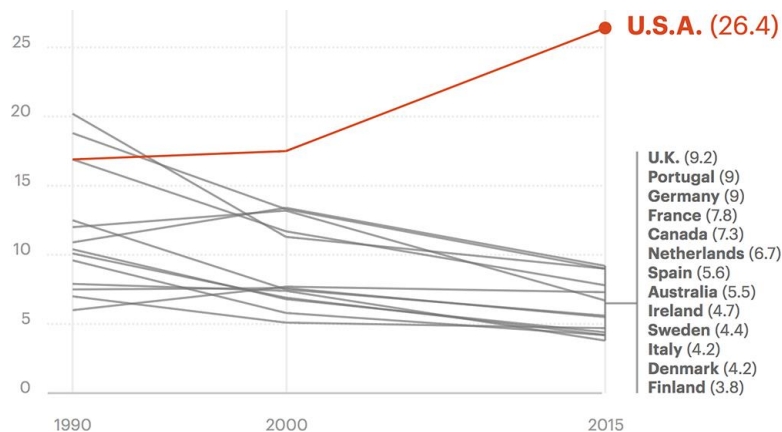


Figure 2. Rising maternal mortality rates in the United States (Martin, 2017).

In addition to increasing maternal mortality rates in the United States, infant mortality rates are also problematic.

MacDorman and Mathews (2010) call attention to the concerning infant mortality rates in the United States in Figure 3 below. What is concerning here is “Infant mortality is an important indicator of the health of a nation, and the recent stagnation in the U.S. infant mortality rate has generated concern among researchers and policy makers” (MacDorman & Mathews, 2010, p. 577).

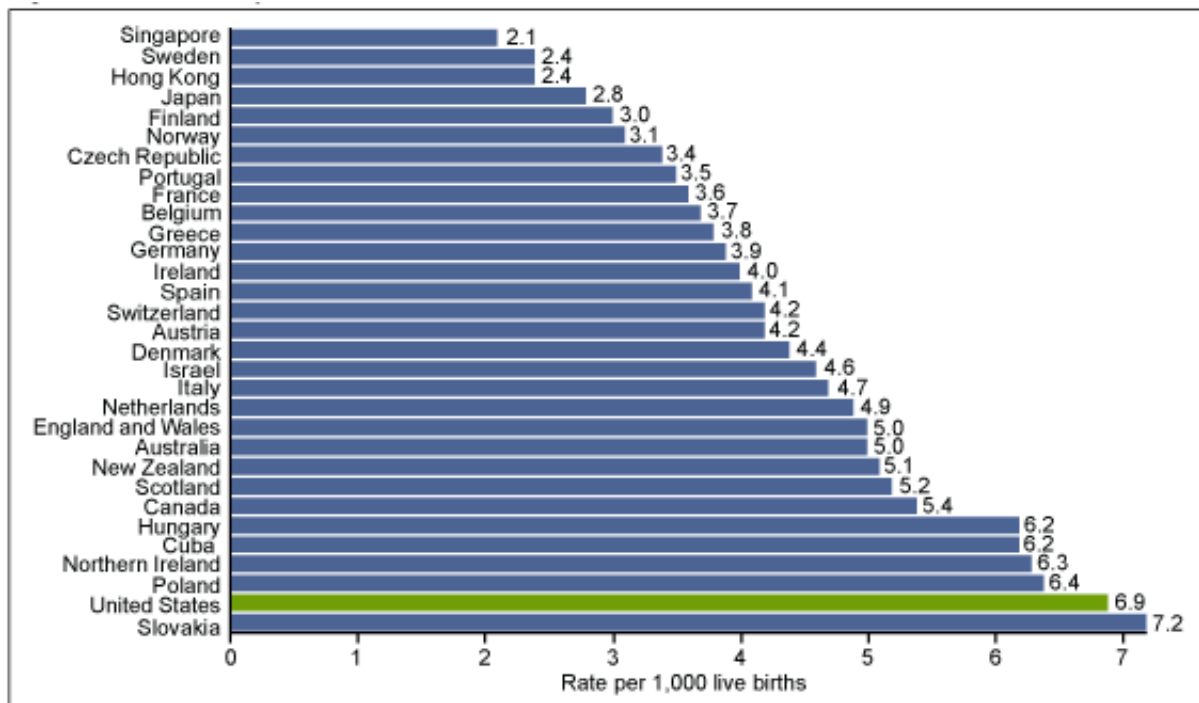


Figure 3. Comparison of infant mortality rates in 2005 (MacDorman & Mathews, 2010).

In addition to death, other negative birth outcomes include preterm birth, low-birth-weight babies, and delivery complications. All of these occur far more frequently in the United States than in other first-world countries (Martin et al, 2011). Developing countries such as Guam and Cuba (CIA, 2011) have better infant survival rates than the United States. These data make clear

the exigency of examining maternal healthcare practices in order to discover strategies for improvement. The focus in this study is to examine high-risk pregnancy communication between patients and providers in order to better understand the current situation, lend support to current research, and provide potential recommendations for practice. I will begin by describing my orientation towards organizational communication for this study.

Patient-Provider Communication

This study is based on the discipline of organizational communication, as patients and providers interact within healthcare systems. It is important to be aware that interactions between patients and providers are not occurring independent of healthcare organizations. Organizational factors such as policies and resources influence and direct communication between patients and providers. Further, the enculturation of paternalistic communication practices during medical training influences the ways in which providers communicate with patients. These communication interactions cannot be separated from the healthcare organizations; they must be considered together. What follows is a brief discussion of past theoretical approaches to the study of patient-provider communication and an argument for incorporating an organizational communication approach to this study. Healthcare systems exist to promote and maintain health, yet these goals are often enacted upon by institutional factors which may enhance or constrain effectiveness (World Health Organization, 2000; Ako-Arrey, Brouwers, Lavis, & Giacomini, 2015). Providers (staff) and consumers (patients and families) interact within healthcare systems and encounter various tensions such as technology and electronic health records, institutional policy, and decision-making based on financial considerations (Steffensen, 2012; Strong et al, 2014). These interactions quickly become complex and are also influenced by the past experiences of the individuals who are

communicating with each other (Gurzik & Kesten, 2010). Individuals operating within healthcare systems are both acting upon and being enacted upon by institutional factors, and these factors certainly can impact communication. Further, organizational practices may be overt or latent in that people who “take up” rituals of communicating may either be aware of these practices or may adopt them unconsciously (Koschmann & McDonald, 2015).

While some studies have examined communication interactions with patients and providers, the research has been performed from the institutional perspective of healthcare providers (Johnson & Ramaprasad, 2000; Fagerlin, Zikmund-Fisher, & Ubel, 2011; Khan et al, 2013; Hawley et al, 2014). For example, Greiner and Conklin (2015) developed an instructional framework for providers on how to break bad news of fetal abnormalities detected on ultrasound. While some of the recommendations are sound, such as “Providers should discuss this information in a straightforward and sensitive manner to help the woman cope with the weight of the diagnosis of a fetal anomaly;” conclusions remain focused on the provider and do not get below the surface of what is happening with communication at institutional and personal levels (Greiner & Conklin, 2015, p. 43). Existing research which does include patient perspectives is helpful in expanding knowledge about patients concerns and priorities, but is not specifically related to discussions of pregnancy and risk between patients and providers (Turner, 2003; Reszel, 2014). The gap, then, which exists in current literature is examining patient-provider communication regarding pregnancy and risk within the organizational settings of healthcare systems. In this study I seek to build upon existing work and to narrow this gap in knowledge.

Overview of the Dissertation

The overarching purpose of this exploratory study is to improve communication between patients and providers at both individual and organization levels by understanding the lived

experiences of the individual. More effective communication in high-risk pregnancy scenarios is likely to impact patient outcomes as well as patient's personal experiences. Further, improved communication in this area may be personally empowering to women experiencing high-risk pregnancy, as women facing loss and uncertainty are frequently silenced in healthcare organizations (Toller, 2011). In this chapter I have introduced the motivation, my orientation to the discipline of organizational communication, and the focus and goals of the study. In Chapter 2 I synthesize the literature on organizational communication theories and various related and relevant sets of literature. My work in Chapter 3 describes in detail the research context, the data collection and analysis procedures. In Chapter 4 I report the results of this study. Lastly, in Chapter 5 I conclude by discussing the theoretical and practical implications of this research. I also discuss future research possibilities for expanding on my study. In the next chapter, I introduce the relevant research related to high-risk pregnancy and patient-provider communication within healthcare organizations.

CHAPTER 2. CONCEPTUAL BACKGROUND AND LITERATURE REVIEW

In this chapter I discuss and critique existing literature related to patient-provider communication. Understanding how patients and providers communicate during high-risk pregnancy requires first an exploration of the history of patient-centered, patient-provider communication, and patient empowerment approaches to healthcare. I will review existing literature addressing current recommendations for practice. Organizational communication is the foundation of this study. It is important to explore how feminist theory and existing research about pregnancy are connected within organizational communication. This is where I begin.

Feminist Theory, Pregnancy, and Organizational Communication

Scholars have critiqued the ways in which healthcare organizations have discussed pregnancy and defined pregnancy risk through the language being used within healthcare (Tucker, 1998; Lagerwey, 1999; Dahlen, Jackson, & Stevens, 2011; Hallgrimsdottir & Benner, 2014). As discussed in Chapter 1, the current maternity care paradigm in the United States has undergone great transformation over the past hundred years, and much of that change has included major shifts in the language and strategies surrounding health communication. These changes have been problematized by scholars such as Hallgrimsdottir and Benner (2014), who articulate that exaggerated assessments of risk during pregnancy developed alongside the medical management of pregnancy during the 21st century. As the practice of medicine became more professionalized (composed primarily of male practitioners), physicians assumed authority on matters related to pregnancy and childbirth (Arney, 1982; Barker, 1998; Leavitt, 1987; Conrad, 1992; Seigel, 2014). The concentration in maternal care shifted from one of mothers being managers of their pregnant body to being fragile individuals requiring the expertise and

instruction of male physicians (Apple, 1995; Hallgrimsdottir & Benner, 2014; Pierce, 2008). Scholars argue that the development of paternalistic medicine has resulted in unnecessary monitoring and interventions during pregnancy, as well as stripping pregnant women of their autonomy (Hallgrimsdottir & Benner, 2014; Pierce, 2008, Seigel, 2014). Resultantly, healthcare organizations have transformed into systems in which providers exert power over pregnant patients while ignoring the experiences and values of those patients (Apple, 1995; Hallgrimsdottir & Benner, 2014; Pierce, 2008; Seigel, 2014). Feminist scholars continue to call for the completion of pregnancy-related theory and practice research, and feminist approaches to healthcare communication are salient to this study (Coxon, Scamell, & Alaszewski, 2017; Hallgrimsdottir & Benner, 2014; Scamell & Stewart, 2014).

Feminist theory is a useful lens with which to explore patient-provider communication of pregnancy and risk because it values lived experiences of individuals, as well as multiple ways of knowing. In order to examine the complexities surrounding provider-patient communication regarding high-risk pregnancy, I use feminist theory as a guiding theoretical framework while approaching my research through the lens of a critical-interpretive paradigm. Critical research is particularly appropriate for my topic of communication regarding high-risk pregnancy given that the traditional ideology in the healthcare and birthing system is based in patriarchy, and provider-patient interactions are mediated by perceived and actual power within those relationships (Hallgrimsdottir & Benner, 2014; Pierce, 2008; Owens, 2015).

Here I will focus on what feminist theory specifically contributes to the study of organizational communication. Gender issues in organizational communication have been under-researched, which has prevented new opportunities for theory and research within the

field (Buzzanell, 1994; Coxon, Scamell, & Alaszewski, 2017; Hallgrimsdottir & Benner, 2014; Mumby, 1993; Scamell & Stewart, 2014). Feminist theory is indispensable to organizational communication, as it:

urges us to examine core feminist issues: women's economic, political, social, psychic, and biologic oppression; trivialization of women's concerns, values, contributions, and language; presentation of alternative viewpoints and ways of knowing as deviant and second class; and, women's power to make change collectively (Buzzanell, 1994, p. 340).

Mumby (1996) posits that researchers should view gender as a central, significant feature of organizational communication, and not simply a peripheral variable. Feminist research has worked to overcome and rewrite traditional works that ignored the experiences of women and created false portrayals of neutral gender enactment (Buzzanell, 1994; Mumby, 1996). It is essential for scholars to analyze how gender is enacted, both knowingly and unconsciously, within organizations, and how gender ideologies are perpetuated. Feminist theory focuses on domination—how various persons have been oppressed and silenced through patriarchal systems in economics, institutions, politics, etc. (Coxon, Scamell, & Alaszewski, 2017; Hallgrimsdottir & Benner, 2014; Mumby, 1996). The core issue of much feminist research involves knowledges—whose knowledge is valid, valued, and where do these forms of knowledge come from? (Olesen, 2011). This study seeks to understand multiple forms of knowledge not just that of the physician, but also of the pregnant patient, whose perspective is often overlooked (Crossley, 2007; Hallgrimsdottir & Benner, 2014). It is important to note that while this study explores the ways in which patients and providers communicate about risk during pregnancy, the emphasis is not directed towards risk communication itself. This is

because I am examining how organizational forces and traditional approaches to gender enactment are impacting patient provider communication. I seek to discover systemic practices of communication which or may not serve both patients and providers as they interact with one another. More specifically, feminist approaches to organizational communication can shed light on the embodied experience of pregnancy and childbirth, which has historically been underexplored (Coxon, Scamell, & Alaszewski, 2017; Hallgrimsdottir & Benner, 2014; Turner, 2011). Even within feminist theory there are a variety of perspectives that could be used to critique organizational communication (Buzzanell, 1994). One such perspective relevant to the current study is revisionist feminism.

Revisionist Feminism Approaches

Revisionist feminists argue for a reconstruction of society that supports all genders so that no individual is oppressed by gendered stereotypes (Buzzanell, 1994). Potential advantages of the revisionist approach include the posing of different questions/approaching things from various viewpoints to identify what should be maintained and what should be changed (Buzzanell, 1994). For example, by examining the ways in which healthcare providers and patients communicate about pregnancy, by approaching things from a revisionist feminist perspective I can generate recommendations for practice. These recommendations for practice may be both liberating to women and may also maintain status/image of healthcare providers, as revisionist perspectives are “capable of including multiple interpretations without hierarchically arranging some as more important or significant than others” (Buzzanell, 1994, p. 361). As Mumby (1996) identifies, feminists “are particularly interested in the role of discourse in the construction of gendered relations of power” (p. 265). I argue that the feminist revisionist perspective is a useful framework to study pregnancy risk communication for two chief reasons.

First, by including self-reported experiences from study participants I am able to accept each narrative without privileging provider over patient or vice versa. Secondly, as I explore data provided by study participants, I may gain insight into how gender and power dynamics are constructed during patient-provider interactions. Insights in these areas may drive recommendations for practice change.

I seek to explore how communication about pregnancy risk and decisions related to that risk (for example, elective C-sections) are influenced by dynamics of power between healthcare providers and patients, in addition to the enactment of gender. Through critiquing and questioning fundamental assumptions of pregnancy risk, such as the notion of “doctor knows best”, I will be able explore revisionist feminism within the organizational communication realm. I am particularly interested to assess which feminine principles are overlooked or dismissed. Marshall (1993) identifies core female values as: “interdependence, cooperation, receptivity, merging, acceptance, awareness of patterns, whole and contexts, emotional tone, personalistic perception, being, intuition, and synthesizing” (p. 124). These key values have not been explored as they relate to pregnancy risk communication, and have largely been ignored, as value systems have traditionally privileged and maintained male values (Coxon, Scamell, & Alaszewski, 2017; Mumby, 1993; Olesen, 2011). Since male perspectives and forms are the “norm to which organization members adapt,” by the very nature of being a pregnant female, women are classified as “other” (Marshall, 1993, p. 126). It is important for me to note here that I am approaching pregnancy risk research through a critical perspective, and I need to be aware of my assumptions and prejudices. As I have developed here, I am working from the viewpoint that women have been traditionally marginalized through patriarchy, even when they are living out experiences, such as pregnancy, which are uniquely female in nature. Crossley (2007) and

McCallum (2005) argue that hegemonic controls are enacted on a regular basis as pregnant women navigate and participate in healthcare systems. This is consistent with early feminist works that posit women have been repeatedly dismissed from being “legitimate meaning makers if their interpretations of reality differ significantly from established, male-cased notions of truth” (Marshall, 1993, p. 128; Spender, 1982).

Perhaps even more troubling, is that women who go against patriarchal rules and values are likely to face negative repercussions in their personal and professional lives (Marshall, 1993; Miller 1988). Women already face extraordinary challenges in reconciling successful careers with childbirth and mothering, and often feel the need to justify their embodied experiences within professional organizations (Gatrell, 2013; Turner & Norwood, 2013). For example, pregnant and lactating women might feel the need to “hide” their maternal bodies at work due gendered expectations of how a working mother’s body should be presented (Gatrell, 2013; Turner & Norwood, 2013). Maternal bodies can be considered unprofessional, and mothers often resort to practices such as breast binding while lactating and disguising pregnant bodies via loose clothing and/or shapewear. The issue here is that maternal bodies are typically not welcomed in the workplace; they are viewed as being weaker or “less than” those of male employees (Gatrell, 2013; Witz, 2000). The dynamics of shifting in and out of various situations (e.g. work, doctor visits, etc.) may be challenging to women as they seek to understand organizational settings in which their maternal bodies are considered to be acceptable rather than weak. These dynamics are particularly concerning in relation to pregnancy and healthcare because of the inherent risk involved in routine pregnancy. In cases of high-risk pregnancies these dynamics become even more important to examine due to the life or death nature of risks to women and fetuses. Next, I will explore the connections between pregnancy and risk.

Risk in Pregnancy

In order to contextualize this study a discussion of risk is warranted, particularly since pregnant women interact within organizations as they discuss pregnancy, risk, and childbirth decisions. According to the National Institutes of Health, a high-risk pregnancy “threatens the health or life of the mother or her fetus” (2017, p. 1). Various risk factors include: pre-existing health conditions such as hypertension or diabetes, being overweight or obese, carrying more than one fetus at a time, and being a teenager or over age 35 (NIH, 2017). Complications from high-risk pregnancy occur in six to eight percent of all pregnancies, which impacts approximately 480,000-640,000 women annually (University of California San Francisco, 2017). Given these facts an exigency exists to address the impact of conversations and interventions surrounding pregnancy and risk, as these are impacting nearly a half-million women each year. Women experiencing high-risk pregnancy are typically referred to a healthcare provider for increased observation (and possibly intervention) during pregnancy and delivery. Lee, Ayers, and Holden (2012) argue that healthcare providers and patients must reach an agreement before proceeding with prenatal care, that is, women must accept the designation of being “high risk”, and the provider must communicate about that risk. While existing literature addresses the negotiation patients and providers undergo in determining whether or not a woman is experiencing high-risk pregnancy, to date no research has been conducted about the actual communication of risk between providers and pregnant patients (Lee, Ayers, & Holden, 2012). The conceptualization of high-risk pregnancy is situated within the context of a society that views pregnancy as a period of inherent danger (Coxon, Scamell, & Alaszewski, 2012). Further, there is no such thing as a no-risk pregnancy; pregnancies are identified on a continuum from low to high risk, but the concept of a risk-free pregnancy does not exist

(Hallgrimsdottir & Benner, 2014; Lee, MacVarish, & Bristow, 2010; Ruhl, 1999). Given that pregnancy and risk have been so coupled together the fact that patient and provider communication about pregnancy risk is underexplored is surprising. In this study I aim to explore the ways in which patients and providers communicate with each other about high-risk pregnancy. Doing so may provide insight into current practices as well as assist in recommendations for changing current communication practices. My work in this area connects with and extends healthcare scholarship addressing healthcare and communication. The interconnectedness of healthcare and communication have been explored in depth (yet not exhausted) over several decades. These works have contributed to three interrelated concepts in healthcare: patient-centered care, patient-provider communication, and patient empowerment. Each of these components, visualized below in Figure 4, influences the others as patients and providers encounter each other within healthcare organizations.

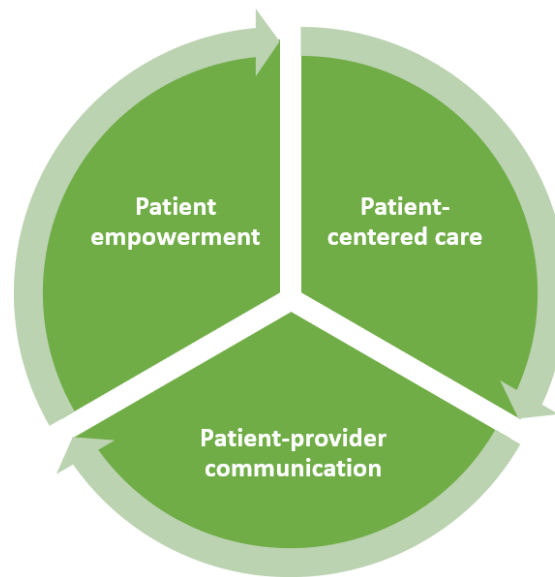


Figure 4. The interrelated concepts of patient-centered care, patient-provider communication, and patient empowerment.

One must have a thorough grasp of literature related to patient-centered care, patient-provider communication, and patient empowerment in order to gauge where additional work is needed. I will examine and evaluate research for each area before demonstrating how this study connects with and builds upon these concepts. I will begin with the area of patient-centered care.

Patient-Centered Care

Over the past several decades, “patient-centered care” has emerged as trope within healthcare systems. The term was identified in 1969 by Edith Balint, who emphasized the need for healthcare providers to understand and respect each patient as being an individual human being with unique needs (Mead & Bower, 2000). Subsequent fine-tuning of the concept emerged throughout the following decades; Byrne and Long (1976) posited that patient-centered care occurred when physicians took the patient’s understanding and experience into consideration during clinical interactions. During the 1980s and 1990s, increasing research called for involving patients in the healthcare decision-making process (Laine & Davidoff, 1996; Lipkin, Quill, & Napodano, 1984; Mead & Bower, 2000; Winefield, Murrell, Clifford, & Farmer, 1996). Previous to this supposition, the reigning model had been one of the physicians directing and controlling interactions with patients (Ishikawa, Hashimoto, & Kiuchi, 2013; Mead & Bower, 2000; Mead & Bower, 2002). The physician-centered healthcare delivery system was widely criticized as being paternalistic, and outcry from the public, patients and families, and even healthcare workers brought about impetus for change (Mead & Bower, 2000; Pinto et al, 2012). A landmark report published by the Institute of Medicine (2001) called for a revisioning of healthcare systems to better provide quality care, with an emphasis on patient-centeredness (IOM, 2001; Meterko, Wright, Lin, Lowy, & Cleary, 2010). The Institute of Medicine report called attention to the poor state of healthcare delivery in the United States,

urged practitioners and researchers to focus “more broadly on how the health system can be reinvented to foster innovation and improve the delivery of care” (IOM, 2001, p. 2).

Practitioners and researchers flocked to the calling, producing study after study extolling patient-center care and the correlation with positive health outcomes (Mead & Bower, 2000; Pinto et al, 2012). However, this new research became problematic due to varying meanings of patient-centered care and the tendency of healthcare professionals to work in silos, not connecting with or applying each other’s work (Ishikawa, Hashimoto, & Kiuchi, 2013; Luxford, Safron, & Deblanco, 2013; Street, 2013). While the phrase “patient-centered care” is commonly used when discussing healthcare systems and practices, the meaning behind the phrase has a history of opacity. The Institute of Medicine defined patient-centered care as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” (2001, p. 3). Trust and empathy are interrelated concepts with patient-centered care and are often used at the base of assessing the effectiveness of patient centeredness (Hall, Zheng, Dugan, Camacho, Kidd, Mishra, & Balkrishnan, 2002; Pinto et al, 2012). In general, the currently agreed-upon concept of patient-centered care contains the following general elements:

1. The biopsychosocial perspective: understanding that illness is complex and involves biomedical, social, and psychological elements.
2. The ‘patient-as-person’: acknowledging that each patient has a unique perspective regarding their illness and experiences.
3. Shared power and responsibility: assessing patients’ preferences for information and decision-making and then responding appropriately.

4. Therapeutic alliance: establishing a trusting, working relationship in which patients and providers develop goals for treatment.
5. The ‘doctor-as-person’: awareness that physicians personal characteristics and experiences influences they ways in which they practice medicine and encounter patients (IOM, 2001; Ishikawa, Hashimoto, & Kuichi, 2013; Mead & Bower, 2000; Mead & Bower, 2002).

At the core of patient-centered care is communication, and prolific research in the past two decades has focused on it (Bensing, Verhaak, van Dulmen, & Visser, 2000; Ishikawa, Hashimoto, & Kuichi, 2013; Smith, 2002; Street, Makoul, Arora, & Epstein, 2009). Existing research supports the claim that patient-focused communication “can improve patient outcomes, such as in satisfaction, in psychosocial adjustment, and adherence to treatment, thus contributing to a better state of health” (Ishikawa, Hashimoto, & Kuichi, 2013, p. 147), and patient-centered care and communication are viewed as highly desirable elements in healthcare systems (Mead & Bower, 2002; Stewart et a, 1999; Venetis, Robinson, Turkiewicz, & Allen, 2009). However, along with praise for patient-centered care and communication comes criticism. The concept of patient-centered care remains poorly defined, and while much research exists to promote it, very little exists in the way of instruction or tangible tools for practice (Epstein et al, 2005; Mead & Bower, 2000; Stewart et al, 2003; Street, 2013). To that end, there have been repeated calls for researchers to develop a clearer, theory-based definition of patient-centeredness (Epstein et al, 2005; Ishikawa, Hashimoto, & Kuichi, 2013), as well as provide concrete tools and recommendations for practice (Ishikawa, Hashimoto, & Kuichi, 2013; Luxford, Safron, & Deblanco, 2011; Mead & Bower, 2000; Pinto et al, 2012; Street, 2013). Although lacking a consistent, clear research agenda for patient-centered care, abundant

research exists which explores and differentiates various theoretical perspectives on patient-provider communication. Individual providers may subscribe to various approaches (either consciously or unconsciously); my emphasis here will be on addressing existing theoretical literature regarding patient-provider communication. There are four main theoretical approaches to patient-provider communication in the medical field: functionalist, conflict, rational choice, and social construction. I will describe and critique each perspective, beginning with functionalism.

Functionalist Perspective

The functionalist perspective was first developed in the field of sociology. This approach was then modified as scholars explored the connections between sociology and scientific medicine (Lupton, 2012). In the functionalist perspective of patient-centered care, the working relationship between patients and providers is a social system based on the division of labor (Ishikawa, Hashimoto, & Kuichi, 2013; Lupton, 2012). During the 1950s, the role of the patient was as the “sick” individual, however, that transitioned to a more consumer-based relationship during the 1960s and 1970s (Hermann & Mayer, 1997; Ishikawa, Hashimoto, & Kuichi, 2013; Parsons, 1951; Reeder, 1972). In this transition, patients evolved from being sick clients to being consumers, leading the functionalist perspective to also commonly be referred to as the consumerism model of healthcare (Charles, Gafni, & Wheelan, 1999; Emanuel & Emanuel, 1992; Ishikawa, Hashimoto, & Kuichi, 2013; Roter, 2000). The consumerism model depicts the patient as a customer or consumer of healthcare, and the physician is considered to be a technical consultant. The increasing emphasis on patients as consumers of healthcare led to a strong emphasis on patient satisfaction as being the key indicator of quality for patient-centered care (Ishikawa, Hashimoto, & Kuichi, 2013). However, this consumerism model has become

increasingly problematic in healthcare circles due to the emphasis of patient perceptions of satisfaction, while little to no attention is placed on outcomes or provider input (Ishikawa, Hashimoto, & Kuichi, 2013; Yasin, Meacham, & Alavi, 1999). For example, patient satisfaction surveys are sent out following healthcare visits. These could be routine clinic appointments, hospital stays, or emergency room visits. Patients are asked to report on their satisfaction with the care they received. Companies (such as Press Ganey) are hired to distribute and tabulate satisfaction surveys, which then “grade” the organization and are tied to insurance reimbursement rates. The main trouble with satisfaction surveys is that the emphasis on consumerism tends to shift the organizational focus from quality of care to the patient *perception* of quality (Berge & Burkle, 2014; Junewicz & Youngner, 2015). Healthcare organizations and providers may practice “Bad medicine by honoring patient requests for unnecessary and even harmful treatments” in order to keep their customers/patients happy (Junewicz & Youngner, 2015, p. 43). The most notable example of this type of harmful medical practice is the over-prescription of controlled substances, which has greatly contributed to the opioid crisis (Berge & Burkle, 2014; Bernstein, Magill, Beaudoin, Becker, & Rish; 2018). When patients became consumers, the consumerism/business model emphasized doing everything to keep the “customers” happy and overlooked potential dangers of facilitating opioid addictions. This is an ongoing issue and much litigation is underway regarding the over prescription of opioids (Bernstein, Magill, Beaudoin, Becker, & Rish; 2018; Dhalla, Persaud, & Juurlink; 2011). In short, the functionalism model does not adequately address the complexity of the interplay and working relationship between patients and providers due to its overemphasis on patients as consumers.

While the functionalist theory of healthcare emphasizes patients-as-customers, the conflict theory perspective pits providers and patients against each other in a struggle for power. I will discuss this approach next.

Conflict Theory Perspective

Conflict theory emerged in the sociology and social psychology areas, and is attributed to Karl Marx (Halpern, 2007). The conflict theory approach to patient-centered care emphasizes that working relationships between patients and providers are rooted within power systems (Collins, 1994; Haug & Lavin, 1981). The physician or healthcare provider is the individual in a position of power, and they control healthcare options such as diagnostic tests and treatments. The relationship between patient and provider is inherently based on a conflict of interest and seemingly opposing goals on a continuum; physician-centered versus patient-centered communication (Ishikawa, Hashimoto, & Kuichi, 2013). In contrast to the role of patient-as-consumer in the functionalist perspective, with conflict theory patients and providers assume the roles of professional-client. Patients are considered to be “clients” and are taking up the “sick role” in seeking professional help from a physician who is the decision maker regarding the nature of the services to be delivered. This is different that the functionalist/consumer model of healthcare in which the patient/customer is considered to be a purchaser of professional services who is capable of making all decisions related to their healthcare (Ishikawa, Hashimoto, & Kuichi, 2013). Patient-centered care and provider-centered care are essentially located at two opposite ends of a continuum and each participant in the care encounter is attempting to stake their claim by exerting control (Bensing, 2000; Ishikawa, Hashimoto, & Kuichi, 2013; Smith & Hoppe, 1991). Conflict is enacted in patient-provider interactions by verbal dominance during healthcare visits (i.e. the physician talking for the majority of the visit, interrupting the patient,

and using close-ended questions), and the resulting conflict is a power struggle between patients and providers (Beckman & Frankel, 1984; Ford, Fallowfield, & Lewis, 1996; Marvel, Epstein, Flowers, & Beckman, 1999; Mead & Bower, 2000). Conflict theorists recommend that physicians avoid interrupting conversations and that patients should “actively seek as much information as they need from the physician and take control of the conversation” (Ishikawa, Hashimoto, & Kuichi, 2013, p. 149). Conflict theory approaches to patient-centered care can be helpful in that the communication goal is achieving patient autonomy (Halpern, 2007; Ishikawa, Hashimoto, & Kuichi, 2013; Mead & Bower, 2000). However, conflict theory approaches to patient-centered care may have limited potential for application. The key limitation to enacting communication via conflict theory is that at some level it does require providers to participate in the process. This is problematic due to findings that “Physicians often interrupt patients’ descriptions of their concerns at the beginning of the medical encounter and use closed-ended questions to control the discourse (Ishikawa, Hashimoto, & Kuichi, 2013, p. 149). In essence, conflict theory-based communication between patients and providers works well in theory but is more difficult to enact in practice.

Rational Choice Theory

Rational choice theory is an economic principal based on the premise that individuals always make logical decisions in response to the options presented to them (Bekker, 2010). Health professionals in the patient education realm took up rational choice theory as a means to assist patients with medical decision making (Bekker, 2010; Rubinelli, 2013). In the rational choice or utilitarian theory approach to patient-centered care, the emphasis is on medical decision making in accordance with patient priorities (Eddy, 1990). The two main factors influencing decision making in rational choice theory are facts (such as objective health data)

and personal values or preferences. Also referred to as the shared model, and mutuality, patient-centered care emphasizes what each individual brings to the working relationship; physicians possess technical knowledge, while patients are experts about their lifestyles and values (Charles, Gafni, & Wheeler, 1999; Eddy, 1990; Forrow, Wartman, & Block, 1988; Roter, 2000). The shared model is similar to the consumer model in that the physician is expected to provide the patient with technical information regarding the patient's healthcare, yet also expands on the consumer model by expecting patients to discuss their values and preferences so that decision-making is a mutual process (Ishikawa, Hashimoto, & Kuichi, 2013). Rational choice theory and the shared model have increased in popularity with the emphasis in healthcare systems on evidence-based medicine (EBM). Much communication research has been conducted in order to develop decision aids and pathways for decision making, but assumptions inherent in this approach weaken its potential effectiveness. Key assumptions to the rational theory approach are that physicians can and do clearly and concisely explain medical information, that patients are able to make accurate decisions based on this information, and that the most optimal healthcare decision will be among the options presented by the physician (Elwyn, Edwards, Wensing, Hood, Atwel & Grol, 2003; Ishikawa, Hashimoto, & Kuichi, 2013; O'Connor, 1995). However, these assumptions do not hold true and cannot be universally applied to all healthcare decision making during patient-provider interactions. Physicians are notorious for poor/unclear communication, and the emotional nature of healthcare decisions may prevent individuals from always making the most rational choice for their care (Ishikawa, Hashimoto, & Kuichi, 2013; Rubinelli, 2013).

Patients and providers each come into encounters with their own experiences and values in mind, which is not well accounted-for in the rational choice approach to patient-centered care. Rather, one must take the complex nature of social constructivism into account when orienting healthcare around patients. I will discuss this next.

Social Constructionism

Housed in communication theory and sociology fields, social constructionism has been applied to patient-centered care (Lambert, Street, Cegala, Smith, Kurtz, & Schofield, 1997). In the social constructionist approach, theorists assert that patients and physicians each bring their perspectives into patient-provider interactions, resulting in the mutual creation of reality (Ishikawa, Hashimoto, & Kuichi, 2013). It is worth noting that terminology is important; constructionists specifically define *disease* and *illness* as being separate yet related concepts in healthcare. Disease is considered to be abnormalities in functioning and/or structure of body systems, while illness is experienced by individuals as they undergo changes in their state of well-being and social functioning (Collins, 1994; Ishikawa, Hashimoto, & Kuichi, 2013; Lupton, 1994). Thus, providers and patients approach interactions differently; patients are constructing meaning of their medical issues based on their individual experiences and social interactions, while providers tend to approach interactions using medicalized knowledge gained through formal education and training in medical practice (Ishikawa, Hashimoto, & Kuichi, 2013). Conflict during patient-provider interactions can and does arise due to the gap in perspectives between patient perception of illness, and physician perception of and orientation towards disease. This conflict differs from that present in conflict theory, which is based on

power inequality; conflict in social constructionism arises from differing orientations to discussing health, illness, and disease (Mead & Bower, 2000; Ishikawa, Hashimoto, & Kuichi, 2013).

Social constructionists have criticized physicians as being overly focused on disease itself and ignoring the patient (Ishikawa, Hashimoto, & Kuichi, 2013; Lambert, Street, Cegala, Smith, Kurtz, & Schofield, 1997; Mead & Bower, 2000). Scholars have called for greater recognition and legitimacy of the lived experiences of patients (Mead & Bower, 2000; Stewart et al, 1995). Using the social construction approach, patient-centered care integrates the perspectives of both the patient and physician as they interact and create meanings of illness and disease together (Mead & Bower, 2000; Stewart, Brown, Freeman, Weston, & McWilliam, 2009). In this model of patient-centered care, physicians are to identify disease using the traditional biomedical model and also take into consideration four key factors for patients: their ideas about what is wrong with them, how they feel about being ill, how they are experiencing problems based on their condition, and what they expect to be done (Stewart et al, 1995). Scholars believe that providers will be better able to understand the patient as a complete person and to find shared values during the process of diagnosis and treatment (Ishikawa, Hashimoto, & Kuichi, 2013). However, the social constructionist approach to patient-centered care is not without critique. Inherent challenges to patient-centered care include the lack of articulation for patient care models, inconsistency due to differing patient experiences and perspectives, and the difficulties patients may have in being aware of their values and/or articulating them during interactions with providers (Ishikawa, Hashimoto, & Kuichi, 2013; Masse, Legare, Cole, & Dodin, 2001; Mead & Bower, 2000).

While currently poorly articulated, the social constructionist perspective to patient-centered care demonstrates potential for improving patient-physician interactions and positively influencing health outcomes (Ishikawa, Hashimoto, & Kuichi, 2013; Shapiro & Ross, 2002). Scholars recommend that narrative approaches based on story-telling be adopted as a framework for patients and physicians to mutually construct meaning together (Shapiro & Ross, 2002). An offshoot of the narrative framework is that of a “shared mind” concept, in which the emphasis is placed on relational, rather than individual, autonomy (Epstein & Peters, 2009; Epstein & Street; 2011). The shared mind concept is enacted when patients and physicians reach mutual decisions and share agreement during interactions, which is in the spirit of constructing meaning, rather than just an interaction to deliberate options (Epstein & Street, 2011; Ishikawa, Hashimoto, & Kuichi, 2013). While physicians still hold power, it is not viewed as dominating or coercive because the provider is using it to meet expectations of the patient (Epstein, Kones, & Quill, 2010; Epstein & Street, 2011). For example, physicians may enact power by withholding irrelevant or overwhelming information from patients if it will interfere with the ability to engage in important discussions. Rather than being paternalistic or provider-centered, scholars claim this is patient-centered care if power is enacted in appropriate contexts and the provider’s communication is based on a thorough understanding of the patient’s values and desire for information (Epstein, Kones, & Quill, 2010; Ishikawa, Hashimoto, & Kuichi, 2013; Lambert, Street, Cegala, Smith, Kurtz, & Schofield, 1997). While the social constructionist perspective is in alignment with my scholarship, the emphasis on loosely-defined contexts and lack of any training for patients and providers are particularly

problematic. Communication is at the core of patient-centered care, yet more scholarship needs to be completed in the area of patient-provider communication. I will next discuss and critique current literature regarding patient-provider communication.

Patient-Provider Communication

Effective communication is considered to be the key to delivering high-quality patient-centered care (Belasen & Belasen, 2018; Clever, Jin, Levinson, & Meltzer, 2008; Dunn, 2012; Epstein et al, 2010). Scholars generally agree that providers have a poor history of communicating clearly and empathetically with patients (Belasen & Belasen, 2018; Clever, Jin, Levinson, & Meltzer, 2008; Epstein et al, 2010; Lambert, Street, Cegala, Smith, Kurtz, & Schofield, 1997). Poor communication between providers and patients is a key barrier to patient-centered care, and improved communication is still needed (Beck, Daughtridge, & Sloane, 2002; Belasen & Belasen, 2018; Bensing & Dronkers, 1992; Marvel, Epstein, Flowers, & Beckman, 1999). Patients themselves consider communication skills in providers as one of the highest priorities, yet consistently report dissatisfaction in the quality of communication during their healthcare encounters (Beck, Daughtridge, & Sloane, 2002; Belasen & Belasen, 2018; Dunn, 2012). Further, physicians tend to have an inflated view of their own communication skills and believe themselves to be more competent in communicating than others perceive them to be (Beck, Daughtridge, & Sloane, 2002; Belasen & Belasen, 2018; Godolphin, 2003). Research indicates that participatory decision making can be an effective strategy for effective patient-provider communication (Beck, Daughtridge, & Sloane, 2002; Belasen & Belasen, 2018; Ong, de Haes, Hoos, & Lammes, 1995). During participatory decision making, patients and providers cooperate together in health management decisions. However, while researchers agree that participatory decision making is a good thing, there is a

lack of consensus as to what specific elements of communication should be included and/or updated (Beck, Daughtridge, & Sloane, 2002; Belasen & Belasen, 2018; Ong, de Haes, Hoos, & Lammes, 1995; Roter & Hall, 1989). Thus, the concept of patient-provider communication remains loosely defined; touted as critical to the success of healthcare systems yet generalized about in a manner unlikely to directly influence practice. Researchers in the medical field do agree that additional work must be completed regarding patient-provider communication and should contain common elements: consistent incorporation of theoretical frameworks, addressing challenges to the ongoing training of physicians, teaching a wide range of skills, and providing ongoing feedback (Beck, Daughtridge, & Sloane, 2002; Belasen & Belasen, 2018; Brown, Bowles, Mullooly, & Levinson, 1999). There are multiple stakeholders involved in the efforts to improve patient-provider communication: organizations and providers, and patients.

Impact on Organizations and Providers

Institutional changes are perhaps the biggest driver behind improving patient-provider communication due to the financial incentivization of patient satisfaction (Belasen & Belasen, 2018; Clever, Jin, Levinson, & Meltzer, 2008). The two main changes have driven healthcare systems to aggressively work on improving patient satisfaction: The Hospital Consumer Assessment of Healthcare Provider and Systems (HCAHPS), and the Affordable Care Act. The HCAHPS survey is a patient satisfaction survey which is tied to Medicare reimbursement rates for healthcare facilities (Belasen & Belasen, 2018). In addition to directing insurance reimbursement for hospital claims, HCAHPS scores are publicly reported and are available on the internet, influencing each healthcare organization's reputation (Belasen & Belasen, 2018). While many healthcare systems accumulated data over the years, there was no universal standard for assessing the quality of patient care. In response to this dilemma, as well as the

landmark IOM report calling for an improvement in quality of care, HCAHPS was developed in 2005 by the Centers for Medicare and Medicaid Services (CMS) to achieve three main objectives. First, the survey is set up to gather comparable data across all healthcare systems, allowing for objective and comparable data between facilities. Second, the publicly available reporting of survey data was created to incentivize healthcare systems to improve the quality of care. Lastly, the public reporting of data is intended to increase levels of accountability and transparency across healthcare organizations (Belasen & Belasen, 2018; CMS, 2019). In addition to HCAHPS functioning as a driver of quality care, the Affordable Care Act (nicknamed Obamacare) was passed in 2010 and directly influences hospital and clinic funding.

Under the Affordable Care Act (ACA), healthcare facilities receive incentive payments from Medicare. These incentives are based on HCAHPS scores, and facilities are paid based on how well they performed on each measure of the survey, as well as how much the facility has improved performance from their baseline (Belasen & Belasen, 2018; Clever, Jin, Levinson, & Meltzer, 2008). In what is essentially a pay-for-performance system, funds are distributed to facilities based on their performance scores; the best performers are reimbursed at the highest rates (Belasen & Belasen, 2018; CMS, 2019). It is possible for lower performing facilities to increase their scores, thereby increasing their payment rates. While the incorporations of the ACA and HCAHPS have been highly politicized, I maintain focus here on the impact on organizations and the impetus to participate in effective patient-provider communication. In addition to direct financial incentives for care, healthcare organizations work to improve patient-provider communication because it is correlated with positive health outcomes (Belasen & Belasen, 2018; Clever, Jin, Levinson, & Metzler, 2008; O'Malley et al, 2005). Scholars have stressed the importance of improving patient-provider communication for the past 20 years, but

little progress towards changes in practice had been made until financial consequences related to HCAHPS and the ACA have been reinforced outcomes (Belasen & Belasen, 2018; Clever, Jin, Levinson, & Metzler, 2008; O'Malley, Zaslavsky, Hays, Hepner, Keller, & Cleary, 2005). Still, instruction on specific strategies for effective patient-provider communication are sparse (outcomes (Belasen et al, 2015; Belasen & Belasen, 2018; Clever, Jin, Levinson, & Metzler, 2008; O'Malley et al, 2005; Osterberg & Blaschke, 2005). Patient-provider communication continues to be a problem in healthcare, and its impact spreads beyond organizations and physicians to the individual patient.

Impact on Patients

Patients consistently report low levels of satisfaction with their communication experiences in healthcare systems (Deveugele, 2015; Levinson, 1994; Oliveira, Ferreira, Pinto, Filho, Refshauge, & Ferreira, 2015). It is important to note that low patient satisfaction is a general phrase used to group patient experiences together as a whole, when in fact, each patient experience is individual and unique. Patient experiences and perspectives will differ, even for those circulating within the same healthcare systems or with the same diagnosis. For example, a pregnant patient with diabetes may experience her care very differently from another pregnant woman with diabetes, even if they are cared for in the same facility. In general, the poor quality of provider communication is the most frequent complaint from patients. Most patients report that they want caring, empathy, and clear communication from their healthcare providers (Ong, de Haes, Hoos, & Lammes, 1995; Deveugele, 2015; Kee, Khoo, Lim, & Kho, 2017). If patient expectations of communication are met, the patient generally reports satisfaction with their care. When expectations for provider communication are not met, patients may experience increased levels of stress, fewer incidence of compliance, and are more likely to sue providers (Greiner &

Conklin, 2015; Levinson, 1994; Oberman, 2000). Approaches to raising the quality of patient-provider communication vary. To date, the most widespread strategies to improve patient-provider relationships lie in the patient empowerment realm. I will discuss patient empowerment and its connections with patient-provider communication and patient-centered care next.

Patient Empowerment

Patient empowerment, and specifically women's health empowerment, has been extensively discussed and researched over the last several decades (Anderson, 1996; Ashcraft, 2000; Einstein & Shildrick, 2009; Gore, 1992). The two main disciplines contributing to the ongoing discussion are medicine and women's studies, and each of those disciplines views patient empowerment differently. Medically-based works on patient empowerment echo the calls for improved patient-provider communication, increased patient satisfaction, and shared decision-making (Anderson, 1996; Anderson & Funnell, 2010; Björkman, Simrén, Ringström, & Ung, 2016; Funnell, 2016; Luxford, Safron, & Deblanco, 2011). Scholars in the women's studies arena have emphasized how power dynamics and the historically paternalistic structure of healthcare systems have been oppressive to patients (de Aguiar, 1998; Einstein & Shildrick, 2009; Gore, 1992; Layne, 2006). I will discuss and critique both the medical and feminist approaches to patient empowerment.

Medically-Based Patient Empowerment

The growing trend towards patient empowerment exhorts physicians and other healthcare providers to be more responsive to patient needs and preferences, as well as encouraging patients to be more participatory in the healthcare process (Godolphin, 2003;

Wensing, 2000). These exhortations to empower patients are connected with the conflict theory approved discussed previously and are meant to protect the fragility of patients as they encounter healthcare (Björkman, Simrén, Ringström, & Ung, 2016; Funnell, 2016; Wendell, 1996). However, medically-based initiatives regarding patient empowerment are developmentally retarded. Current literature in medicine supports the need for patient empowerment; researchers are in agreement that it's essential to patient-centered care (Anderson, 1996; Einstein & Shildrick, 2009; Godolphin, 2003; Rowland, McMillan, McGillicuddy, & Richards, 2017; Wensing, 2000). Beyond that, medical scholars have only generic suggestions for implementing patient empowerment into healthcare. These recommendations include generic items such as encouraging patients to participate in their care, implementing satisfaction surveys, and being sensitive to patient needs (Anderson, 1996; Björkman, Simrén, Ringström, & Ung, 2016; Godolphin, 2003; Wensing, 2000). Beyond those suggestions there is a dearth of information, which prevents healthcare organizations from practically implementing strategies for patient empowerment. Medical literature in the area of patient empowerment is severely underdeveloped, leading to vagueness and confusion for patients and providers alike (Edwards & Elwyn, 1999; Stoff & Swerlick, 2013). Feminist-based approaches to patient empowerment have been much more developed than medically-based approaches. I will discuss feminism and health empowerment next.

Feminism and Health Empowerment

As discussed previously in this chapter, feminist scholars have critiqued the paternalistic domination of healthcare systems within the United States (Crossley, 2007; de Aguiar, 1998; Einstein & Shildrick, 2009; Gore, 1992; Layne, 2006). At the center of much of the critique towards healthcare and the medicalized birthing paradigm was the germinal text *Our bodies*,

ourselves: A book by and for women published by the Boston Women's Health Book Collective in 1976. This earthshaking text was produced in order to "Restore to women the autonomy and control that had been wrested from them by biomedicine" (Layne, 2003), and to inspire a grassroots movement in response to paternalized reproductive care (Anderson, 1996; Davis-Floyd, 1988; Layne, 2003). The primary goal of the women's health empowerment movement has been to restore control and autonomy of reproductive care (Layne, 2003; Layne, 2006). Facilitators of the women's health movement sought to restore this sense of control through exhortations for women to view reproduction as being normal and healthy, to perform cervical self-checks with speculums, and to take steps to control the environment (e.g. home versus hospital birth) in which they delivered babies (Boston Women's Health Collective, 2011; Gore, 1992; Layne, 2003). These types of interventions may be helpful for women, but the women's health movement has two main problem areas: the avoidance of discussing poor birthing outcomes, and the failure to acknowledge the role of biomedicine in women's healthcare. Poor birth outcomes such as miscarriage and stillbirth impact approximately 25% of pregnancies (Layne, 2003; NIH, 2017). These types of outcomes are not accounted for in the women's health movement due to the overemphasis on pregnancy and birth being natural, normal processes (Layne, 2003). Women experiencing negative pregnancy outcomes may not be adequately prepared for such outcomes. This lack of preparation can be extremely damaging to their psychosocial functioning and may also impact their future pregnancy decisions and outcomes (Fertl, Bergner, Beyer, Klapp, & Rauchfuss, 2009; Swanson, Karmali, Powell, & Pulvermakher, 2003). The second problem area with the women's health movement is the failure to acknowledge biomedicine in relation to reproduction (Layne, 2003; Layne, 2006). Regardless of how empowered and in control a woman feels, she may indeed experience issues

in her pregnancy which require medical monitoring and/or intervention. While it is not the focus of this study, it is important to note that the women's health field would be strengthened by additional research about the appropriate role of medical care in women's health.

Overall, scholars and practitioners have extensively researched approaches to patient care and communication. Progress has been made towards improving the quality of care delivered in healthcare organizations, but much work remains to be done. In particular, I seek to examine the gap in knowledge regarding patient-provider communication during high-risk pregnancy. I will next provide an overview of my approach to this study.

Research Questions

To sum up, pregnancy management in the United States has migrated to a medical model since the beginning of the 20th century. It is generally acknowledged that being pregnant is inherently risky and that affects approximately five to seven million women each year (CDC, 2017). In the United States, roughly 500,000 women are impacted by complications related to high-risk pregnancy each year (NIH, 2017). Further, clear and compassionate communication between patients and providers is essential to successful healthcare practices and outcomes (Fagerlin, Zikmund-Fisher, & Ubel, 2011; Shoebridge, 2015). However, research about high-risk pregnancy communication between healthcare providers and patients is scarce. In light of this, I seek to answer the following research questions through my research:

RQ1: How do patients communicate with providers about high-risk pregnancies?

RQ2: How do providers communicate about high-risk pregnancy with patients?

CHAPTER 3. METHODOLOGY

The purpose of this study is to examine patient-provider communication about high-risk pregnancy within the United States healthcare system. More specifically, I seek to better understand the ways in which patients and providers communicate with each other during high-risk pregnancy. In addition to a deeper understanding of communication practices, the data gathered may provide insight into potential recommendations for changes in provider and/or patient practices. As a currently practicing registered nurse and certified pediatric nurse, my tacit knowledge of healthcare systems and my experience with healthcare communication is beneficial to my interactions with both patients and providers in the context of this study. In order to examine these communication phenomena, I am approaching this research from a critical-interpretive perspective. Chapter Three contains the presentation and rationale for the utilization of qualitative research methodology situated in a critical-interpretive grounded theory approach. Participant recruitment and data collection methods will also be discussed. Likewise, the methods for collecting, sorting, coding, and analyzing the data are discussed in this chapter as well as the processes for producing trustworthy and reliable data. In this chapter I address the following:

- Paradigmatic influences,
- Theoretical framework for critical-interpretive grounded theory methodology,
- Use of thematic analysis,
- Terminology regarding type of provider,
- Participant recruitment,
- Data collection procedures, and
- Data analysis.

To provide context and grounding for my choice of qualitative research, I now turn to a discussion of the guiding paradigmatic approaches of this study.

Organizational Communication and Paradigms

Organizational communication emerged as a field in the 1940s and 1950s (Taylor, Flanagin, Cheney, & Seibold, 2001). Developed from traditional rhetorical studies, and a subset of the larger communication studies discipline, organizational communication focuses on interactions and outcomes between members in open, yet structured systems (Katz & Kahn, 1978). As the field developed, four main paradigms emerged: functionalists, radical humanists, radical structuralists, and interpretivists (Burrell & Morgan, 1979; Deetz, 2002; Taylor, Flanagin, Cheney, & Seibold, 2001). The functionalist, or positivist, paradigm emphasizes a tangible and concrete reality outside of the individual experience. Researchers practicing such ideology typically engage in empirical work, believing truth exists and can be discovered. In contrast, radical humanists believe that reality is both socially and intersectionally constructed, however, these constructed realities are subjected to ideological factors of individuals (Taylor, Flanagin, Cheney, & Seibold, 2001, p. 104). In essence, the core of one's beliefs and reality more generally are socially constructed. While radical humanists view reality as socially constructed, radical structuralists are similar to functionalists in that they believe in an objective reality. The key difference between radical structuralists and functionalists is that radical structuralists believe various aspects of society are oppressive, which leads to a goal of uncovering sources of such oppression. The final paradigm within organizational communication is that of the interpretivists, who explore the subjectivity of the individual experience and view reality as a social construction (Burrell & Morgan, 1979; Krone, Jablin, & Putnam, 1989; Taylor, Flanagin, Cheney, & Seibold, 2001; Redding, 1979). Organizational

communication scholars in this area view communication as not just documenting experiences, but as actively constructing it (Taylor, Flanagin, Cheney, & Seibold, 2001). However, the various paradigms, originally developed by Burrell and Morgan (1979), have been criticized for being oversimplified not accurately addressing the need for critical theoretical approaches Deetz (1996) warns that the continuation of the four original paradigms is problematic due to its continuance in debating between subjective and objective viewpoints. This debate perpetuates the tendency of scholars to deliberate about which paradigm is best, based on the perceived value of being subjective or objective, which can divert focus from more pressing research matters. Rather, he recommends that researchers focus on making meaning and connections in their work, and reminds scholars that paradigms are not neatly ordered in separate boxes, but rather can intersect and be borrowed from as appropriate to each situation. Instead, Deetz (1996) proposes using various “discourses” to indicate one’s orientation and approach to research. Such discourses signify a way of articulating an argument (rather than simply naming a group one belongs to and can help to facilitate the connection to other discourses and arguments previously divided into different paradigm camps. Engaging in multiple, intersectional discourses is productive in facilitating collaborative problem-solving (Deetz, 1996). As Deetz (1996) posits, the meanings and implications drawn from research orientations are more important than aligning with one specific orientation; these orientations should be tools used to craft research, and not stringent paradigms. I draw off Deetz’s clarification of both interpretive and critical works. Most notably, he identifies that the “First major goal of interpretive research is the creation of insight” (Deetz, 1982, p. 138). In addition, the goal of criticism is to open up further discourse about a topic or problem (Deetz, 1982). The concepts of insight and opening discourse are in keeping with my research questions for this study; in order to provide

discussion and recommendations for the practices of patient-provider communication, I must first gain insight into current practices. In Deetz's own words, "The task of critical-interpretive research is not only to reveal those blockages and repressions and the forces which sustain them, but also to provide appropriate action to overcome them" (1982, p. 140). With this in mind, I will next elaborate on the type of discourse with which I most align. .

Using a Critical-Interpretive Approach

The discourse I most closely identify with is that of a critical-interpretive approach, which emphasizes reformation. In general, critical researchers view organizations (e.g. healthcare systems) as socially constructed systems that promote domination and can suppress and marginalize individuals (Deetz, 1996). Further, the goal of critical research is to identify and critique ways in which distortions within socially constructed realities can contribute to domination of certain interests, while silencing alternative (i.e. those with less power) social constructions of reality (Deetz, 1996). Scholarship on power structures in organizations intersects between multiple fields: organizational communication, women's studies, and feminist theory.

Women's studies and feminist works are particularly salient to this study. As discussed in Chapter 2, pregnant women have been marginalized in healthcare settings (Barker, 1998; Seigel, 2014). Feminist and women's studies scholarship identifies areas of power struggles in society and organizations, which may be helpful in exploring and addressing marginalization of pregnant women (Jefford & Sundin, 2013; Lazar, 2005; Loftsdóttir, 2011). In addition to highlighting inequities based on gender, critical research by feminist scholars connects well with organizational communication. Feminist scholars have directly contributed to research in organizational communication by shedding light on how privilege and power often mediate

gender relations during interactions (de Lauretis, 1986; Taylor, Flanagan, Cheney, & Seibold, 2001). As was discussed in Chapter 2, feminist contributions to the organizational communication field are important to note. Women experiencing high-risk pregnancy may experience marginalization and the loss of power when interacting with providers. Feminist theory may be of particular value when exploring marginalization and loss of power during patient-provider interactions because it's emphasis on power structures. These topics will be explored as interview data are gathered.

Interpretive research can be particularly effective when combined with a critical perspective (Deetz, 1982; Willis, 2007). The initial goal of critical-interpretive research is to gain insight into and deeper understanding of the ways in which organizations create and enact meaning (Deetz, 1982; Scotland, 2012; Willis, 2007). This insight developed through critical-interpretive research can be used to direct both understanding and action (Deetz, 1982; Willis, 2007). Understanding and action are key elements of this study. I seek first to understand the ways in which patients and providers communicate during high-risk pregnancy in order to develop recommendations for practice. Next, I provide an overview of the terminology used to refer to various types of providers. It is helpful to be familiar with the general titles and classifications of providers, as patients frequently used those terms during their story telling.

Types of High-Risk Pregnancy Providers

During high-risk pregnancy, patients worked with a variety of healthcare providers: some received care from their primary care physician or obstetrician, some from specialists such as perinatologists or fetal-maternal practitioners, and some from multiple providers due to relocation or insurance changes. Table 2, below, provides an overview of the various types of

providers that women encounter during pregnancy. This glossary is helpful to refer to while reading patient stories, as patients often referred to their providers by role.

Table 2. Glossary of healthcare provider descriptions.

| Provider Type | Overview of Provider Services |
|----------------------|--|
| General Practitioner | A medical doctor providing care to patients of all genders and ages; focuses on management of both acute (e.g. upper respiratory infection) and chronic (e.g. diabetes) medical conditions. Some general practitioners may also provide obstetric care throughout pregnancy and delivery. |
| Midwife | Midwives are often referred to as Certified Nurse Midwives (CNM), which helps to separate them from “lay midwives,” or those who practice midwifery based on folk knowledge/without medical training. CNMs are licensed as advanced practice registered nurses, which means they possess either a master’s degree or doctorate of nursing practice. Midwives provide routine gynecologic (e.g. pap smears) and obstetric care (e.g. delivering children), but do not typically provide care during high-risk pregnancy. Midwives will refer patients experiencing high-risk pregnancy to OB-GYNs or other specialists, although they may continue to provide care during high-risk pregnancy if no other practitioners are available in the practice area. |

Table 2. (continued)

| | |
|------------------------------------|--|
| Obstetrician-Gynecologist | Also referred to as an OB-GYN; medical doctor specializing in women's health. OB-GYNs provide care during numerous processes, such as menstruation, fertility, pregnancy, childbirth, and menopause. Care provided by OB-GYNs is focused on the female reproductive system and is not intended to replace the medical supervision of a general practitioner. |
| Perinatologist | Perinatology is a sub-specialty in the obstetrics field, focusing on complicated and high-risk pregnancies. Perinatology is sometimes also referred to as fetal-maternal medicine. Medical doctors in this field have additional training in diagnosing and treating medical complications for both mothers and fetus' during pregnancy, although the emphasis in treatment is on the developing fetus or newborn child. |
| Maternal-Fetal Medicine Specialist | Often referred to as an MFM, a maternal-fetal medicine specialist is a trained OB-GYN providing care for women with medical complications before, during, and after pregnancy. Although MFM is sometimes used interchangeably with perinatologists, the emphasis is on maternal (rather than fetal) care. |

Next, I present the methods being used to understand the communication experiences of patient and providers during high-risk pregnancy.

Methods

In order to answer my research questions, I conducted semi-structured interviews with two different sets of participants. The first set included women who had experienced at least one high-risk pregnancy. The second set of participants included providers who have cared for patients experiencing high-risk pregnancy. Before I expand the explanations of my methods below, I will first identify the terminology to be used in this study.

For the purposes of this project, the term “patient” refers to a woman who has experienced at least one high-risk pregnancy and/or delivery. I will be using “provider” as an identifier for a healthcare professional involved in the care of patients experiencing high-risk pregnancy and/or delivery. These providers may include physicians, nurse practitioners, midwives, and physician assistants. In my research I will be using “high-risk pregnancy” to refer to any pregnancy in which the life and health of the mother and/or baby are threatened. Any factors such as advanced maternal age (over 35), obesity, diabetes, high blood pressure, fetal anomalies, or other chronic health conditions result in a pregnant woman being labeled as “high-risk” (NIH, 2017).

Participant Recruitment

In order to participate in the study, respondents had to meet the following criteria. First, patients needed to have experienced at least one high-risk pregnancy and/or delivery at least six months but not more than ten years prior to the interview. This timeframe for the recency of pregnancy was developed based on research presented by Lundgren, Karlsdottir, and Bondas (2009) who found that participants giving birth fewer than six months prior to the interview are likely to have experiences which are “too fresh” and may cause psychological and emotional stress, and participants may have difficulties recalling interactions with providers for births over

ten years ago. I chose to exclude any participants who were currently pregnant due to the higher potential for psychological and emotional stress as a result of their involvement in the study. The second group of participants, providers, had to have provided care to patients experiencing high-risk pregnancies at least once within the last year. This timeframe also expanded the window for participant in order to help with recruitment.

Patient recruitment. Participants were recruited in a number of ways. Recruitment efforts varied depending on the type of participant. Patients were recruited primarily through convenience sampling. First, the study was announced through CRTNET emails via the National Communication Association. Secondly, advertisements for the study were posted on Facebook. Flyers were posted in the following local organizations:

- Ames Public Library
- Boone Public Library
- Hy-Vee grocery stores in Ames, Ankeny, and Boone
- Fareway grocery stores in Ames, Ankeny, and Boone
- Mid-Iowa Community Action in Ames
- IMPACT Community Action Partnership in Boone

Lastly, patient participants were recruited via snowball sampling. Patients were asked to provide information about the study to others who might be interested in participating. Snowball sampling was utilized due to the difficulty in accessing participants. Snowball sampling has been identified as a particularly effective strategy in identifying hard to reach or hidden populations and can be of particular use in healthcare-related research (Sadler, Lee, Lim, & Fullerton, 2010).

Provider recruitment. Providers were also recruited primarily through convenience sampling and secondarily through snowball sampling, as the provider population proved extremely difficult to access. First, providers were contacted through email and networking via local and regional care facilities. I did not have prior interactions or working relationships with any of the participating providers. Participants were not limited to those working in local area facilities, but recruitment began there due to convenience purposes and networking opportunities. Providers were next asked to provide information about the study to other providers who might be interested. Participant recruitment and interviewing continued until theoretical saturation was reached (Charmaz, 2009; Glaser and Strauss, 1967). In sum a total of 32 patients and 6 providers were interviewed.

Participants

Recruitment efforts yielded a total of 38 participants: 32 patients and 6 providers. All of the patient participants identified as being female. Their ages ranged from 28-45, with a mean age of 35.5 years. Two participants were divorced, 1 participant was legally separated, and 29 participants were married. Participants self-identified their ethnicity as 29 Caucasian Americans, 2 Asian Americans, and 1 African American. Overall the sample was well-educated. 12 participants self-identified as having a PhD, 6 participants as having a master's degree, 11 participants as having a bachelor's degree, 1 with an associate's degree, and 2 with some college. Self-identified employment statuses for participants included (25) working full-time, (3) working part-time, and (4) work in the home/homemaker. Household annual income ranged from (1) \$30,000 to \$50,000, (9) \$51,000 to \$75,000, (11) \$75,000 to \$100,000, (8) \$101,000 to \$150,000, and (3) greater than \$150,000. Patient participants reported a total of 93 pregnancies, with (2) termination/abortions, (31) miscarriages, (3) stillbirths, (25) live births

with complications, and (32) healthy live births. An overview of pregnancy histories for each participant can be found in Appendix C.

Of the provider participants, 5 self-identified as female, and 1 as male. Their ages ranged from 38-75, with a mean age of 43.5. Participants self-identified their ethnicity as 6 Caucasian Americans. Provider participants included 3 physicians and 3 nurse practitioners/certified nurse midwives (these labels are often interchangeable in healthcare). Years of professional practice ranged from 12 to 50, with the mean length of professional practice being 30 years. When asked to provide information about how many children they have, 2 providers reported having one child, and 4 providers reported having two children. No providers or their significant others reported experiencing a high-risk pregnancy. Full details about all study participants can be found in Appendix C.

Data Collection

Interviews were arranged at agreed upon times and locations for each participant due to the potentially confidential and emotional nature of the topic. Interviews were conducted in person, via video chat (Skype, FaceTime, Google Chat), and by phone if face-to-face interviewing was not feasible due to travel time, distance, or technological constraints. Of the 32 patient participants, 12 were conducted face-to-face, 14 were conducted through video chat, and 6 were conducted over the phone. Of the 6 provider interviews, 4 were conducted face-to-face and 2 were conducted over the phone. Despite the potential limitation of conducting interviews at a distance, it was an accommodation necessary to obtain a more diverse sample

All participants were asked to read an informed consent form and then provide verbal consent. Upon obtaining informed verbal consent per Iowa State University's Institutional Review Board guidelines, interviews were audio recorded and later transcribed verbatim.

Interviews were transcribed both by me and by a professional transcription service. Interview length for patient participants ranged from 17.8 minutes to 2.2 hours, with a mean length of 36.4 minutes. Interview length for providers ranged from 18.3 minutes to 23.6 minutes, with a mean length of 20.8 minutes. Interview length was consistent regardless of the medium (face-to-face, phone, video chat) used. Each participant was offered a copy of their transcript for review and respondent validation. Using member checks in this way is a key step to reducing the validity threat of misinterpreting or misunderstanding what participants say (Charmaz & Belgrave, 2012; Maxwell, 2013). Participants were also offered a copy of the final research report and asked if the findings are consistent with their experience. Of the patient participants, 8 out of the 32 participants declined to receive their transcripts and/or the final report. No participants in either group requested changes to their interview transcript. In order to ensure anonymity and confidentiality to the highest degree possible, pseudonyms have been used in transcripts and the final research report. Similarly, the names of healthcare organizations in which participants worked and participated in maternity care were also changed to protect participant identity. Finally, the names of any healthcare staff, spouses, children, or friends were also changed in this report.

In the first stages of data collection for this study, participants were asked to complete a brief demographic survey. Participants were provided with both the informed consent form and the demographic survey and instructed to return the survey either prior to completing the interview. Of the participants, all 6 provider participants returned their demographic survey prior to the interview. Among patient participants, 18 returned their demographic survey prior to the interview, and 14 participants reported not having had enough time to complete the demographic survey before the interview. Of those 14 patient participants, 9 completed the

demographic survey within one week of the interview, and the remaining 5 patient participants completed the demographic survey after a follow-up message from the interviewer. Information gathered from demographic questionnaires was used to provide additional information about the participant groups (such as total numbers of pregnancies, levels of education, years of medical practice, etc.) and illuminate potential patterns in the reported experiences of participants. The demographic questionnaire for patient participants included basic information such as age, ethnicity, household income levels, and number of pregnancies. A complete copy of both the patient and provider demographic questionnaires is included in Appendix A.

In addition to completing the demographic questionnaire, participants were asked to participate in the interview portion of the study. In an effort to stimulate discussion, narrative interviews, or asking questions to assist participants with telling their stories, were used (Hollway & Jefferson, 2013). This narrative interview approach was particularly important for patient participants, as they were encouraged to tell their story of high-risk pregnancy. For example, the first question asked of patient participants was a two-part question; “Can you share with me your story about your high-risk pregnancy? When did you first become aware that you were experiencing a high-risk pregnancy?” Complete interview protocols are included in Appendix B, as well as the demographic surveys, which have been included in Appendix A.

In terms of data collection, I used a semi-structured interview protocol. I was interested in examining the ways in which patients and providers report communicating about high-risk pregnancy according to their perspectives. The use of semi-structured interviews provided an opportunity for participants to share their experiences. Participants were asked open-ended questions to ensure that their responses reflected their experiences as they remembered them. For example, patients were initially asked to share their story of when they first became aware

that they were experiencing a high-risk pregnancy. Providers were initially asked to elaborate on their definition of high-risk pregnancy. Complete interview protocols for both patient and provider participants are included in Appendix B.

Using these protocols, participants were interviewed until theoretical saturation was reached. Saturation is reached when enough information exists to replicate the study, when additional new information has been obtained, and when further coding is not feasible (Fusch & Ness, 2015; Guest, Bunce, & Johnson, 2006; O'Reilly & Parker, 2012; Walker, 2012). In essence, theoretical saturation is the point at which no new information is revealed by participants. As discussed by Fusch and Ness (2015), data saturation in qualitative studies can be particularly challenging since there is no universal study design. However, the overall consensus is that saturation has been reached when researchers would be able to replicate the study, no new data, no new coding, and no new themes exist; these were the criteria by which I determined that theoretical saturation has been reached in this study (Guest, Bunce, and Johnson, 2006; Fusch & Ness, 2015). Overall, 38 interviews (32 patients and 6 providers) were conducted for this study. Interviews ranged in length from 17 minutes to 2.5 hours, with an average length of 35 minutes for patients and 22 minutes for providers. After each interview was completed, audio recordings were transcribed, which resulted in 347 pages of single-spaced text from participants, and 74 pages of single-spaced text from providers.

Methodological Rigor

In addition to building upon grounded theory and incorporating thematic analysis, my approach to methodology is also grounded in Tracy's (2010) eight "big-tent" criteria: worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence. Tracy (2010) posits that these eight criteria are "*universal* hallmarks for

high quality qualitative methods across paradigms” (p. 837). I designed this study to incorporate all eight elements in order to bring forth rigorous, high-quality research in the following ways:

1. *Worthy topic.* First, the proposed study is a worthy topic, as exploring the ways in which patients and providers communicate during high-risk pregnancy may affirm current practices, highlight areas for improving communication within healthcare organizations, and identify areas for further research.
2. *Rich rigor.* Rich rigor indicates the quality of research, and Tracy (2010) explains that “the most important issue to consider is whether the data will provide for and substantiate meaningful and significant claims (p. 841). By ensuring that I followed appropriate research procedures (e.g. IRB approval, informed consent, recruitment efforts, etc.), gathering enough data via theoretical saturation to support claims, and clarifying the goals of the study throughout each chapter of this dissertation, rich rigor is present.
3. *Sincerity.* I enacted Tracy’s third criteria, sincerity, by being transparent about my own biases, goals, and weaknesses during this study, as well as engaging in self-reflexive practices such as journaling throughout the research process. I was transparent with participants, situating myself as both a doctoral student and a currently practicing registered nurse. It is important to note that I have never provided care for, nor worked with participants prior to or after their participation in this study; as such no professional or previous power dynamics will have factored into my interactions with participants. Additionally, I journaled throughout the study and interview processes, focusing on my experiences and feelings upon interacting with participants. Also, I allowed myself to be vulnerable when interacting with

participants; several women shared their stories of infant and pregnancy loss, and we shed tears together. It is important to me to be aware of how my interactions with participants have impacted me intellectually and emotionally, as high-risk pregnancy can be a very emotionally charged topic.

4. *Credibility*. Using member checks and having tacit knowledge of the researched topic are two ways to demonstrate Tracy's fourth criteria of credibility, and both of those elements were incorporated into my research. My tacit knowledge of 10 years spent working in healthcare in general, and working at a large local clinic in particular, contributed to credibility. Additionally, as described previously in this methods section, member checks were conducted with participants to verify the accuracy of their interview transcripts.
5. *Resonance*. The next and fifth criteria is resonance, which refers to the ability to contribute meaning and to impact an audience. Tracy (2010) indicates that resonance can be achieved through personal narrative, storytelling, and embodied engagement (among other techniques), which were all incorporated in this study. Embodied engagement refers to the act of integrating one's entire experience; mind, body, and emotion, to understand an experience (Johnson, 2015). That is to say, when patients were describing their experiences communicating during high-risk pregnancy, they described what was happening in their mind, in their physical body, and in their emotions during communication interactions with providers. Additionally, participants in both groups engaged in storytelling regarding their experiences; patients described their personal stories regarding high-risk pregnancy, and providers shared examples of communication interactions they'd experienced with patients.

6. *Significant contribution.* Significant contribution includes both heuristic and practical significances. The heuristic significance of the study will advise researchers to “further explore, research, or act” upon this research (Tracy, 2010, p. 846). Practical significance centers around determining whether the knowledge generated is useful; this study makes a significant contribution by extending current knowledge of communication in healthcare settings, improving practice based on recommendations driven by the data, and by generating ongoing research in the topic areas of high-risk pregnancy and communication within healthcare organizations.
7. *Ethical.* This study was monitored by the Institutional Review Board (IRB) at Iowa State University. The IRB approval memo for this study can be found in Appendix E. In keeping ethical considerations, participation in the study was voluntary and based on informed verbal consent. Participants were instructed that they could pause or stop the interview at any time, and that they could also revoke consent at any time during their participation. I made efforts to ensure that participants understood the goals of the study were to understand their experiences and communication interactions, and that the results of the study will be used to foster stronger communication. Improving experiences for future high-risk pregnancy patients is in the spirit of ethics as well.
8. *Meaningful coherence.* Finally, I worked to meet Tracy’s final criteria of meaningful coherence (2010). Meaningful coherence of research interconnects “research design, data collection, and analysis with [their] theoretical framework and situational goals” (Tracy, 2010, p. 848). Specifically, I used grounded theory, as theorized by Glazer and Strauss (1967) and further developed by Charmaz (2013), as a practice to reveal

sets of themes in the data, which is recommended by Tracy. Next, I will discuss my use of grounded theory and thematic analysis.

Foundations for Data Analysis

For the analysis portion of this dissertation project, I draw upon grounded theory and thematic analysis (Charmaz, 2006; Glaser & Strauss, 1967). Specifically, I primarily draw upon Charmaz's grounded theory approach, as it emphasizes originality and flexibility in gathering and analyzing qualitative data. Rather than following a prescriptive set of rules, grounded theory provides flexibility and general principles. Following such guidelines leads to the foundation of theory, and then the analysis of the data anchors, or "grounds" the theories within the data themselves (Charmaz, 2006). A specific benefit of adopting Charmaz's perspective on grounded theory is that while most qualitative methods facilitate the ability of researchers to follow-up on items of particular interest, grounded theory is based around guidelines that direct how to proceed during follow-up and further data exploration. Charmaz both builds upon and differentiates herself from Glaser and Strauss' (1967) foundation work on grounded theory.

Glaser and Strauss (1967) were the pioneers of grounded theory, emerging during a time when qualitative research was considered to be unsystematic and weak. Previous researchers had been passing along implicit knowledge, while Glaser and Strauss published work on tangible, explicit guidelines for qualitative researchers (1967). These guidelines specified steps in analyzing qualitative data, which led to the overall strengthening and credibility of qualitative methods.

Grounded theorists begin studying the data early in the research process by qualitative coding, which "distills data, sorts them, and gives us a handle for making comparisons with other segments of data (Charmaz, 2006, p. 3). The strength in this type of coding is that data is

abstracted at various levels, and additional data is sought out, resulting in the grounded theory portion. One important aspect to note here is that with grounded theory, a literature review is conducted after analysis, which helps researchers to maintain an open mind during the data collection and analysis portion of the study (Charmaz, 2006; Glaser & Strauss, 1967).

Use of Thematic Analysis

Thematic analysis is particularly appropriate for research involving health-related topics, as it provides rich and unique insights into perspectives of patients and healthcare providers, as well as indications for improvement (Braun & Clarke, 2014; Chapman, Hadfield, & Chapman, 2015). Thematic analysis is a useful tool in this particular study, as I seek to understand the communication experiences of patients and providers, as well as develop potential recommendations for practice. These purposes and applications are consistent with data analysis guidelines within healthcare research (Chapman, Hadfield, & Chapman, 2015). Further, the flexible approaches to analyzing data afforded by implementing thematic analysis are a strong benefit of the practice; and researchers posit that thematic analysis “should be seen as a foundational method for qualitative analysis” (Braun & Clark, 2006, p. 78). Thematic analysis is a particularly apt choice for this study, as I am exploring an under-researched area, which is consistent with recommendations from Braun and Clark (2006). By using inductive coding in my analysis, I am able to avoid the trap of attempting to fit the data into a preexistent coding theme, thus permitting the data to be coded and analyzed holistically. More specifically, in this study I analyze data at the latent level; that which goes beyond the simple meanings of the words that participants use, but that explores the meanings behind those words. This latent analysis can be particularly useful in identifying and examining the ideologies and conceptualizations at play within healthcare communication (Braun & Clark, 2006). Such latent

thematic analysis is consistent with the constructivist paradigm discussed at the beginning of this chapter, in which I subscribe to the belief that knowledge and reality are socially constructed.

In incorporating thematic analysis in this study, I used an ever-narrowing approach to the data. First, I interrogated the data at a high level by performing a quick reading of interview transcripts and demographic survey data. Next, as seen below in Figures 5 and 6, after a close reading of transcript data I used initial coding to separate into emerging categories for each group of participants.

| Phase 2: Patient group | Generating codes for initial themes |
|-------------------------------|-------------------------------------|
| Stigma | Choice of provider |
| Time factors | Stigma |
| Would have done differently | Nutrition/calories |
| Information seeking | Policy and procedure |
| Advocacy [...] Power | Get what I want |
| Husband | Health/Healthy |
| Withholding information | Anger, resentment |
| Trust | Fetus > Mother |
| Credibility | Judging |
| Good emotion | Embodiment |
| Bad emotion | Fear |
| Villain/poor characterization | Panic |
| Mommy guilt | Mental health |
| Insurance | |

Figure 5. Generating initial codes for data analysis of patient group per Braun and Clarke's (2014) guidelines.

| Phase 2: Provider group | Generating codes for initial themes |
|-------------------------|-------------------------------------|
| Medical illness | No training in communication |
| Face-to-face | Noncompliance |
| Technology | Patient choice |
| MyChart | Obesity |
| Control disease | Diabetes |
| Judgment | Patient perception of risk |
| Don't have time | Relationship |
| Perfect/ideal patient | Outcomes (good/bad) |
| Credibility | Judging |
| Midwife vs. OB | |

Figure 6. Generating initial codes for data analysis of provider group per Braun and Clarke's (2014) guidelines.

With each additional level of analysis, I continued to fracture and interrogate the data, and to refine codes of analysis. As I placed the data into the final categories and sub-categories, I made note of emerging themes and concepts, seen below in Figures 7 and 8.



Figure 7. Reviewing emergent themes for data analysis of patient participants per Braun and Clarke's (2014) guidelines.

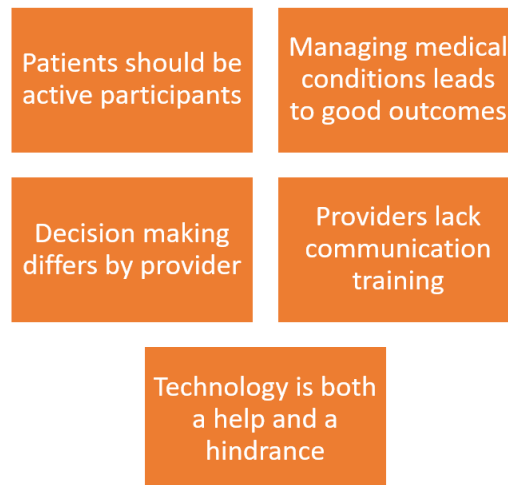


Figure 8. Reviewing emergent themes for data analysis of provider participants per Braun and Clarke's (2014) guidelines.

Summary of Methodology

Data for this study were gathered from two different perspectives, patients and providers, and through two different instruments: interviews and demographic surveys. In order to protect participants' anonymity, I used pseudonyms for both patients and providers. Interviews of both participant groups were conducted concurrently during the data collection phase.

The objective of this research was to explore the ways in which patients and providers communicate with each other during high-risk pregnancy. This study investigated two questions:

RQ1: How do patients communicate with providers about high-risk pregnancies?

RQ2: How do providers communicate about high-risk pregnancy with patients?

In the chapters to follow, I explore themes present in the data and provide potential recommendations for providers as well as patients. In Chapter Four I share the significant findings of my data and provide an analysis of them.

CHAPTER 4. THEMATIC ANALYSIS RESULTS

For this study I was interested in gaining a more complete understanding of the ways in which patients and providers communicate with each other about high-risk pregnancy. Two main research questions guided my investigation of this topic: how do patients communicate with providers about high-risk pregnancies and how do providers communicate about high-risk pregnancy with patients? I conducted a grounded theory-based thematic analysis on transcribed interview data, as discussed in Chapter 3. This chapter highlights the results of my thematic analysis surrounding these questions. I will discuss research findings for each group of participants, beginning with patients.

Patient Perceptions of Provider Communication

In this section I present interview data for the patient group of participants. I interviewed 32 patient participants, asking them about their experiences communicating with providers during high-risk pregnancy. Interviews were audio recorded and later transcribed verbatim by myself and a professional transcription service. Following member checks of the interview transcripts, I conducted a thematic analysis of the data. This thematic analysis was grounded in a critical-interpretive grounded theory approach, as described in Chapter 3. Patient interview data were categorized into three themes during thematic analysis. For patients, themes present in the interview data are:

- Relationships with providers require trust.
- Experiencing stigma and judgment.
- Loss of control.

In this section I will present each theme with the corresponding codes, along with excerpts from patient interviews which exemplify the themes. I begin with a discussion about the desire of patients to establish strong working relationships with providers.

Establishing Strong Relationships with Providers

As they described the ways in which they communicated with providers about high-risk pregnancy, patients discussed the working relationship with their healthcare provider(s). When asked about ways in which patients and providers communicated about high-risk pregnancy, patients discussed the centrality of trust in establishing strong relationships with their providers. Some patients reported strong, trusting relationships with providers and expressed a positive perspective towards communication interaction regarding high-risk pregnancy. Other participants expressed concern and distrust towards their providers and found their communication interactions to be troubling. As seen in Figure 9 below, multiple codes corresponded with the first patient theme.

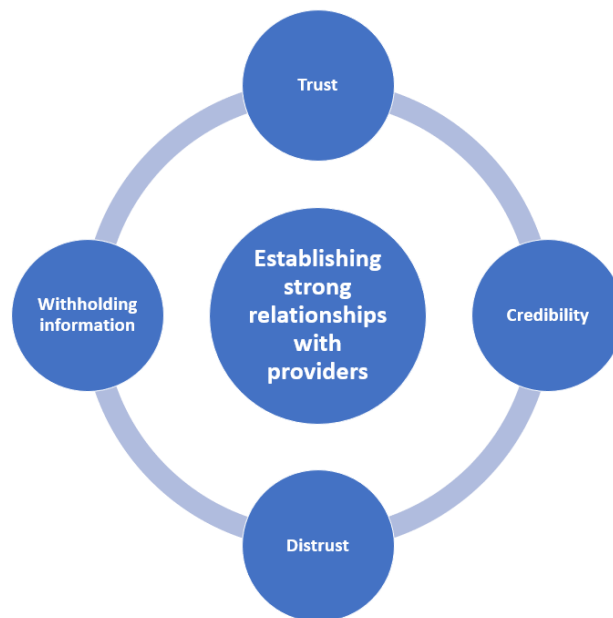


Figure 9. Theme of establishing strong relationships and coding elements for patients.

Elements of this first theme include trust, distrust, credibility, and providers withholding information from patients. I will elaborate on each element as it contributes to the overall theme of establishing trusting relationships with providers. I begin with a discussion of trust-based interactions.

Trust-based interactions with providers. Below are interview data in which patients reported how they came to trust providers during their high-risk pregnancy. The communication actions of these providers demonstrated caring and credibility, and patients shared their positive experiences as they narrated their high-risk pregnancy stories.

Evelyn explained how she sought out a specific obstetrician and established a trusting relationship with him over the course of her three pregnancies, which followed an emergency room visit for a respiratory infection. She was classified in the high-risk category due to her history of two previous miscarriages, allergies, and severe respiratory problems.

And I called every day for two weeks trying to get different medicine for this respiratory infection that I had. And I wasn't getting anywhere. I wasn't getting anywhere. So I called this other doctor, Dr. Selert. And I told them the situation of what happened. He said, "Can you be out here in 15 minutes?" I said, "Yes, I will do whatever". I go out there within 15 minutes. He pulls me into a room. I'm on a nebulizer, taking my first breathing treatment so that this was the first time I was actually feeling like I was breathing in several weeks at this point. But while he had me on the breathing treatment, he brought in the prenatal monitors and everything. Once he got me breathing better, he took me into the ultrasound room. I love my doctor, I have the most amazing doctor and I wish that more people could experience him...

Evelyn felt that Dr. Selert's concern for her well-being and his willingness to listen to her and take action demonstrated his trustworthiness. Even while facing complications during the birth of one of her children, Evelyn was able to maintain trust in her provider.

It was a good thing that I had the epidural because (Baby) had the cord wrapped around his head, like around his face, not around the neck, but because of that they had to basically do a, a type of version [delivery] with the ultrasound to try to work the umbilical cord off his face inside of me. Extremely painful even with the epidural, like I was sore for a long time after that... it was really scary. And painful and you know, you just... you hear about babies dying from the cord being wrapped around their neck and you know, now I'm panicking in the middle of labor that I've made it to 39 weeks and my child is still alive right now and am I going to kill it trying to get it here and you know, and that's, that was a huge deal. But if they couldn't, if that procedure hadn't worked, I was immediately going to go in for a C-section because he's the type of medical provider that does not believe and messing around with stuff. "We don't take chances. That's not what we're here for". This isn't like, you know, it's not a research project and it's not something that, you know, we can't be like, "Oh well we tried," like that's not his, his standpoint about all of this. He is very much like, "We don't take risks. We do the safest thing and sometimes it may not be what you want, but it's going to be". He goes, "I will never tell you to do something that's not in your best interest or the best interest of your child". [I] truly believe that. So by this point in my pregnancy, he had totally won my trust. I was going to do whatever he told me to do and I am lucky and I know I am lucky that I have a doctor that I can trust that much.

Evelyn's trust was founded on her provider being direct in his communication and emphasizing the safety of her and her child. She was willing to follow Dr. Selert's recommendations and was comfortable with the care he provided because she believed he was looking out for her best interests.

Scarlett shared that her attending physician was not selected with a specific purpose, but that together she and the provider established a trusting relationship. This relationship was of great support when Scarlett experienced pregnancy complications.

So I just kind of randomly picked a doctor. Um, and we thought everything was normal. It just so happened that when I was trying to schedule the ultrasound, they had had a cancellation in (larger city). Um, and so we went to the place where the specialists were listed, um, and so that's where we actually had our ultrasounds, so it was all just happenstance but it turned out perfect.

At the establishment of her working relationship with the provider, no specific trust was apparent due to the seeming randomness of selecting the provider. Trust developed as Scarlett's provider was willing to perform extraordinary medical measures during the pregnancy. Scarlett became aware of her pregnancy being considered high-risk when, during a routine ultrasound at her 16-week checkup, it was discovered that she was already dilating and having contractions. In order to prevent labor from progressing, her physician placed her on bed rest, which was successful until seven weeks later. After Scarlett went into labor prematurely, her physician delivered the infant and was willing to perform life-saving measures (such as CPR or placing the infant on a ventilator) if necessary. Scarlett explained that this was against hospital policy, and she felt her provider truly cared for her.

So my water broke, so hospital policy was, it was, it was before 24 weeks, not considered viable. But, um, it was too far along in the delivery process to stop it [labor]. But we were like, right away from 23 weeks. No less than that. We were two days away from 23 weeks and she [the physician] just felt like he was big enough, maybe we need to [try to deliver]. This is close enough to that line in the hospital just said no. And she asked permission if she could continue the case and they gave her permission to do so. There were just a couple of nurses that signed on to do the same thing. So yeah, that was our, that was our thing that had they not thought he would make it. And I understand why, I understand that most babies born at that point in time are devastated and for whatever reason their life is not right. So I understand. But I also think how many other babies could have had that same story.

While she was in labor and waiting for her physician to arrive at the hospital, Scarlett was visited by a perinatologist (a physician specializing in pregnancy complications), and contrasted the interaction with her experiences with her primary provider.

And then the perinatologist came down and said, literally, he walked into a room and he said, “Your baby is not viable. He is not going to survive.” Oh my goodness. I'm like, “Okay, well thank you for that.” So he just pretty much said he's not going to be able to do anything [medical interventions]. He clearly had no facts, like he hadn't looked at the chart to see how big (baby) was. He, none of that, like, he just spoke based off of where we were gestationally. So that, that was part of I think a very hard time. Our regular doctor we'd had then for four months. She was wonderful and took great care [of me]. So I was maybe speaking out of ignorance, but I think there were a couple times where doctors were not dealing with us well. Maybe they just didn't quite know they were

making a harsh judgment in, “We don't do it this way. So I'm done.” It was horrible. Yeah. I think just to know this is a nightmare and stuff has been horribly wrong, and, and my doctor is not in the building and I know that if anything happens and I have to wait for her to get there. So that was really hard. But I also understood sort of the flip side that she was going way above and beyond what anybody else in the hospital is willing to do and that she was breaking rules. And so that was just kind of the... I have to go through this to give my child a chance, and I will do that.

Scarlett shared that she didn't trust the perinatologist and didn't want him to provide any healthcare for her as she waited for her provider to arrive at the hospital. Her infant was delivered and survived, which further reinforced Scarlett's trust in her provider.

Charlotte is an example of a participant who switched providers several times throughout the course of her pregnancy. Due to the discovery of a placental hemorrhage in the early stages of her pregnancy, Charlotte was classified as being high-risk. She initially found a high-risk provider based on her primary physician's recommendation, but then moved on to a provider with whom she had established trust.

I worked with a number of providers, so like I said, my first doctor was family practice, and then I went to her and said, “Who do you recommend and who do you think would be good to work with me?” She recommended a particular doctor, um who ended up not being a great fit, he was just a regular OB, but um, I didn't love him as much and I didn't make appointments with him anymore. I started making appointments with another OB/GYN at the practice, um, and he ended up setting me up with a specialist. So I'm in State, and the Big Clinic is obviously here. And so every week some of these OB specialists would come to the clinic locally and I would see them while they were

there. And interesting enough, my story has a happy ending, as we kept watching what was happening with this hemorrhage, we were seeing that it was stabilizing and that the baby was growing just fine, so there was a point late in the pregnancy where my OB was able to say, “I deem this a normal pregnancy,” um, and I could actually switch over to a midwife. And I felt so very fortunate to be able to do that, and the problem with the pregnancy was not what ended up being a delivery problem. And I also had a screening with the midwives, and they also did not see anything about the pregnancy that was concerning.

Charlotte had originally wanted to work with a midwife, but early complications in her pregnancy required her to see a physician for prenatal care. Her discussion of feeling fortunate about being able to switch back to a midwife is indicative of the type of trust-based working relationship she was hoping for. Charlotte did not actually deliver with the midwife due to having an unexpected birth at home, yet reported that the trusting relationship she’d forged with the midwife was still a support during delivery.

And we were on our way out to the car, and things [labor] started, it didn’t go as anticipated. My doula [labor coach] had the midwife on speaker phone and my baby cried right away, and my midwife was able to hear that on the phone right away and say, “That’s a good cry, sounds like your baby is breathing. So congratulations, now it’s up to you whether you still come into the clinic or our hospital”. And I still wanted to have the midwife to treat the birth as a success and something to be proud of rather than oh, things went wrong because you didn’t get here in time. And we did end up still going to the midwife to get things checked out.

As described in these excerpts, some patients reported the ways in which trust was established between themselves and their providers. Conversely, some patients described a lack of trust and lower quality relationship with their providers based on communication interactions. I will provide data exemplars and an overview of this theme element next.

Distrusting experiences with providers. Some patients reported poor relationships with providers due to distrust established during patient-provider interactions. Patients described the establishment of distrust based on various communication behaviors enacted by providers. Examples of these behaviors included discounting patient preferences and communicating in sterile ways about traumatic pregnancy-related events. The reported distrust in providers was associated with low credibility and patient perceptions of the provider withholding information, which are the remaining elements of this theme. Below are interview excerpts exemplifying the ways in which participants experienced distrust in their providers.

Maria experienced increased pregnancy risk when she lost her mucus plug at 28 weeks of gestation, increasing the likelihood of infection and/or premature labor. She shared that her initial doubts in her provider were well-founded, and that after her pregnancy she considered the provider to have a low level of credibility.

And they told me I needed to be on bed rest [after losing the mucus plug]. Well, my provider told me. And I researched bed rest...I asked my provider about like, “Well what are the benefits of bed rest?” And she's like, she couldn't really tell me. So that was early on. I was starting to kind of doubt some things we were being told, which was frustrating. Well, she gave me the rundown on not eating lunch meat, but I'm a vegetarian and so that doesn't really matter, but also like, “Let your husband clean the cat box,” and I'm like, “No need, ha, to worry about toxoplasmosis or whatever because

they're indoor cats but I, I'll let him clean it.” I mean some of that old wives’ tales that even I know, it was like, kind of made me question her credibility right off the bat. So that set me up to not trust her, although I guess that was well-placed.

After being hospitalized overnight for premature labor, Maria received contradicting information from two different providers, which further diminished trust in her main provider.

I didn't seem to be progressing any further into labor. Again, I didn't feel any contractions, so they sent me home. But [they] also booked me with a perinatologist at a big hospital probably three hours away. So we went. I went to that four days after I had been booked into the hospital. He checked me out. I was two centimeters dilated. But again, he didn't seem really worried about it. He said “You know, you didn't progress before.” What were they aiming for? Thirty-two weeks I think. Thirty-four weeks. He said “You'll be fine”. So [I] went home; I had another appointment booked with my general practitioner two days after meeting with perinatologist and I met with her and she checked me and says “Not dilated at all.” And my husband I looked each other and were like, completely innocently in retrospect. “I'm kind of embarrassed that I didn't know this, but like can it close back up? Because the perinatologist said I was 2 centimeters dilated.” She's like, “Oh really?” She checked me again and she said, “Oh, you're five centimeters” [50% dilated, which is active labor]. So yeah.

Some patient participants reported distrusting providers and poor working relationships due to communication practices. Hazel experienced multiple high-risk pregnancies due to polycystic ovarian syndrome (PCOS), diabetes, and multiple miscarriages. She described how a provider interacted with her upon discovering a miscarriage.

And I remember very vividly actually that the ultrasound tech was chatting and we were talking about it. I was excited, when was my last period, when do you think I was due. My husband was there with me and my daughter was there with me. “Oh congratulations, this is a really wonderful thing.” And then all of a sudden, she stopped talking and she just quit. And like her entire demeanor shifted and she, just, the conversation like literally just stopped and she pulled the little ultrasound wand out and she said “You know, just a minute, I'm going to go see if the doctor is free to talk to you.” And at that point I knew something was wrong. My husband is very optimistic and he is like “Oh no it's fine,” you know. And he was in the room, he was in the room with [me] and he's like, he's like “You know it's fine, not a big deal,” but I'm like, “Now I know something is not right.” And then the doctor came in and he was very brusque, very abrasive almost. And he's like, “Well, in all likelihood you've lost the baby. This is a miscarriage. You know, it doesn't look like your body knows what to do with it. So, you know you have these two options,” and it was just very clean and dry and very sterile. There was no like, “I'm very sorry for your loss.” It was almost like because it was the first trimester like I shouldn't be upset about it, like I shouldn't be attached to it. And he was such a jerk about it. And then I had to go get some, some bloodwork done and I'm bawling, I'm going to cry anyways, and I'm so, I'm so upset. And the only person who was really nice to me was the guy driving [the hospital bed].

Hazel was displeased with the care she received through that physician, and she contrasted the communication surrounding miscarriage between this former and her current provider. Hazel miscarried twins during a subsequent pregnancy, and shared that her new provider communicated in a more caring and trustworthy manner with her.

Dr. Fong said “Ok, there's three different ways that we can that we can treat this” [the miscarriage]. “Your body is not doing what it needs to do; your babies [twins] have been gone for three weeks. That puts you at a really high risk of infection. You can't wait to see if you pass them naturally. We can give you some medication to kind of like help things along. Or we can go in for surgery.” And he's like, “I'm fine with any of those options. I don't want to see you at risk or an infection,” and [he] explained like the pros and cons of each alternative and again I felt very empowered to make that choice. I ultimately chose to have to have the D & C [dilation and curettage, a surgical procedure in which the cervix is dilated and fetal remains are removed from inside the uterus with scraping and suction] for a number of different reasons. But I felt listened to. I felt empowered. I felt like he was helping me make the best of a really crappy situation at that same time.

Hazel trusted her new provider because he took the time to explain what was happening and communicated in a caring manner. This was in direct contrast to Hazel's first provider who appeared to be brusque and uncaring, which resulted in Hazel changing to a new provider. Other patients reported that they did not trust providers after discovering that information had been withheld during their pregnancy.

Morgan's daughter was born and lived for 5 days on life support before she passed away. Morgan and her husband tried to mentally and emotionally prepare themselves as much as possible because they were aware of potential complications. Their first daughter was born with severe birth defects, Morgan had experienced three miscarriages, and they were prepared for their second daughter to be born with potentially life-threatening defects. Following the birth and brief life of her daughter, Morgan shared that she believed the specialist providing care

withheld essential information, which undermined any sort of trust-based working relationship.

I think my biggest complaint is basically, that really is that perinatologist who withheld information from us. I think that's horrible. You need to give the parents the full story. Good and bad. You prepare for the worst but hope for the best and that was my mother-in-law's saying. So you seem to be just, you're thinking the worst is going to be happening. I'm like, I'm preparing for the worst. I have to prepare for the worst. I am hoping and praying for the best. I hope it's not going to be this, but I need to prepare in case it's not because it's so much more difficult. Um, so on day five, we finally got her chromosome results back and it was a full Trisomy 13 or 19. We also found out that not only did she have that, her corpus callosum [a band of nerves joining the two sides of the brain] was missing [and] her two hemispheres were fused together. And that's bad...So, we also found out these are things that the perinatologist, they never told us. She would have seen them in the ultrasound. She would've seen that she had a cleft palate. It was bad, it was a severe, severe one. She would have seen that. She would have seen that the brains were fused together. That's an obvious thing on it, and she would have known also that the brain had stopped developing. It had stopped developing a long time [ago] and not only her, her higher brain, but her lower brain had stopped developing. These are things the perinatologist just never told us.

Morgan reported feeling upset with the provider. She would have been better prepared to cope with her daughter's birth and death if she had known more information about her daughter's health complications. Morgan was not able to trust the perinatologist once she discovered that information had been withheld from her.

While some patients experienced similar incidences of providers withholding information, others shared that they wished providers would not have communicated with them about certain issues or options. Victoria had a difficult time establishing rapport with her provider once he offered an abortion during her first appointment. She had a history of preeclampsia and two previous miscarriages. During preeclampsia, high blood pressure develops approximately midway through the 40-week gestational period. Preeclampsia is concerning because the high blood pressure can lead to eclampsia, which can cause organ damage, bleeding issues, seizures, and death for the mother and/or infant (Mayo Clinic, 2019).

So it was Large Research Clinic, and we said “It’s gotta be something”, and he said, I think that was a perinatologist also, that “Sometimes it’s [miscarriage] just a fluke.” And then he said “You know, you should be able to have a normal pregnancy” And we were very concerned about if we should even try, so we went to talk to the perinatologist. And he said, “If you want to terminate the pregnancy that’s something we can consider.” I basically shut down at that point. Maybe other people would do that, but I wouldn’t. I absolutely wish he would not have said that. I mean, it’s just weird to me that that’s even like an offer. It just seemed really odd, but that was the only thing I wish he would have not said to me. I mean, there was no reason to at that point, there was nothing wrong with either one of us [mother or fetus] and it was just really strange. I mean, we were nervous and emotional just being at that place, but I wanted the baby. We were nervous about the pregnancy, obviously, but I would never, ever do that, so it just seemed very odd that it was something they would offer.

Victoria was so bothered by the provider's offer of an abortion that she felt unable to listen to or trust anything else he said to her. Further, she did not feel comfortable with letting the provider know how much his comments had disturbed her.

Overall, the first theme presented here for patients indicates that positive working relationships with healthcare providers during high-risk pregnancy requires trust. Patient participants able to establish trusting relationships with providers reported satisfaction with their care, while patient participants unable to trust their providers experienced doubts and displeasure with the quality of care provided. Next, I will introduce and provide exemplars for the next theme of experiencing stigma and judgment.

Experiencing stigma and judgment. When explaining the ways in which they communicated with providers during high-risk pregnancy, patients described experiencing stigma and judgment. These feelings were based on interactions with providers and healthcare workers during and after high-risk pregnancy. This theme and the corresponding coding items are visually depicted below in Figure 10.

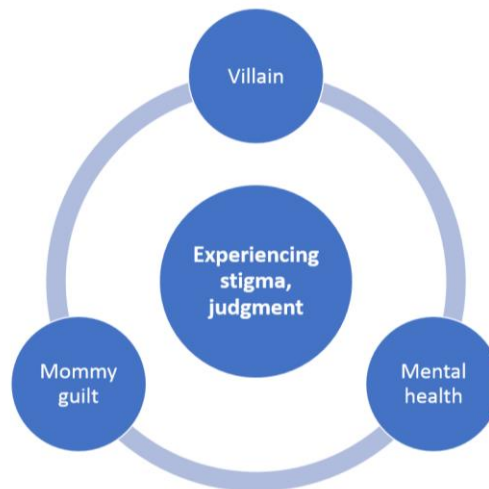


Figure 10. Stigma and judgment theme with coding elements for patient participants.

In relation to this theme, some patients reported feelings of judgment and/or guilt following interactions with providers, while others felt the disapproval of providers even more directly through comments made during those interactions. Patient perceptions of judgment were at times related to factors inherent in their high-risk pregnancy, and at other times patients perceived being judged negatively because of a characteristic (e.g. obesity) they possessed. Three interrelated coding elements for this theme are being villainized, mental health, and mommy guilt. Below are data exemplars for each coding element corresponding with the theme of experiencing stigma and judgment. I will begin with the element of villainization.

Considered a villain. Some patients described feeling like a villain following encounters with providers during high-risk pregnancy. For these patients, their experiences being judged by providers resulted in feelings of being a bad person/bad mother for getting pregnant. Lily felt villainized by the care providers she encountered and reports that it still greatly impacts her to this day. She was classified as having a high-risk pregnancy due to her weight. As a result of her experiences, she and her husband decided not to have any further children.

So at my next appointment when I went in, well I asked to be seen when I called; I asked to see the midwife again. And they said “well, she’s not taking people on,” and I said that’s ok, I just want to see her again. And at my second appointment, she seemed surprised to see me, and I said, what do I have to do to become a patient, because I heard you took on another patient after you saw me. And her face kind of went ashen, and she was like, “well, actually I can’t be your care provider because of your weight”. And I said ok, [and] then kind of started to get emotional. And I really wanted to have a midwife because I have anxiety and I don’t like doctors and [midwives are] the closest I could get to a natural birthing experience. And it was like, “I’m really sorry but I’m not

allowed to take care of you because of your weight, and you're going to have to have this doctor." And so I was devastated. And so at the appointment where I found I was lied to and couldn't have a midwife because of my weight, I got a doctor who came in and she was my doctor for the rest of the pregnancy. And right away the first thing she said was "You can't gain any weight, you can gain about 10 pounds, we're going to go ahead and check for the fetal heartbeat," and I laid down. And she started like squishing my stomach around, and I heard her say "Well it's going to be really hard to find the heartbeat because of your size." And then when she couldn't find the heartbeat I started to get... [tearful] because I thought maybe we lost the baby. And she kept just going on and on about how it was just because I'm fat. And I just remember laying there crying, and once we heard the heartbeat I started bawling, because I was so relieved that the heartbeat was found because I felt like this monster that was irresponsible and shouldn't have gotten pregnant, and I just kept thinking about the things she said like, "Well you really should have lost weight before this, but here we are, so"...don't eat this, don't eat that, and exercising and everything. It was, "Ideally you would have gotten smaller before you got pregnant, and so we'll have to work with you on certain things; not eating fast food and taking good care of your health." It was definitely implied that I did a very bad thing by getting pregnant at the weight that I was. It was chastising, and to this day it affected me so much that we haven't had other kids and [Baby] is our only child. It has stuck with me. And I don't know if it's sharing too much, but after [Baby] was born I developed agoraphobia, and now I have a panic disorder and now I've been

in therapy, and that was a huge part of motherhood, starting off immediately feeling like you were less than, and irresponsible, and incapable of making good decisions, so how can you be a good mom if you can't take care of yourself?

Lily was not the only patient who reported feeling like a villain due to her weight. Lydia was classified as being in the high-risk pregnancy category due to her obesity, Type 2 diabetes, and high blood pressure. She felt judged as a "shitty mom" even before giving birth.

I mean, I know I'm overweight and have health issues, but does that mean I shouldn't have kids? At my first, um, at my first appointment, which was at like 12 weeks, it was like she [the provider] was condemning me, judging me for even being pregnant. It was like, she was reviewing my conditions and quizzing me about them and even raising her eyebrows at me, which to me felt really judge-y. She was like, "And you have diabetes, right? Are you taking your meds? Are you checking your blood sugars? Are you eating junk food?" I mean, I am not binging on McDonald's every day. I am a responsible person. And it's not like this [conception] was an accident. My husband and I wanted to start a family together. It just seemed like she was, like, totally disapproving of me. And there's enough crap out there about being a good mom and it's so ridiculous anymore. I don't need you putting all this pressure on me before the baby's even born. So yeah, here I am at my 12-week appointment and I already feel like a shitty mom.

Lydia's experience with judgment continued while in the hospital for the delivery of her daughter. She reported that comments made about her medical condition and care requirements furthered her stresses about being perceived as a bad mother.

So like, let's say the nurses are changing shifts, right? They do this thing called bedside report where they both come into your room and go over stuff so the new nurse knows

what's going on. So there I am, I'm just in labor and chilling cause I have my epidural, and these nurses are in there. And most of it was fine, but then they were talking about "She's a diabetic, so she needs [blood sugar] checks every hour" and stuff like that, and the nurse coming on was kind of like, "Ugh." Excuse me?! I thought that was rude. And then when she [baby] was born, they made a big deal about how she would probably have problems with her [blood] sugars because I guess when babies are still in utero their body doesn't have to worry about that stuff. But um, when they're born then it can be a rough adjustment. But like, she was fine. I just fed her and she was just fine. So don't make me worry if it's not needed, I'm already feeling overwhelmed just being a new mom. And yeah, I think that really made for a rough pregnancy and transition [to motherhood]. Like the whole time I'm wondering "Am I a bad mom? Have I screwed my kid over? What if there's some problem that we can't handle?" And that's a bunch of shit to deal with.

Similar to feeling like a villain as a result of healthcare encounters, another component of the stigma and judgment theme was that of mommy guilt. I will provide examples of this next.

Experiencing mommy guilt. The concept of "mommy guilt" emerged in the 1980s and 90s as more women left traditional home-based roles of motherhood and joined the workforce (Bort, Pflock, & Renner, 2005; Zimmerman, Aberle, Krafchick, & Harvey, 2008). Mothers experience judgment as they interact in various facets of society, constantly being critiqued and categorized on a scale of good to bad mom. While mommy guilt is not exclusive to high-risk pregnancy, some patients discussed experiencing guilt as they interacted with providers during high-risk pregnancy. Below are examples of interview data exemplifying this component of the stigma and judgment theme.

Mia birthed healthy twins following a high-risk pregnancy, which included factors such as a family history of Down's syndrome and obesity. During her pregnancy, she also felt judged by her provider about being an overweight mom, but her experience with judgment occurred during follow-up visit that still bothers her to this day. Struggling to breastfeed twins, Mia and her husband had decided to start supplementing her breast milk with formula. When her provider heard about this at an appointment, she informed Mia that her infants would be 50% more likely to die from SIDS because of bottle feeding (research on this is controversial and contradictory). Mia explained that she felt so judged by her care provider that she had to hide that she was feeding her infants with prepared formula at a future visit.

Um, yeah, I wish that, I mean, obviously the risk for SIDS is real. And obviously um, yeah, there are precautions that you can take to ensure that they are, whatever the phrase is, as much as we can possibly do, um, but there were a few times where more nonchalantly, like throwing out statistics like "Babies fed by bottles are 50% more likely to have SIDS," and if that's potentially the case, then at that given time it was not a constructive comment to make, and it becomes this construct of talking about I'm having a hard time nursing, and I feel like I have to supplement, and I think that's fine, but it completely changed my outlook like, so um, I really wish there had been a courtesy in how that was delivered. Yeah. Absolutely [I was shamed]. Because I remember taking the girls back. We had been discharged from the hospital and I remember taking them back and then to the clinic one final time. And I didn't bring any formula with me, and it was taking longer than I anticipated and the girls needed to eat. And I hid from her [the midwife] that the nurse, actually one of the nurses, had brought in some infant formula in the OB office. In the room, they hid bottles of formula from

the midwife. Um, and so I could feed the girls, which was good, but we had to hurry and do it before the midwife came in so she wouldn't know we fed them formula. And since I had to feed both the girls, this nurse helped me so it would go faster. So there was definitely some shame, and obviously I'm not the only one who felt this way, if one of the OB nurses was um, helping me to sneak and hide this from the midwife.

Mia discussed hiding information from her provider because she didn't want to feel judged for her choices. Similarly, Lydia expressed feelings of guilt related to her mothering.

Well, you know, there's just so much pressure to be a good mom already, and I feel like with this pregnancy I blew it. Um, like after being high-risk that means I probably shouldn't have gotten pregnant and so I'm already starting off in the hole.

Lydia was concerned that her parenting skills were viewed as being deficient due to her high-risk classification. Other patients reported similar experiences and did not feel able to openly discuss concerns with their providers. I will discuss this component of the stigma and judgment theme next.

Mental health and stigma. Sophie experienced a high-risk pregnancy complicated by gestational diabetes, and shared that she didn't get the treatment she needed for post-partum depression due to the stigma of mental illness and her provider's reluctance to engage in discussing the topic with her. Sophie believed that her post-partum depression was linked with/caused by her trauma and stress during her high-risk pregnancies and deliveries.

With the first time I didn't know what it [post-partum depression] was until it was done. Like, 6 months after his birth at one of the checkups I kind of mentioned, I think this is what's going on, and he was like "Yeah, probably so." And then with the second [baby], whew, with the second, I was writing my dissertation, analyzing data, all of that, and I

was teaching, and I went in, and I said, like, “I think this is what’s going on,” and he said “Well you know, like, let’s, you’re coming back in 2 weeks or something like that, let’s talk, see how you feel and let’s talk then.” Um, which was not the best advice. It was not good advice at all. Um, yeah, I mean, I got no help. Yeah, yeah. They never asked, like it was like, “How are you feeling?” Like it was never, you know, “Are you thinking about hurting yourself, are you thinking about hurting your baby?” I don’t really know. I do know that I was thinking about hurting my baby. And I would have told them that. So when I did ask for help, telling me to wait 2 weeks and see if you feel better was probably the worst thing he could say to me. I think he probably did ask a few questions like that [safety check], but I, I didn’t, I think I got scared and I started covering it up and saying, “Oh but you know, I’m teaching full-time and I’m working on a dissertation and it’s probably just exhaustion from that.” And I think he might have kept asking questions but he was uncomfortable and I think he was happy to agree that it could have been those other things.

Jasmine had a traumatic birth experience following her high-risk pregnancy. She reported wanting to discuss her experience when interacting with her provider and being unable to do so due to the provider’s reluctance to engage with her.

I feel like it’s, like, you’re not allowed to talk about this stuff. Because it’s scary or something. Yeah, it’s so freaking important...and like people don’t want you to talk about it. They want you to move on. And I’m just like, yeah, they’re uncomfortable with you being upset because you didn’t get to see your daughter be born, you didn’t get to see her for 3 days, you’re just like mourning the loss of the end of your pregnancy, and

the birth that you thought you might have... so all of that, and yeah everyone just kind of wants you to move on. And that's how I felt with my doctor. I felt that he just like... I don't know, I've never felt more abandoned in my life.

Jasmine further discussed feeling judged by her provider and other healthcare staff; she believed they thought poorly of her because she kept wanting to discuss her birth experience. Jasmine felt that her provider brushed off her concerns, and that this contributed to her mental health difficulties following her pregnancy.

Overall, patient participants perceived being judged by healthcare providers. In some instances the judgment was related to an aspect or assumed aspect of the mother's character (e.g. feeling villainized for being overweight while pregnant), choices that mothers made (such as feeding infants formula rather than breastfeeding), or stigma associated with mental health concerns. In addition to experiences of stigma and judgment, many patients discussed losses of control in relation to their high-risk pregnancy. I will present and discuss those next.

Loss of control. One of the most salient themes that emerged for patient participants involved the loss of control, either during high-risk pregnancy, delivery, or post-pregnancy. For some participants the loss of control involved decisions which were out of their hands. Other participants reported specific events, such as medical complications, which interfered with their autonomy as a patient. Some patients advocated for themselves, some had partners advocating for them, and some reported how they would advocate for themselves if the situation were to be repeated. Figure 11, seen below, depicts the connection between coding elements and loss of control theme for patients.



Figure 11. Loss of control theme and coding elements for patient participants.

In this section I will describe each aspect of the theme and provide exemplars to demonstrate how each component contributes to loss of control for participants. I will begin with information about how loss of control and the choice of providers are interconnected.

Choice of provider. Some patients reported being able to choose providers to work with during high-risk pregnancy, while other patients discussed not having control over which high-risk pregnancy providers they worked with. Some patients also changed their provider due to due to either experienced or anticipated losses of control. Paisley shared how her initial experiences with a healthcare provider prompted her to change healthcare providers. She shared how she worked with a new provider to regain control and ownership of her pregnancy experience.

Well I, um I underwent IVF. So it's not always the high-risk, but at my 10-week ultrasound they found that I was pregnant with twins. And so that automatically boosted their interest in my pregnancy and when I went to my normal OB for my, what is the normal one [appointment], 12 weeks? That they actually found that I was pregnant with

triplets. I was officially considered high-risk. That particular OB I stopped going to after that appointment because she literally told me that there weren't tests and processes designed for three babies and that I should "Put it in God's hands."...And I thought no, that was not what I wanted to hear from my doctor.

As a result of this encounter Paisley switched providers. Although she did go into premature labor and experienced the loss of her triplets; she shares that even during this difficult time her chosen provider facilitated feelings of being in control of her pregnancy decisions.

I feel like when I was with my initial OB I didn't have any control. She was basically saying, "No one has any control". Um, you know, "Let's just see what happens". When I moved to my current OB, he really was great about giving me information and talking to me about the pros and the cons and letting me make a decision. So I, I felt very empowered, I felt like I had a lot of agency in that relationship. And even when I was in labor...they gave me the option of whether or not I wanted to sew up the [amniotic] sac because it was the sac that had ruptured because I delivered one of the identicals first. I wanted to wait, I wanted them to just induce and continue so I could birth all of them at once. That was an important moment, and I was able to make the decision that, um, to wait and see what happens.

Similar to Paisley, Maria was displeased with her provider during high-risk pregnancy.

However, she did not feel that she had control over who her provider was at the time.

It's a rural area. There's not a lot of choices and weirdly it's hard to find and even get associated now with a general practitioner. I'm now with a PA [physician assistant] I really like and is probably going to be the best care I've gotten in many years.

Hazel also was constrained in her choice of provider. Information about her poor working

relationship with a provider during several high-risk pregnancies was presented earlier in this chapter. Hazel was not able to choose which provider she wanted to see at the time due to her insurance. She discussed some of the challenges of her lack of choice.

You know...really the guy at any point seemed to be kind of more of an old-school type of doctor, like, "I'm the authority figure and I know everything and you know nothing and so shut up and do what I say now."

Some patients reported being able to choose their provider, and others discussed the lack of choice in providers. People who were able to exercise choice in provider selection reported feeling more in control and being more satisfied with their care. Closely linked with the element of choice (or lack thereof) was that of advocacy. Advocacy during high-risk pregnancy often spawned from a loss of control, which included lack of choices. I will present data for this component next.

Partner and self-advocacy. Throughout the interviews patients discussed advocacy as a strategy for coping with/preventing loss of control during high-risk pregnancy. Some patients were able to advocate for themselves. This advocacy sometimes occurred during losses of control, and sometimes afterwards as a response to the loss of control. In addition to self-advocacy, patients discussed instances of others advocating on their behalf. Advocates were typically spouses, family members, and friends. Provided below are data excerpts demonstrating the presence of advocacy in relation to loss of control during high-risk pregnancy.

Camila discussed how her experiences with preeclampsia during her first pregnancy impacted what she would do for any future pregnancies. She wanted to direct her healthcare during future pregnancies by initiating conversations with providers about managing her condition.

So this was our first child, so it made me think about if we have a second child, would I just go ahead and say, ok, does my high-risk status last time automatically consider me as high-risk [this time]? Because if so, let's have that conversation today so we can manage the actual risk around high-risk so I can help manage to bring my blood pressure down.

One of the factors spurring Camila to be more assertive in communicating with future healthcare providers was the excellent care she received during labor and delivery.

I feel very lucky in that the delivery nurses... all three of them [delivery nurses]...all really, like, listened to what I was concerned about. And so I felt the nurses were my biggest advocates, and the biggest people who were like, actually willing to help me understand why we were using another medication or something like that. And so um, you know, I do feel like in labor and delivery I probably had the best communication out of the whole process. And it kind of made me mad that we spent almost 10 months to get to this point where, like, thank God that was the best part of the communication, but all the communication that happened that night and morning would have, you know, been way better six months ago. We have not been at that point of doing an induction if, I feel, we may have avoided the like, problems I had if I just had a better understanding 6 months prior.

While aware that she received quality healthcare during her labor and delivery, Camila identified the need to not only advocate for herself in the future, but also identified with and desired to advocate for other women.

I could probably rant about proactive communication because I feel like that can solve a lot of problems...And I just imagine that if it's that way for me, how much worse for

people who aren't in as good of a position. Like I have a degree, I know the language, and I even know how to interpret the data a little bit because I touch on it in my day-to-day work. And so, um, there's a lot of women who aren't even in the same position as I am, and that just made me so angry... it's such bullshit that other women don't even get the opportunities to ask questions like I did with this, and it can really negatively impact things then, because they don't even know about it.

Grace experienced a high-risk pregnancy due to preeclampsia and being pregnant with twins. She advocated against a physician's recommendations during an episode of pre-term labor with her twin girls.

When I got admitted at 23 weeks it was a Friday and a doctor from Other City was on call at the hospital. At the high-risk pregnancy center or whatever at Hospital. And they put the monitor on and monitored for 8 hours a day, and so they were looking at contractions and so basically I was dehydrated. And he was like, he put oxygen on me and "We are going to surgery," and I was like, "No we need to wait and see if my contractions slow down before we just jump in." Because I knew that at 23 weeks at least one of them wouldn't make it. And so I was like, please wait and see, I know there are medications we can take. Let's rehydrate and try other things before you take me to surgery. And they kept pushing and pushing and I'm like, "No I'm done, I'm not doing anything until I get at least two liters [of IV fluids] in." I pushed them back. If they're [the twins] not going to make it inside my body, they're not going to make it outside my body. I was like "Let's just wait," so that was the only time I really pushed.

Grace's intuition was correct; her twins were born at a later date and both survived. She told the story about how a previous delivery experience influenced her to advocate for her daughters.

I wish I would have said “Can I go home and lay on the couch and see if I feel better?” But they were like, “We need to break your water and get the labor started,” because they were just afraid that I was going to have a seizure. But I should have just asked because my husband’s sister is a nurse, I’m a nurse, and his mom’s a nurse. I feel like I would have been fine in their hands and had good care. That’s the one thing I wish I would have said, let’s see if the contractions would wait. Just be monitored in the ER for a while to see if that would get better. So I think I learned from that just to ask and say can we just wait a little bit with the twins, because I knew there was no way they would make it at 23 weeks. So fortunately they made it to 26 [weeks], and they both survived.

While some patients like Camila and Grace were able to advocate for themselves during high-risk pregnancy, others were not. Some participants shared that others stepped in to advocate for them during a loss of control, either due to being ignored by a provider or an emergent situation. Esmerelda explained that her refusal of an epidural during delivery was so ignored that her husband stepped in to advocate for her requests. After he spoke with the physician, Esmerelda’s wishes were followed.

Um, so during delivery it wasn't my specific doctor, but somebody else in the practice, um, that I had met once and she, uh, kept pushing the epidural and was pestering and wouldn't let up the fact that I didn't want it, and I'm to the point that my husband had to jump in and intervene and say, “Look, stop it. She said she doesn't want it, she doesn't want it.” And then she [the physician] kept saying like, “Oh, I just want to make sure that you understand these are your options and you really consider it.” Yes. This is not my first delivery. Right. So I could see in other situations if I was a first-time mom and I've been asked by the doctor, who is the specialist, multiple times, I probably would

start second guessing myself and my decision. Yes. Again, because it was not my first rodeo, right. But that, that kind of, um, in a situation it could easily have played out differently and somebody could feel pressured to make a different choice because maybe the doctor knows something that I don't and I think they're the expert, I should follow what I'm told.

Camila discussed that she and her husband had agreed on an action plan prior to delivery, and that she counted on him to stick with it. Together they were proactive in discussing how he might advocate for her during her delivery.

I will say that I kind of already had to give the ultimatum to my husband that like, at some point I am probably going to be cuckoo crazy and like with some certain things, but we've already agreed to a plan and I need you to hold me to a plan because you know, uh, we want everybody to live. Yes, we know that C-sections are not optimal, but we want everyone to be alive and that's the most optimal situation. You know, that's kind of what I already had built in, my husband and I, we are the accountability system for each other so, um, I don't know that everyone has that same support in their partner, but I feel like that also helped me because he'd, he already knew what I wanted so when we were listening to the doctor giving feedback he would say, "Hey, remember this is what you wanted so it sounds like this decision kind of makes sense for you." Then we would talk it out if we needed to.

Maria explained that her husband stepped in to advocate for her preferences while they were preparing to be transferred between hospitals in an ambulance. Her attempts to advocate for herself were ignored until her husband spoke up.

They booked me into the hospital first in the town where I live. And it was scary. I wasn't really worried about it until then because we were all these nurses that didn't know what to do. They wanted to hook me up to an IV but they couldn't find a vein. And then they want me to take off my clothes prior to getting into the ambulance. Right. And I'm like, "No, I don't want to take off my clothes." Like if things start going, then they will happen. They were insisting and insisting, and they wouldn't listen to me. And then my husband said, "She's not taking off her clothes." And then they left me alone and then they wanted to pray over me. This was not, this was not a religious city hospital. We are not really religious or anything, and at that point I started to get really freaked out. I'm like, "Oh god if there's prayers happening it's gonna go badly," and then off we went in the ambulance. It strikes me too, that one time I did push back to not take off my clothes. And it took my husband, and he's fairly intimidating when he wants to be, and he was like, "She's just not doing it." And then there was no question. But you know, they're sticking you, like giving your IVs and everything. Well I'm going to be walking outside and I don't want to be wearing a hospital gown want to be walking outside the hospital with strange men in a truck. Like I'm not, I'm not going to do that.

Kim's husband advocated for both her and their child during a chaotic delivery by staying with the infant after birth. Kim felt this was particularly helpful to her due to a chaotic childbirth experience.

And there were so many specialists and people popping in and out of the hospital room that I didn't really know what was happening. And they took him [infant] away right away and I didn't even see him and I told my husband, "Follow that baby," and I don't even remember actually seeing him [infant]. I just felt like I was in this room and

everybody was watching and hadn't said anything. And I get it now, years later, but at the moment I was thinking ok, what's really going on here? And I had no idea, absolutely no idea. It was absolutely frightening. And then I couldn't hold the baby or anything. I don't think I've ever been more nervous about possibly getting pregnant again. And they didn't say anything to me. Not one word. I was not engaged with it at all. There were no conversations about what was happening, ok again, why are all these people in here? What's happening? And then immediately after the delivery they took him and I had no idea why. So that's why I told my husband "Follow that baby." And he did; he took off down the hallway after them. And I said, "Is something wrong?" And she [physician] said "Oh no, they're just taking care of everything." It was a horrifying, exciting time. And it was hard because I couldn't really take pictures and I couldn't hold him.

Addison's husband kept track of questions and concerns to discuss with providers at each appointment they attended. The umbilical cord had a malformation, which resulted in increased monitoring by providers throughout the pregnancy.

It [communication] was ok, but there were a couple times when it was confusing...So I would try to think of questions before we went in, and then Husband had this notebook that he would write questions down and then ask them in appointments. Otherwise I felt like they just wanted to get you in, weigh you, take a listen to the baby's heartbeat and then get rid of you.

Thus far we have seen that patients reported advocacy as a response to loss of control during high-risk pregnancy. This advocacy was enacted by both patients and their partners.

Additionally, some patients reported that advocacy during their high-risk pregnancy came from other sources such as family, friends, and even providers. I will present these examples next.

Support systems and advocacy. Some participants were supported during their losses of control by larger social systems and networks of people. These people were able and willing to step in to assist with and advocate for patients during difficult times in their high-risk pregnancy experience. Morgan's daughter was born with severe complications and passed away several days later. Morgan shared how her support system was present throughout that process and how she was able to maintain a sense of control over the situation even during that difficult time.

And her brain had stopped developing. I mean, she had no lower brain function either. And these are things, like I said, the perinatologist never told us. And I would have prepared for this a different way [if] I would have known it was coming. I would have discussed it with my husband, um, you know, a simple thing is I would have arranged to have somebody come and take pictures, so I would have had at least a few pictures of her before she passed. So when we finally found out that she had the full Trisomy, we decided to take her off life support. Um, my mom, his mom were both there. They [nursing staff] brought my daughter in; they bathed her. I had a friend who brought baby clothes, doll clothes for us and we put her in the doll clothes and we had just, um, they just had the pump system to give her oxygen when we all said our goodbyes, we were like, okay. And we took her off life support completely and we were allowed to be alone, just my husband and me in the room and we let her die on her own.

Even during this difficult time, Morgan's support system, including her husband, provided her with strength and hope.

One of the things that we said, I know that there are moments that you look back, it was a terrible, terrible. I would not wish it on my worst enemy...but there were moments of the most profound beauty and love in it and I will tear up every time I think about it because it was just such an amazing moment to see who somebody truly is. Watching my husband hold her in his arms and rocking her back and forth like this tiny thing just in two hands and say, "How do you fit a lifetime of I love you's into a few moments?" And I truly don't think I've ever loved him more than that moment because it showed in your most profound moment of grief, what do you focus on as well? And just every time I think of it, it just, it warms my entire body for him to say, "I can't let her go," and me having to say "We have to, we have another child in another room who we have to be able to be with." That night, Baby definitely slept with us and we were very lucky to have another child that we could shower our love upon...I think I lucked out to have a great husband. I had some really good friends who were able to support me through this.

Hazel described how her physician provided support to both Hazel and her husband during a time when they were unsure and experiencing the loss of multiple pregnancies due to unknown causes.

Having had that support and having had that kind of like...not from not only our immediate caregiver but his whole staff of people was amazing. I felt like the doctor seemed like, constantly going to bat for us. And it wasn't just me as his patient. It was him caring for my husband. You know from one father to another. And you know I remember him talking with my husband early on like, "You know, I remember how excited I was when I was trying to become a dad for the first time." And he told my husband he's like, "But you know what," he's like, "You're already a dad" [to his

stepdaughter]. He's like, "You have this this wonderful little girl, and I don't know you very well, but she is obviously crazy about you," because she was sitting there holding his hand through the ultrasound you know. And for him to just notice those little things and kind of offer both those kinds of support meant a lot to me.

Throughout the interviews, patients described ways in which they, their significant others, and their extended support systems engaged in advocacy related to high-risk pregnancy. This advocacy was in response to losses of control at various points during pregnancy. Some patients experienced loss of control due to medical events during their high-risk pregnancy. I will share this information next.

Medical complications. Some patients explained how medical complications contributed to a loss of control during their high-risk pregnancies. These complications were unexpected and at times emergent, which left patients feeling out of control of their bodies and pregnancies. For example, Jasmine was diagnosed with placenta previa early in her pregnancy. This condition is considered high-risk in pregnancy, as a portion of the placenta covers the opening of the cervix; this can possible lead to hemorrhage and injury and/or death of mother and infant. Because of her risk factors, Jasmine knew she would be required to have a C-section. She shared that even with her limited options, she still had opportunities to plan for what she desired during delivery.

What I did feel like I had a choice with was the environment of that C-section. It was really important to me, and then of course none of this actually happened, that it was really important to me to have a peaceful birth as much as possible, and to help her, the baby, feel connected to me... And they were really great about that. The doctors had already assured me that both of those were no problem at all.

Even with her birth plan in place, Jasmine's delivery didn't quite turn out as expected. She shares how her initial plans for birth changed when she unexpectedly went into labor.

I went to my parent's house, which was a two-and-a-half-hour drive. This is something that I wish they would have talked to me about, that like, they told me that I shouldn't be flying in the third trimester or anything, but nobody talked to me about, even being out of town...And then like Christmas morning I wake up. I'm getting ready to go to church with my parents and I go to the bathroom and like nothing, everything's fine. I stand up to flush the toilet, and the toilet is full of blood. Like, bright red blood. And I was just like, holy shit, like oh my word. My parents are super conservative and I was just like, FUCK, FUCK, [yelling] I have to go to the hospital, fuck! And I was just like, oh my gosh, because there was just no pain at all, and like I felt nothing, ever, and it was just, I was bleeding. And so anyways, my husband like, so it was pretty dramatic, so it was Christmas morning, right? So, it was like 10 am so my mom is driving me and my husband is like carrying me to the car and I'm just like hemorrhaging all over the place, trying to like, prop my legs up in the back, trying to stop the bleeding, trying to keep it [the blood] in my body so that my daughter doesn't come out or something, didn't know what was happening.

Jasmine's daughter was delivered and flown to the nearest NICU, where she received excellent care and is healthy today. Jasmine explained that she is unsure whether or not she and her husband will have more children due to the difficult experiences during high-risk pregnancy. Kim also experienced an emergency delivery. She shared her feelings of confusion and of being out of control during her experience. She had made a birth plan with her preferences for delivery but was not able to enact her preferences due to the emergent nature of her delivery.

I didn't have any choices...all of a sudden people were running everywhere and putting me into a wheelchair. Like they literally leapt into action. And then they just told me I was having the baby.

As described above, some patients experienced losses of control related to medical complications. Participants reported that during those times they experienced a lack of communication and/or a lack of information regarding what was happening with their high-risk pregnancy. A related element in the loss of control theme is that of information seeking behavior. Some patients discussed working to find additional information about their high-risk pregnancy. The types of information sought were typically not provided during healthcare interactions, and patients sought out additional information in response to their sense of loss of control. Examples of this are presented next.

Information seeking behaviors. Many patient participants discussed seeking information in order to understand factors surrounding their high-risk pregnancy experience; information seeking took place for some during their pregnancy, and for others after their pregnancy experience was completed. Charlotte shared how she actively sought out information regarding potential complications with her child's development, and that by doing so she was able to feel more in-charge of decision making and outcomes.

I am the kind of person that I like to have as much information as possible. So I'm already reading online everything I can find that relates to my situation, um, because it seems like he [primary OB] didn't want to share a lot of information with me.

Grace's high-risk factors included her being considered a geriatric pregnancy (over the age of

35) and being pregnant with twins. She shared that she experienced confusion during her pregnancy, and that she took specific measures to find information to help her feel that she was in control of her decisions.

Like I'm a health person [a registered nurse], and I still didn't know what some of the stuff they were talking about was. Most of the information I got from the Twin to Twin Foundation. The clinic told me some stuff, but I needed more information. I think maybe some people don't think about as much stuff, but I was like, I wanted to get every detail that I can. To know what I can do, what could happen so that I can prepare myself. And so I asked my doctor if I could have a consult with Dr. Lee. And then they called him while I was at that appointment and they talked to Dr. Lee on the phone. There weren't any brochures or packets [about her condition].

As described above, some patients reported seeking additional information in response to their loss of control experiences. Other patients described how they had concerns during their high-risk pregnancy and those concerns were ignored by others. This last component of the loss of control theme is presented next.

Intuition and ignored concerns. Within the loss of control theme, some participants reported multiple instances of intuition into what they were experiencing during high-risk pregnancy. In some cases patient concerns were taken seriously, and in others they felt ignored. For example, Madison felt “off” during her second pregnancy, and shared how both her husband and her doctor diminished her experiences.

I would just have to sit at the top of the stairs and just be like okay, you know, and I kept telling my husband “I feel so much different than the first pregnancy.” First pregnancy I was, I felt pretty good, and now I feel like something's off. He was like “Oh, you don't

know how bad it was when you were pregnant the first one.” I brought it up to my doctor, telling them. [And they said] “Oh, you're probably just gonna have a hard pregnancy and this is just normal pregnancy symptoms.” It just continued to get worse. I would mention it every time, like I still don't feel right. Then my husband was gone at the time when things got worse. I started actually going into labor early, I believe I was like 30 weeks and so I had to go ... I went to the hospital then. I was ... They gave me a shot of some sort to stop the contractions from progressing. Once that happened I think the doctors were taking it a little more seriously. I went back to the doctor; they didn't let me go home in case it happened again, start going to go in to labor again so I went back to the hospital... At this time I felt really awful; just distraught and crying, like “I know something is not right”. So I guess she performed all these tests for preeclampsia. She was like, “You're showing all of the signs of preeclampsia. You have protein in the urine.” Everything was checked off basically. I just always kinda felt like nobody was listening to me. I felt like okay, I know something is not right. I don't know what it is but, I just kinda felt like, I don't know I was just not taken that seriously. When the doctor was like, “We're gonna have to probably deliver the baby—you could die or the baby could die,” then I knew it was a big deal then when they really took the steps to find out what it was. I just wish that the issue was taken seriously.

Kim also felt that something was wrong with her pregnancy and was likewise ignored. She visited her provider and expressed concerns that something was amiss during her high-risk pregnancy.

But my mommy gut was telling me something's not ok. But my thinking wasn't validated. And so I went into labor and he was born prematurely. Luckily everything

worked out, but he was a whopping 4 pounds. And he was so tiny and little you could hold him in one hand. And he was just very small. Nothing was developed and they thought he was 32 weeks, but I wonder if they miscalculated. And, of course, my water broke and I told my husband, “You need to drive me to the hospital”. And I thought, “Oh this is really going to be bad.” And that just pissed me off.

Similarly, Esmerelda shared that her intuition about what was happening in her body was ignored. During a routine visit, the provider over-intervened due to her high-risk status as a geriatric mother and didn't respect her motherly intuition that all was well with her baby.

Um, well this was later on and maybe it's an over-intervention; was a point that I didn't care for. So I can't remember. I think this was either early or trimester or late second trimester. I'm at a checkup. Um, I can't recall, but it was a long wait and then he [baby] was moving a lot, I could feel it. Um, but then during the scan itself, um, they thought the baby wasn't moving and so they would poke and prod and, and like, um, still didn't see any kind of movement and then they insisted I go to the hospital for some kind of monitoring. I was telling them that I was fine and baby was fine, but they wouldn't listen to me. And then from there on, um, even though after a while I had everything checked out, he was fine. It was suddenly everyone was on high alert and then from there on I had to go in for a scan every week, every other week just to be safe. Even though the checks at the time you visit, there was nothing wrong.

Many patients reported experiencing losses of control surrounding the time period of their high-risk pregnancy and delivery. Some patients were able to regain a sense of control

through self or partner advocacy, and some patients with the support of their providers.

Additionally, some patients shared strategies for information seeking about their pregnancies.

Next, I will review the themes present in the patient data.

Three themes were present in the patient interview data. First, patients desired to establish trusting relationships with providers. During their healthcare encounters patients observed both trust-establishing (such as demonstrated caring) and trust-diminishing (such as withholding information) communication behaviors by providers. Second, patients experienced stigma and judgment at various times during their high-risk pregnancy journeys. These experiences involved comments from healthcare providers which seemed to convey disapproval based on the patients' perceived character. Lastly, many patients reported experiencing losses of control. Losses of control during high-risk pregnancy were typically associated with a lack of communication from providers. An example of this might be when a patient mentions a concern during an office visit and their concern is disregarded by the provider. All three of these themes were prevalent throughout the transcribed interview data for patient participants. Next, I present themes present in the interview data for provider participants.

Provider Perceptions of Communication with Patients

In this section I present thematic analysis results for provider participants. I interviewed 6 providers, asking them about their experiences communicating with patients during high-risk pregnancy. Interviews were audio recorded and later transcribed verbatim by myself and a professional transcription service. Following member checks of the interview transcripts, I conducted a thematic analysis of the data. This thematic analysis was grounded in a critical-

interpretive grounded theory approach, as described in Chapter 3. Provider interview data were categorized into five themes during thematic analysis. For providers, themes present in the interview data include:

- Patients should be active participants in their care.
- Managing medical conditions leads to good outcomes.
- Decision-making differs by provider.
- Providers lack communication training.
- Technology is both a help and a hindrance.

I begin with an overview of the theme that patients should be active participants in their care.

Patients should be active participants in their care. The first provider theme I will discuss centers around patients taking (or conversely, not) an active role in the care they received during high-risk pregnancy. Some providers shared concerns about patients not being compliant with doctor's orders. Figure 12, below, displays this theme with corresponding coding elements for provider participants.

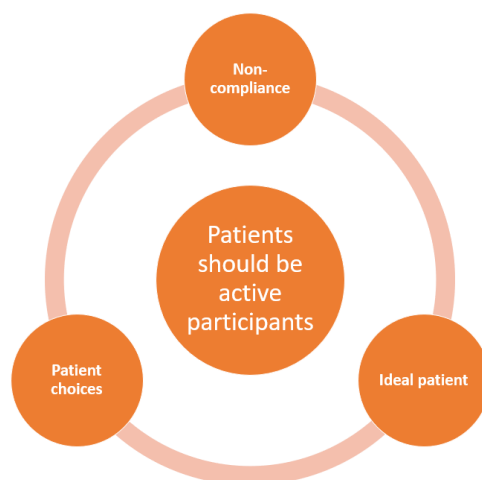


Figure 12. Active participants theme and coding elements for provider participants.

Categorization of the belief that high-risk pregnancy patients should be active participants in their care was based on interview data coded in three common areas: noncompliance, the notion of the “ideal patient”, and patient choices. I will address each of these categories contributing to the overall theme below. First I will present data for noncompliance.

Noncompliance in patients. Providers expressed being concerned about high-risk pregnancy patients who were not compliant with recommendations from the provider. These recommendations were typically related to items such as medications, lifestyle choices (e.g. diet and weight gain), and future pregnancies. For example, Dr. Fern discussed patients who were not in compliance with her recommendations. She also discussed some ways in which she has attempted to help patients to problem-solve potential barriers which might contribute to noncompliance.

Patients are just not compliant. They don't take their medicine, they don't stay on their diet and they come in with either blood sugars that are really high on their records...Sometimes they make them [blood sugar records] up because they haven't checked them, and that kind of communication makes it really difficult to take care of the patient. Yeah. I try to see if there's obstacles. For example, if they're working a night shift or their job interferes with their ability to check their blood sugars, to write a letter saying she needs to have 10 minutes three times a day to do that, you know, to the employer and then try whatever the obstacle is to hurt being able to do it. Right. Try to overcome.

Mary, a midwife, shared her concern that some patients don't take an active role in their care, and that it can negatively impact their care and outcomes. She believed that noncompliance was related to a lack of caring about the pregnancy on the patient's part.

Well, I think sometimes they just don't care. Maybe they didn't want the pregnancy. I don't know, but they're there.

Mary believed that if patients cared about their pregnancy, they would follow her instructions closely. When asked how she could tell that patients just don't care, Mary wasn't quite sure how she came to her conclusion.

Well, I mean, I don't like actually ask her if she cares. It just seems obvious. It's like, they aren't asking questions or following along, it's just like "Uh-huh," to what I say. And I feel like if they want to keep the pregnancy and have the best outcomes possible they would want to be involved. And then if I tell you do something and the next time I see you, you haven't done it, well then I'm going to think you just don't care about your baby. Like do you even want to be pregnant?

Patient noncompliance was reported as a concern by several high-risk pregnancy providers. In contrast, providers discussed positive aspects of patient involvement. I will next present data related to the notion of an idealized patient.

The ideal patient. When discussing their experiences interacting with high-risk pregnancy patients, providers often described desired characteristic of patients. These characteristics seemed to be components of an idealized patient persona. Dr. Smith, the only male provider participant, described his view of how high-risk pregnancy patients should actively participate in their care.

Well first of all, if they are being good patients, they will actually come to appointments. If they don't show up, then I can't really do anything for them. So, um, coming here is the first step. And then I want to know, like, what they understand about what's going on. Does she know her diagnosis? And is she on board with what we are doing? The

ones [patients] I've seen do really well are the ones who come in a lot and they ask questions and actually do what you tell them [to]. Yeah, and I think education is part of it too. Like, if you don't have a basic understanding of biology then it makes my job a lot harder because I don't even know where you are coming from.

The midwife Mary had expressed some skepticism about high-risk patients who were not compliant with her instructions. However, she did acknowledge that many patients do get involved with their care and are proactive during pregnancy.

Most people try very hard to get it right and do very well.

The ideal patient for providers seemed to be one who was educated, regularly attended appointments, tried to understand the medical information presented, and who complied with provider recommendations. Patient choices are a closely linked concept to the ideal patient, as providers indicated that patient choices contributed to their perception of whether or not a patient is an active participant in care. I will discuss patient choices next.

Patient choices. Some providers discussed how choices made by high-risk pregnancy patients impacted both medical care and birth outcomes. Isabella, one of the midwife participants, discussed how her practice declined to provide care for a patient due to her choices regarding future pregnancies, and that the patient was instructed to seek obstetric care elsewhere.

We had a patient who had really bad diathesis [vertical separation of abdominal muscles], and I had her in labor, and she could not push the baby out because she had such ... I mean, she had no abdominal tone, so the baby ... When she would push, the baby would come out [of] the abdomen... so I ended up getting a physician involved. I assisted them. We got the baby out, and that obstetrician said, "Under no circumstances

should you ever carry another pregnancy." I told her, I said, "If you get pregnant again, you won't be a part of the midwife practice." She had how many babies? Like maybe four or five babies, and so we said if she got pregnant again, we said we wouldn't take care of her. We sent her to the perinatologist. They said there was no reason she couldn't be seen, but we as a practice said we wouldn't see her. She was seen by some of the other doctors. She kept having babies after that, even though she had this complication, and when we won't [provide care at clinic], they [specialists in larger city] cared for her. It didn't turn out very ... I mean, she never had a bad outcome, but she could've had a bad outcome.

Logan, a midwife, shared her perspective on patient choices and how they impact whether or not high-risk pregnancy patients are actively participating in perinatal care.

Well, I think they are just going to choose what they want to do. I mean, if they want to know what's going on and ask questions and follow the plan, that's great. But I can't force them to do it; they have to want to. Most patients are motivated and good about that, but some just really don't seem to care. It, um, it can sometimes stress me out because then I worry about their baby and if they will have problems because of their mom's choices.

Overall, providers discussed the ways in which patients may or may not be actively involved in their care. Providers considered active participation in care to be occurring when patients followed orders and were compliant with recommendations from the providers. Conversely, patients not following recommendations were considered to be noncompliant. A juxtaposition emerging from the interview data will be discussed thoroughly in Chapter 5: patients expressed interest in having more control over their care, while providers desire to have patients follow

their instructions. This potentially competing desires may have some far-reaching implications for patient-provider interactions during high-risk pregnancy. Next, I will present data for the next provider theme of managing medical conditions.

Managing medical conditions leads to good outcomes

Providers discussed their medical management of high-risk pregnancy, and from this data a theme emerged in which providers perceived that managing medical conditions led to good pregnancy outcomes. Some examples of good pregnancy outcomes for high-risk patients might be things such as minimal weight gain, stable blood sugars, preventing additional medical interventions (such as C-sections), and the absence or minimization of any developmental defects in the fetus. Figure 13 below displays the central element and corresponding codes for this theme.

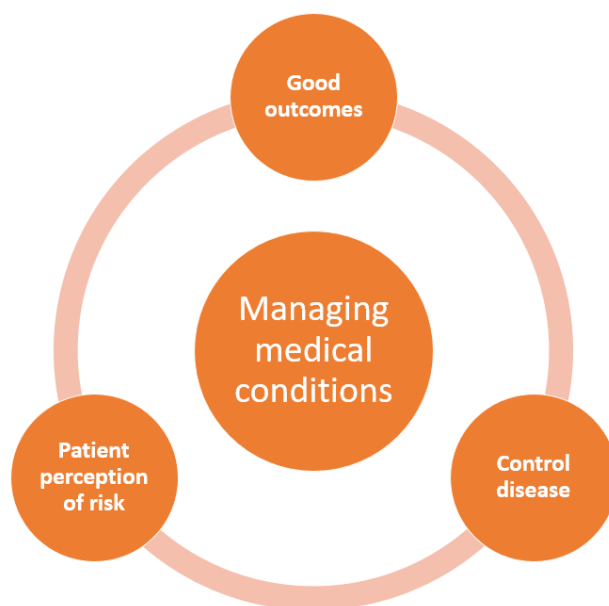


Figure 13. Managing medical conditions theme and coding elements for providers.

In general, three distinct elements of interview data comprised the theme of managing medical conditions: good birth outcomes, controlling the disease process, and the patient's perception of risk during their pregnancy. Included below are exemplars for each component of this theme. I will begin with a discussion of good birth outcomes.

Good outcomes. Providers referred to good outcomes as being a primary goal during high-risk pregnancy. Managing medical conditions (such as high blood pressure, diabetes, etc.) was viewed as the strategy to achieving good birth outcomes. Logan described her approach to discussing outcomes during her midwifery practice.

I think, um, really the goal for me to is keep the pregnancy going as long as possible.

And like, ideally we can get a baby out of it if possible. I know that seems obvious and it's a lot more complicated than that, but, uh, that's the gist. So I tell her...I tell her that if we want good outcomes, we need to try hard. And keep a close watch on her pregnancy and her symptoms.

Mary described her perspective on how medical care during high-risk pregnancy can help to produce good outcomes.

I mean really, at the end of the day don't we all want the same thing? If she didn't want the pregnancy then she could have terminated. So generally we are all working together to try to save mom and baby as much as possible. And what I see as a good result [of the pregnancy] might be different than what another provider thinks. If we can get mom and baby through the pregnancy and keep them alive, I consider that to be a success. And, um, we have to control what's happening on a medical basis so that we can have that success...I have to give you [the patient] like, actual medical care. Not just send good vibes.

Providers viewed good outcomes as something to be achieved through the medical management of high-risk pregnancy. These outcomes were considered to be tangible things such as live birth with minimal complications. While some providers discussed the managing medical conditions in order to achieve generalized good outcomes, others talked about ways in which they attempt to control diseases present during pregnancy. I will discuss these next.

Controlling the disease process. The term “disease process” is a general one used to refer to the progression of any type of medical condition. For example, a patient with preeclampsia would experience the disease process through elevated blood pressure, headaches, fatigue, and potentially seizures and even death (Leeman, Dresang, & Fonatine, 2016). Providers described their attempts to control or slow the progression of disease during high-risk pregnancy.

Dr. Fern discussed some of the specific challenges facing patients with diabetes during their pregnancy.

Well, the main thing is to explain to the patient that if we can keep her disease, whatever that might be, in good control because that will result in the best pregnancy. Um, [the] best example is diabetes. It [disease management] can get their blood sugars really close to normal range. They'll have an outcome almost as good as if they didn't have diabetes. Whereas if the blood sugars are high, they're gonna run into all the complications including miscarriage, stillbirth, and things like that. So, keeping the disease under control, for example, of people with ulcerative colitis would come to me. I remember one patient I saw as a pre-pregnancy consult and she's been told by her family doctor in a small town that she shouldn't take steroids or prednisone while she was pregnant and

in fact just the opposite, that she should take the medicine to control were altered and that will result in a better pregnancy outcome then if she has layers of rare disease from going off her medicine.

Logan explained that she visits with high-risk pregnancy patients more frequently than patients with lower risks. She viewed frequent visits as a way to manage disease throughout pregnancy.

I just...I just really check in with those patients to make sure things aren't getting worse. Like at least once a week [appointment frequency]. And I'm not a neonatal specialist; I mostly focus on mom and what's happening in her body. You know, like, how's the blood pressure doing and how much weight gain has there been. What are the lab results? I feel, uh, like I feel with those things I can keep a close eye on what's happening and hopefully prevent things from getting worse...and sometimes I tell her [patient] why we have to do all this. It's important that she knows.

These examples illustrate the ways in which providers attempted to control various disease processes throughout high-risk pregnancy. Additionally, some providers discussed that the perception of risk on the part of the patient was integral to managing medical conditions. I will present these data exemplars next.

Patient perception of risk. In addition to managing medical conditions through their own actions, providers shared that the patient's perception of risk during pregnancy was an integral part of providing and receiving perinatal care. For example, Dr. Mayn discussed risk factors and disease management during high-risk pregnancy as she emphasized some concerns when working with overweight and/or obese patients.

Probably, the other risk factor that just continues to go up and up in terms of contributing to high risk pregnancy, is obesity in the maternal population. Many of those

people don't plan for pre-pregnancy, so they get pregnant and we have to deal with the complications that come with it. Not many people perceive that [obesity during pregnancy] as a risk. And it's a really difficult situation for the provider because you want to educate them in healthy behaviors, and talk about what is expected, weight gain, and to come back for repeated visits when they are exceeding that recommendation. I have patients who, you know, are [exceeding weight gain recommendations]. The communication breaks down and they choose to go sometimes into someone else who doesn't care about what they're thinking, which is really difficult because that communication is to let you know I care about you and your health and your baby, and you are influencing those risks by being overweight. And, it's, just because weight is such a touchy subject as well; that has been a frustration.

Similarly, Dr. Smith shared some challenges that he and his patients faced when dealing with diabetes and obesity during pregnancy.

Hey, it's not about the weight, it's about what your risks are. And that is absolutely, you know, you may be at high risk for having diabetes in pregnancy, but we will test early and we'll be vigilant to watch for that. But I'd still recommend that you gain less than 10 pounds during the rest of your pregnancy. You know, I try to give little specifics, not just, "I'd like to see you gain less weight". Tell me if there are behaviors you feel you can change. Are there some things you can see? What happened this month that contributed to or like, "I took a trip to Chicago and I ate my mom's homemade food". Okay, so we know that behavior isn't healthy. So, it's more, talking about the behaviors, not about alternate weight gain.

During encounters with patients, these providers emphasized that the patients needed to understand aspects of their pregnancy which contributed to greater risk. This was emphasized in order to assist with managing medical conditions during high-risk pregnancy.

Each provider in this study emphasized the need to tightly control disease and risk factors, such as diabetes, obesity, and high blood pressure, during pregnancy. In doing so, they believed that disease management would lead to healthier pregnancy and birth outcomes for both the mother and infant. While in some ways this theme may seem to be self-explanatory, it becomes more complex when considered alongside the cohort of themes for providers. The previous theme presented strong data to support patients taking on active roles in their care/following doctor's orders. The current theme builds upon that, with providers wanting patients to take responsibility for managing their risks and medical conditions (part of being an active participant in care) yet there is a gap when these themes are considered with the next theme presented. The gap in practice is that providers lack communication training. Much emphasis has been placed on managing medical conditions which requires collaboration and communication between providers and patients yet providers reported no training in communication. This theme is presented below.

Providers lack communication training. While each provider reported that they communicated regularly with high-risk patients, none of them possessed any specific training in communicating during pregnancy, whether during medical school or during their professional practice. Figure 14 below provides an overview of this theme and its associated coding elements.



Figure 14. Coding elements associated with a lack of communication training for provider participants.

Altogether, the interrelated concepts resulted in the theme that providers lack communication training. There were three specific elements of this theme present in the interview data: providers not remembering any communication training, learning communication skills through medical practice, and participating in training only in connection with delivering bad news to patients. I will present examples of the theme component below.

I don't remember. Providers did not recall receiving specific communication training for patients. It is important to note that this refers to all types of communication with all types of patients. Providers also reported no training regarding communicating with high-risk pregnancy patients. For example, upon reflection Dr. Smith was unable to recall any communication training either during school or continuing education.

Um...no, I really don't think we had anything for communication. You know, it's, uh, it's so hard to cram everything you need into med school, so I think they [educators]

probably overlooked that. I mean, we certainly didn't have anything about risk. Yeah, risk in the sense that uh, you know, relates to a medical condition, but not really in talking about it.

Similarly, Dr. Fern reported that her training has emphasized the medical management of patients rather than communication aspects.

I don't think I ever received any specific trainings for that [kind of] communication.

We've got a lot of trainings in the diseases and managing them, but I do not specifically know how to communicate that.

Giving bad news. Logan shared that her midwifery practice did participate in a training seminar with the rest of their multi-clinic system, but that its focus was on how to talk with patients and families when things go wrong during medical care. Logan believed that the impetus behind the seminar was to reduce lawsuits, as the majority of medical malpractice suits are the result of poor communication between providers and patients (Huntington & Kuhn, 2003).

Well, not exactly risk. We've had ... at Our Clinic, we had one about ... talking about bad outcomes.

Mary also referred to intentional discussions at work about delivering bad news to patients, but it was not specifically geared towards high-risk pregnancy patients.

I mean yeah, obviously if you work in healthcare you have to communicate with people.

And, uh, sometimes things go wrong. Or like, they don't even go wrong, it's just that bad shit happens...you know, medically. So you have to figure out how you are going to

talk to people when that happens. And, you know, you have to like, be careful about what you say. So I think we have talked about that at meetings, but it's not like anyone actually came in or anything and like, taught us what to do.

Providers reported participating in workplace meetings during which communicating about bad news with patients was alluded. However, they did not recall actual training regarding communication. Some providers did discuss ways in which they developed their communication skills, which I will present below. The development of professional communication skills was not specifically related to training.

Skills developed during practice. Providers discussed the ways in which they developed some communication skills over their years of practice. For example, Isabella didn't recall receiving any communication training, but reported that she developed listening and communication skills during her years of practice. Much of this was learned through communicating with patients about difficult topics, and Isabella used a method of trial and error during her interactions with patients.

If you're telling someone, "We think that the baby's got a cardiac defect," or, "We think that your baby is going to have Down's," I can only imagine then. I mean, I'm pretty sure you're not listening at all after that either. I think it's probably important that you [the provider] are repeating yourself, and that type of thing, and maybe even having people come back and talk about it at a different time or have them come back with their spouse or significant other. That type of thing because I think they probably, if it's something major, that they aren't going to get it the first round.

Similarly, Dr. Smith reported intuitively adapting his communication skills with high-risk pregnancy patients during his years of practice.

Well, I mean, you absolutely have to communicate with patients. There's just no way around it. Now, do I know officially what to do? No, but I've pretty much figured it out over the years. You know, be sensitive, make sure you use like common words for things. I don't know, I guess it works cause my [patient satisfaction] scores are ok.

In summary, none of the provider participants recalled specific communication training during school or their professional practice. Potential implications and recommendations regarding this issue will be discussed in further detail in Chapter Five. Next, I discuss the theme of decision-making for provider participants.

Decision-making differs by provider. Providers reported different approaches to decision-making during high-risk pregnancy, as visualized in Figure 15 below.

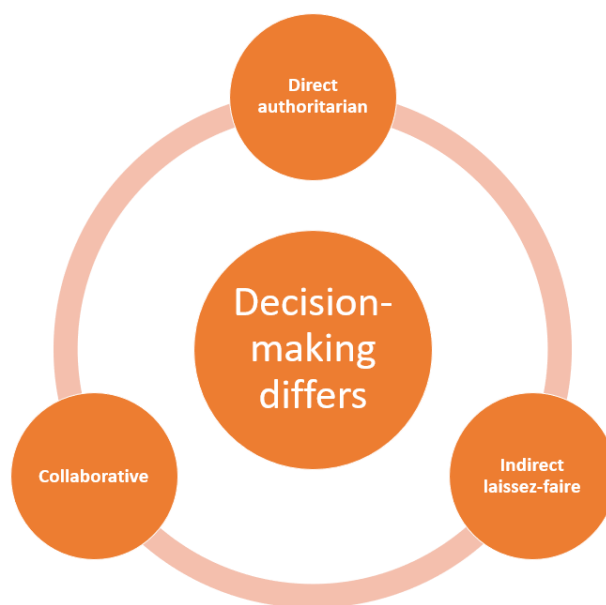


Figure 15. Decision-making theme and coding elements for provider participants.

Midwife participants viewed decision-making as a collaborative process between themselves and the patient, while obstetricians engaged in more directive decision-making efforts. Decision making during high-risk pregnancy typically involves choices to manage risks to the mother and fetus; for example, this might be decisions on whether or not to participate in genetic testing, in-utero procedures (e.g. amniocentesis), abortion or termination of pregnancy, medication changes, and other medical or lifestyle interventions. Patients at higher risk during pregnancy are monitored more closely than patients with routine pregnancies; many high-risk patients visit a provider weekly or even daily. As discussed in the presentation of patient data earlier in this chapter, making decisions occurs before, during, and after pregnancy. Decisions made during patient-provider interactions directly impact patients and infants, as well as the organization in which the encounters are taking place. Therefore, the data gathered from providers related to their decision-making style is a vital link in the healthcare process. Three distinct decision-making styles contributed to the theme of differing decision-making: direct authoritarian, indirect laissez-faire, and collaborative decision-making. I'll tell her, midwife versus OB/GYN decisions, and choices. I will begin by presenting data for the direct authoritarian style.

Direct authoritarian style. Some providers engaged in a direct authoritarian style of decision-making. These providers reported making a decision regarding the care of a high-risk pregnancy patient, and then informing the patient about the decision. For example, Dr. Fern was very direct about the decision-making process and her interactions with patients. She reported being straightforward and telling patients what action they needed to take.

The patient will ask, which of these options do you recommend? I'll tell her. There is one that I recommend.

Similarly, Dr. Smith reported that he has told high-risk pregnancy patients what to do in regards to their medical care.

Oh yeah, I'll tell her [the patient]. You know, some things don't really matter too much and then I'll see what the patient wants, but yeah, if it's an important decision I will tell her what we are going to do... You had a C-section? No VBACS [vaginal birth after cesarean section] here! Nope. You test positive for group B strep? You're getting antibiotics!

As indicated above, physicians reported being more directive in their communication regarding decisions during high-risk pregnancy. In contrast, the midwife participants engaged in a more reflective approach to making decisions for high-risk patients. Their responses are presented below.

Indirect laissez-faire. Midwife participants reported engaging in discussion and indirect laissez-faire decision making with high-risk pregnancy patients. This approach was in contrast with physicians who were more directive in their communication about decisions. During the enactment of indirect laissez-faire styles, midwives reported a more “hands off” approach to care decisions. For example, Isabella shared that her approach to decision making is mediated by her practice as a midwife, rather than an obstetrician.

Most people ask you, "What would you do?" I just had that yesterday. I try not to answer that one. I said, "We're ..." especially as a midwife practice, I say, "We're here to tell you what your options are, explain all of those to you, and help you make the decision, but that's the reason you're coming to a midwife is that we aren't making the decisions for

you." For some people, that isn't what they want to hear, and we fix it by just sending them to the obstetrician, and they will make the decision for them if that's what they want. As midwives, we don't make the decisions.

Similarly, Logan discusses her approach to collaborative decision making with patients.

I mean, if there's a specific medical concern then I would, uh, recommend some course of action. But I don't tell patients what they need to decide. Like, um, for example genetic testing. I'll offer it, but if you don't want it then I'm not going to force the issue. Most of the time it's just them [patients] asking me questions about what their options are, and I, um, I try to work with them so they can decide what's best.

The final aspect of the decision-making theme was related to discussing choices and working with patients to reach a decision. I will present this information next.

Collaborative decision-making. An additional provider strategy not previously mentioned was that of communicating with patients about the choices present during their high-risk pregnancy. Of the provider participants, Dr. Mayn took a more middle-of-the-road approach to patient and decisions. In this collaborative style of decision-making, Dr. Mayn worked with patients to advise them of their options and to support their choices. She reported providing information to patients, while also understanding that each patient's needs and preferences differ.

Well it really depends on the patient. Some patients are super engaged and want to do the best thing for their pregnancy and for their spouse. And there are others who aren't right for this service. So, for example, I have a patient that is 41, who is pregnant with her 5th or 6th child and we had a discussion about the fact that at age 41 the gestational age of 39 weeks for her is almost equivalent in risk of stillbirth to someone who's 25 but

was in 41 weeks and what that might mean for her care. And she felt very strongly about me presenting that information, and she said, "I really don't want to do any intervention," so as long as I can say "Here's the risk, here's the likelihood," it's your choice, and that is my goal. To provide the information to make the best choice for them. So what do I focus on, I guess that was your original question, right? I focus on giving the patient the information that they need to either take better care of themselves or if it's a decision point that they can make the decision that's best for them. And if they are working with risks, we talk about each option within that decision.

Overall, each provider had varying approaches to decision making for high-risk patients. Again, this is a linchpin in the process of communicating with patients during high-risk pregnancy. The nuances and implications of this theme will be discussed thoroughly in Chapter 5. Next, I will address the final theme for providers.

Technology is both a help and a hindrance. During their interviews, providers discussed the ways in which changing technology has impacted their practice and communication with patients. For provider participants, both affordances and constraints were present in using technology within their healthcare organizations. Below, Figure 16 identifies the center and coding elements for the technology-related theme.

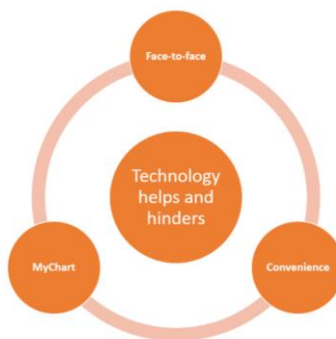


Figure 16. Technology theme and coding elements for provider participants.

Convenience. When asked about the ways in which they communicated with high-risk pregnancy patients, some providers referred to the convenience of electronic medical records. For example, Dr. Fern appreciated the ease with which changes to medications and other medical management aspects (such as at-home blood pressure checks) could be incorporated without the patient having to physically be at the clinic.

We recently had just worked the high-risk clinic and they have a new technology where they could send in their sugars electronically and the nurse sends it to me and I make an adjustment in their medication. [It's] very good.

Mary also discussed the ways in which electronic medical records have made communication easier for patients and providers.

One of the things that's really helped has been the electronic aspect of our communication here. Um, it took us a while to get things set up and like, for all the kinks to get worked out, but it's pretty nice. Patients can just send in a question or ask for a med refill. And they, they have access to their information, like lab results and stuff. So they don't have to keep calling and coming back for the same information...it really saves a lot of time.

Some of the providers discussed the convenience factor of electronic communication with patients. They believed the convenience helped with work efficiency and also appreciated that patients had increased access to their own medical records. However, some providers felt that electronic charts were a potential barrier to delivering care, and instead preferred to communicate with patients face-to face. This information is presented below.

Face-to-face. Although providers acknowledged the convenience of electronic communication with patients, some preferred to meet with patients in person to more fully

assess what was happening during their pregnancy. For example, Dr. Mayn believed there were some benefits to communication via electronic medical records, but also realized the challenge of being unable to assess patients over the computer.

Or, I can't tell what's going on from what you described on MyChart so we'll need to assess that here in the office. All of our MyCharts just go through our nurses first so that triage is through the nurse, and they are very good about, you know, I didn't like what seems concerning. But even on MyChart, it's too complex, get this additional information, then we'll chat about it. So, it's very general, we would give a response to a MyChart question, but come in if it's truly something else.

In a similar manner, Dr. Smith was more ambivalent about how electronic medical records mediated communication with patients.

Oh I don't know, I mean I'm fine with using Epic and MyChart and stuff and it helps with writing notes. But I've had it sometimes, I've had it where a patient emailed in a question, which those aren't high priority, and it's really something they should have called the office about and come in to be seen for. I mean, how much can you really tell in a message? So, I like to actually see the patients and then they are already in the office in case we need to do any interventions. But for quick things like test results or something, it is convenient. I don't know what patients think about it though.

MyChart. Some providers reflected on how adopting new technology altered the ways in which they communicated with patients. For example, Logan contrasted communicating with patients before and after her organization incorporated electronic records.

Back in the day when we didn't have MyChart, it could be such a nightmare to get a hold of patients. Let's say a test result came back. Well, you'd have to call the person,

and actually you have the nurse call, but you'd have to call the person and then you can't leave a message on their phone because of confidentiality, and then they would have to call back and it seemed like it took forever just for little simple things, you know? Now I can just send a quick message in MyChart. It makes my day so much easier. But of course, like, there will always be drawbacks...uh, like if something is emergent, I can't send a MyChart. Or if they are having an actual problem, the person needs to come in and not just like, try to do stuff over the computer. Thankfully we haven't had a bad outcome because of that, but like, I can totally see how it could happen.

Provider participants generally had a favorable view of technology which expedited interventions and treatments yet were more reserved about its usefulness in communicating with patients. While not the focus of this study, it is important to note and discuss the role that technology plays in patient care; particularly in the realm of communication. If providers are not comfortable or amenable to using electronic communication with patients, it is unlikely that quality interactions via technology will occur. This use of technology may result in the potential decrease in the clarity and frequency of communication. This may be particularly troubling for patients with high-risk pregnancies. Before moving on to discuss the implications for all of the themes presented in this chapter, I will first summarize themes for each group of participants.

Summary of Chapter Four

Following thematic analysis, three themes were present for patients and five themes were present for providers. Figure 17 below provides an overview of themes for patient participants.



Figure 17. Themes present in data for patient participants.

Patient participants reflected on their communication experiences with providers during high-risk pregnancy. Conversely, as seen in Figure 18 below, provider participants described the ways in which they communicate with patients during high-risk pregnancy.



Figure 18. Themes present in data for provider participants.

Provider responses centered around reporting on their current communication practices and challenges, while patient responses involved elements of narrative and discussion of how the experiences impacted their personal lives. The implications and potential recommendations related to thematic analysis for both patients and providers will be further discussed next in Chapter Five.

CHAPTER 5. DISCUSSION AND CONCLUSIONS

The purpose of this study was to examine the ways in which patients and providers communicate with each other during high-risk pregnancy. In order to elicit data, I interviewed 32 patients and 6 providers and conducted a thematic analysis, as described in Chapter 3. In this chapter I review key findings of this study in relation to my research questions, discuss the implications of these findings for organization, providers, and patients, elaborate on the theoretical implications of this work, and discuss limitations of the study. I begin with a review of the main research findings.

Review of the Main Findings

In this study I sought to answer two research questions:

RQ1: How do patients communicate with providers about high-risk pregnancies?

RQ2: How do providers communicate about high-risk pregnancy with patients?

I will now briefly review the main findings of my study and explore the overarching implications of this dissertation.

Patient Communication with Providers

Research question one centered around understanding the ways in which patients communicate with their providers about high-risk pregnancy. Patients prioritized establishing a trusting working relationship with providers, regardless of the type of provider (e.g. OB-GYN, perinatologist, general practitioner, etc.). Some patients experienced positive relationships with providers and reported being satisfied with provider communication. These patients felt cared for and supported by their providers, which was helpful to them during challenging events such as infant loss or additional medical interventions. Characteristics of patient-provider

communication helpful to patients were feeling respected by providers, being able to share concerns about pregnancy, being able to ask questions, and feeling that providers had the patient's best interests in mind.

Some patients did not experience positive working relationships with providers. In these situations, some patients did not have the ability to choose a different provider to work with and continued to receive care from providers they were not satisfied with throughout the course of their high-risk pregnancy. Those patients reported frustrations related to communication interactions and the care they received. Patient dissatisfaction was primarily related to brusque or disrespectful communication from providers, as well as feeling judged related to pregnancy factors or personal characteristics (such as being obese). Patients with the ability to choose a different care provider after negative interactions reported more satisfaction with the care and communication of their new providers. Ultimately the results of research question one overwhelmingly indicated that pregnant women want to feel heard and respected. Next I will discuss finding regarding research question two, which emphasized the experiences of providers.

Provider Communication with Patients

Research question two was focused on the ways in which providers communicate with patients about high-risk pregnancy. Providers expressed a desire for patients to actively participate in care. A main focus for providers was on patient compliance with provider instructions and recommendations. Providers believed that good pregnancy outcomes would be achieved through patient compliance such as: regularly attending appointments, following guidelines for weight gain/loss, adhering to medication regimens, and accepting medical interventions such as bed rest or C-sections. While providers reported having access to various

technologies to facilitate communication with patients, such as phone calls and messaging through electronic medical records they did not use them, citing a marked lack of training in the practice of communication itself.

Providers participating in this study reported receiving no professional training (either during their medical education or in their professional settings) regarding communicating with patients. These findings are consistent with current literature highlighting the necessity of improving general communication between patients and providers (Kee, Khoo, Lim, & Koh; Levinson, 2014). Additionally, research has also found that areas of medicine centered around risk and high-stakes outcomes (such as pregnancy, organ transplants, surgery, etc.) require complex communication skill sets that are difficult to achieve without proper training (Fong, Anat, & Longnecker, 2010; Ong, de Haes, Hoos, & Lammes, 1995; Street, 2013). Even with general training in patient communication, providers practicing in high-risk areas have been found to be ill-equipped for communicating with patients and families (Fong, Anat, & Longnecker, 2010; Ong, de Haes, Hoos, & Lammes, 1995). High-risk providers should be trained in a variety of communication practices for routine and complex care, which I will outline below when discussing implications. These findings are in keeping with the results of this study that providers need training in order to improve not only their communication with patients but also health outcomes. The two key desired health outcomes for patients experiencing high-risk pregnancy are preserving the lives of the mother and infant. Additional desired outcomes are related to maintaining the health of the mother and infant (Agrawal, 2015; CDC, 2018; Hillemeier et al, 2014). These include:

- Appropriate weight gain during pregnancy.
- Maintaining provider recommendations (e.g. medications, activity levels, care appointments).
- Early identification and treatment of medical conditions for mother (e.g. anemia, high blood pressure, diabetes, etc.).
- Prevention and/or early identification of birth defects.
- Prevention of complications during birth.
- Minimizing the need for post-birth interventions (e.g. time spent in NICU).

In essence, findings from both patients and providers support the need for provider communication training. Communication training and education for providers can be actualized in both educational (during formal schooling) and professional (during medical practice) settings. A few examples of training topics might include establishing rapport with patients, engaging in decision-making with patients, and discussing bad news. I elaborate on this further in my discussion of implications below. It is important to note that the need for enhanced communication between patients and providers spreads beyond training. In addition to implementing communication training, the effectiveness of the education needs to be assessed.

The need for training assessment is closely tied to the need for training itself. While general communication training for providers has been researched, its implementation is inconsistent and often lacks direction and focus. Additionally, training in communication about high-risk pregnancy requires ongoing assessment since it represents a new type of provider communication. Further research regarding communication training is needed. In addition to identifying communication training as an ongoing need for high-risk pregnancy providers, the salient issue of control was present in my findings. I will discuss this next.

Issues of Control

The issue of control was a salient one for both patients and providers. Patients expressed a desire to be in control of pregnancy-related decisions such as going on bed rest or whether or not to engage in a medical intervention such as an epidural. Providers reported wanting increased compliance from patients to adhere to care regimens (such as tightly controlling blood sugars) and to follow provider recommendations regarding additional pregnancies (e.g. not having more children or losing weight before attempting pregnancy again). A closely linked finding is that providers wanted patients to be active participants in care. They considered following provider recommendations (patient compliance) to be a component of that participation. While both patients and providers expressed a desire to exert control over high-risk pregnancy, the emphasis of that control varied by types of participants. In general, patients desired to exert control throughout their pregnancy: during interactions with providers, decision-making, and advocating to get more information from providers. Meanwhile, providers expressed a desire for patient compliance. They wanted patients to receive provider recommendations and to obey. These competing desires for control during high-risk pregnancy are a key finding. Below I will elaborate on control-related findings for each group of participants. I begin with patients and their experiences with control and loss of control.

Patients and control. Patient desires to exert control throughout high-risk pregnancy stemmed from experiencing loss of control. Patients experienced loss of control in several key areas: choice of provider, medical conditions and emergencies, decision-making during pregnancy, and pregnancy outcomes. While patients acknowledged that they were not able to control specific aspects of high-risk pregnancy (such as whether an infant would have birth defects, or miscarriage occurrence), they sought to exert control in their communication interactions with providers. These instances of control varied depending on the situation, but

they all centered around communication. For example, patients facing miscarriage wanted to be included in the discussion regarding treatment options. Patients can wait and try to let the products of conception (term used to refer to a nonviable fetus) pass naturally, take medication, or undergo a surgical procedure. Patients did not want providers to make decisions for them, but desired to be part of the decision-making process. Being involved in the conversation about medical decisions was important to patients and helped them to feel more in control of their pregnancy experience. While patients wanted to be active participants in making decisions regarding their medical care, providers desired patient compliance. I discuss this below.

Providers and control. Providers reported desiring compliance from patients experiencing high-risk pregnancy. Common areas for compliance included diet, weight management, disease (such as diabetes) management, and recommendations regarding future pregnancies. Some providers reported that they make recommendations to patients and expect patients to follow orders, while other providers reported leaving final decisions up to the patient. These variations in the decision-making process for high-risk pregnancy care appeared to differ by the type of provider. The midwife participants (three of them) reported engaging in more collaborative decision-making processes with the patients, while physician providers (three of them) discussed making a determination about the best course of action and expecting/wanting patients to accept and comply with the physician's decisions. Additional research exploring differing provider orientations towards collaborative decision-making with patients would be constructive in continuing to research patient-provider communication. Also, future research exploring the interplay of decision-making and power surrounding high-risk pregnancy would be beneficial, as it remains insufficiently researched. The juxtaposition between patients wanting to exert control over their pregnancy care the providers wanting more compliance

warrants further exploration and research. Possible implications of such research could have an impact at the organizational level (by way of policy and training) as well as the provider level. Practice changes implemented by providers alter their successive interactions with patients. Therefore, implementing shared decision-making during high-risk pregnancy would likely strengthen organizations and benefit both patients and providers.

Overall there were several key findings of this study. First, patients desired to have a positive and trusting relationship with their provider. Patients wanted to feel cared for and listened to throughout their high-risk pregnancy journey. Second, research findings support the need for formalized communication training for providers with ongoing assessment. Such training could include general communication skills when working with all types of patients, as well as more complex skills when interacting with high-risk pregnancy patients. Lastly, patients and providers both reported wanting some control throughout high-risk pregnancy. Patients expressed wanting to have input on care decisions, while providers emphasized patient compliance. Figure 19, below, provides a visual overview of the disciplinary approaches to this study, theoretical frameworks, methods, findings, and implications of this work. This overview is helpful to understanding how the components of this study work together.

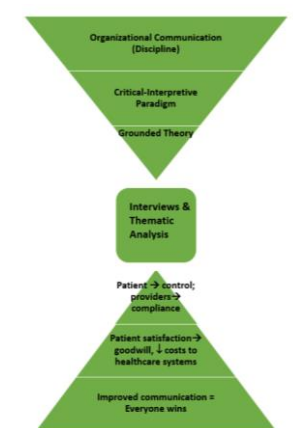


Figure 19. An overview of the study foundations, methods, results, and implications.

In the next section I will discuss the implications of this study for organizations, providers, patients as well as theoretical implication.

Implications

The main focus of this study was to explore the ways in which patients and providers communicate about high-risk pregnancy. The findings of this exploratory work are indicative of the interconnected nature of organizational communication research, as they cannot be easily separated from each other. Additionally, the implications for this research connect with multiple layers: organizations, providers, and patients. What follows is a discussion of the implications for each group. I will first discuss implications at the organizational level.

Implications for Organizations

At the organizational level, the findings of this study support the need for ongoing research and interventions related to patient-provider communication during high-risk pregnancy. Healthcare systems may strongly influence the progression of work in this area by exercising their organizational clout through formal programs and incentives designed to foster more trusting relationships with providers and to empower patients to exert control during high-risk pregnancy. Such initiatives build upon the platform of existing literature and what is already agreed upon in healthcare settings:

- Patient-centered care is imperative to delivering quality healthcare (IOM, 2001; Mead & Bower, 2000; Pinto et al, 2012).
- Communication is at the core of patient-centered care (IOM, 2001; Ishikawa et al, 2013; Mead & Bower, 2002).
- Consistently enacting high-quality communication during patient-provider interactions is particularly challenging due to the lack of provider training and limited research on

communication interventions (Belasen & Belasen, 2018; Friedman & Wolchok, 2016; Helitzer, LaNoue, Wilson, de Hernandez, Warner, & Roter, 2011).

- Key barriers to overcome include lack of standard interventions/training and inconsistent methods among healthcare facilities (Friedman & Wolchok, 2016; Helitzer, LaNoue, Wilson, de Hernandez, Warner, & Roter, 2011; Street, 2013).

My current work extends the previously mentioned literature by focusing on the specific area of high-risk pregnancy. As discussed in Chapters 1 and 2, existing research about patient-provider communication does not address the nuances inherent in high-risk pregnancy. While pregnancy is technically considered to be a disease (see Chapter 1), it is far different from say cancer or irritable bowel syndrome. Further, high-risk pregnancy is more complex due to the spectrum of risk and potential complications resulting from that risk (Coxon, Scamell, & Aleszewski, 2012; Kupperman, Little, Harris, Kukla, & Kupperman, 2009). For example, a pregnant woman who also has cancer or irritable bowel syndrome would be classified as having a high-risk pregnancy, and her care would be complex. In accordance with her perinatal care, her communication needs would also be more complex. Therefore, providers must be prepared to engage communication skills at an advanced level when interacting with patients during high risk pregnancy. Findings of this study not only support current literature regarding the need for increased provider communication training, but also identify crucial areas for impacting communication during high-risk pregnancy. This research is a significant contribution because it identifies specific communication needs, as well as provides some direction for taking action. Improved patient-provider communication about high-risk pregnancy will likely increase patient satisfaction, improve health outcomes, and also increase insurance reimbursement for organizations. As discussed in Chapter 2, insurance payments are closely linked with patient

satisfaction scores and health outcomes. Again, these findings are consistent with current literature about patient-provider communication in general (Deveugele, 2015; Levinson, Lesser, & Epstein, 2010; Oliveira, Ferreira, Pinto, Filho, Refshauge, & Ferreira, 2015). It is reasonable to conclude that successful interventions to facilitate greater levels of patient-centered care (e.g. participatory decision-making, improved communication) in general medicine areas would be likely to also improve care and communication for patients during high-risk pregnancy. Much of the responsibility for implementing communication training and interventions (e.g. soliciting feedback, participatory decision-making) lies with healthcare systems.

Healthcare organizations should engage in ongoing assessment and intervention related to patient-provider communication during high-risk pregnancy. As discussed in Chapter 1, nearly half a million women experience complications (actual, not just potential problems) due to high-risk pregnancy. There is an exigency to this work, and it impacts the United States as whole. Thus, health organizations should take initiative to contribute to lessening the complications associated with high-risk pregnancy through communication training. Key elements of this process might include collaborating with other facilities (e.g. establishing a statewide alliance) in the creation of a taskforce. Such a taskforce might be comprised of administrators, researchers, providers, and patients. Initiatives such as training sessions, scripting tools, and ongoing assessment could be developed jointly and then implemented across the task force area. Follow-up and assessment of communication initiatives could be conducted by healthcare researchers and monitored by the task force. This type of approach would be likely to improve morale through establishing collaborative (as opposed to competitive) working relationships between and amongst healthcare systems. Additionally, improved health outcomes can directly benefit the organization financially. Better health outcomes and increased patient satisfaction

scores result in higher rates of payment from insurance companies (Belasen & Belasen, 2018; Kee, Khoo, Lim, & Kho, 2017). These changes also positively contribute to the prestige of the healthcare system. High-risk pregnancy has been the focus of this study, but all areas of healthcare could benefit as well. Further, healthcare organizations can and should facilitate patient empowerment through incorporating feminist strategies and orientations during communication training. Next, I will provide an overview and examples of how feminist practices could be enacted when training providers in more effective ways of communicating with patients.

Feminist communication practices. Training sessions and ongoing assessment about patient-provider communication should incorporate feminist communication practices and values. Providers need to be aware of and re-educated regarding gendered issues in healthcare. As described in Chapter 1, maternity care has become paternalistic over the past one hundred years. This is particularly important because providers have been trained and practice within a healthcare culture of male privilege. High-risk pregnancy providers need to recognize the ways in which gender inequalities are enacted (either consciously or unconsciously) during interactions with patients. These paternalistic practices directly impact patients and the care they receive making change crucial. This study has been focused specifically on communicating about high-risk pregnancy, but these principles can transfer to virtually any area of healthcare. Training and assessment incorporating feminist values such as receptivity, acceptance, and cooperation (Marshall, 1993) can be operationalized in a variety of ways. I will focus on two specific strategies: self-reflection via case study, and peer review.

Self-reflection via case study. Case studies can be used in the communication training for high-risk pregnancy providers. In particular, these case studies may promote acceptance and

receptivity amongst providers. Providers might be presented with written summaries of hypothetical patients from a variety of ethnic, socioeconomic, and health status backgrounds. Brief video components of the patients describing their concerns could be shown, and then providers could either write or verbally describe their assessment of the patient. This assessment would include information that might be documented in a patient's chart as well as the provider's perception of various elements including but not limited to patient compliance and fitness for parenthood. Next, the provider would be shown additional video clips which could reveal information which challenges or confronts judgments or perceptions of the patient. Providers would then complete a structured, written self-reflection in which they demonstrate their increased awareness of their prejudices and develop an action plan for how they will incorporate more open and welcoming methods of communication into their practice. These action plans could be followed up with in a variety of settings: annual reviews, assigned groups or cadres of providers, and subsequent self-reflective practices. Self-reflection is a valuable practice for professional development. These suggestions may work well in addition to peer review and ongoing assessment of communication practices.

Peer review and ongoing assessment. While self-reflective practices are beneficial, providers may also find peer review and ongoing assessment to be helpful as they work to improve their communication skills. Peer review could be performed at regular intervals (e.g. quarterly, semi-annually, etc.) and could be incentivized by organizations through connecting them with the annual review process. Using scripting and practice guidelines, providers would observe each other during a certain number of patient interactions. Discussing these interactions with peers, supervisors, patients, and administrators can then provide a basis for continuing or adapting communication practices. Additionally, positive examples could be shared with other

providers to exemplify desired behavior. Ongoing assessment, whether formal or informal, may also be helpful in countering the established paternalistic culture in pregnancy care. Taskforces and healthcare administrators can develop ongoing assessment plans to best meet the training and development needs of their providers. This ongoing assessment can build upon and connect with action plans developed during training sessions and completed peer review. Coaching and role playing could also be helpful elements to incorporate. These types of actions by organization to correct and improve communication between patients and providers during high-risk pregnancy can positively impact patient care and satisfaction. In addition to implications such as these for healthcare organizations, there are implications for individual providers. I will discuss these next.

Implications for Providers

There are several implications for high-risk pregnancy providers based on the findings of this study. Providers can improve their communication with patients about high-risk pregnancy through working to establish a trusting relationship, engaging in patient-centered care, and through soliciting patient feedback. The first implication for providers relates to the findings that patients want to establish a trusting relationship with their providers. During initial visits with patients experiencing high-risk pregnancy, providers can communicate in intentional ways to facilitate the establishment of trust. Providers would do well to focus on developing their bedside manner. While not new to the practice of medicine, the emphasis on bedside manner has diminished as healthcare has prioritized cutting-edge technology and new developments in medical techniques (Birkhäuser et al, 2017). In this study patients indicated their desire to receive caring communication from providers, and for providers to listen to and take patient concerns seriously. Patients indicated that providers often seemed to be task-focused rather than patient-focused. For example, a provider might enter a room and not even

introduce themselves or greet the patients. Elements of demonstrating a caring bedside manner include using eye contact, light touch, and listening (Birkhäuser et al, 2017; Hall, Dugen, Zheng, & Mishra, 2001). For example, physicians might make eye contact when speaking with the patient rather than looking at the patient's medical chart on the computer. Providers can demonstrate caring through light touch (after performing hand washing, of course) of the patient's arm or hand. Listening to understand the patient and their concerns rather than being distracted or listening just to respond is the foundation of good bedside manner (Birkhäuser et al, 2017; Croker, Swancutt, Roberts, Abel, Roland, & Campbell, 2013). For example, a patient experiencing high-risk pregnancy might express concerns about feeling fatigued. A provider engaging in active listening might make eye contact and nod while the patient is speaking, avoid interrupting the patient, and check to make sure they understood the patient's concerns. These types of actions are likely to contribute to a positive working relationship between providers and patients during high-risk pregnancy, which was desired by patient participants. In addition to establishing trusting relationships with patients, findings of this study indicate that patients want to participate in directing their pregnancy care. Patients often reporting feeling a loss of control and wanted to regain a sense of control about healthcare decisions. These findings support the need for providers to work to increase patient control and empowerment. I will discuss recommendations for this next.

Providers can engage in patient-centered care by working to incorporate more elements of patient control and empowerment. The findings of this study indicate that patients want to exert control during high-risk pregnancy, while providers desire compliance. I posit that both parties can meet their goals through patient-centered care, particularly when providers promote patient empowerment. Patient empowerment can be enacted through collaborative goal-setting,

which is sometimes referred to as patient-directed care. When engaging in patient-directed care, providers and patients work together in order to decide on the desired outcomes for the patient (Scherger, 2009; Tinetti, Naik, & Dodson, 2016). For example, a patient pregnant with triplets may decide to carry all three fetuses as long as possible or may decide to electively reduce (i.e. abort) one or two of the fetuses in order to increase the full gestation and healthy birth of one fetus. Decision-making should be facilitated by the provider and the patient should feel in control of her care (Lines, Lepore, & Wiener, 2015; Tinetti, Naik, & Dodson, 2016). These types of interactions do require focused effort on the behalf of providers but can be effective in facilitating patient's sense of control during interactions (Anderson, 1996; Rowland, McMillan, McGillicuddy & Richard, 2017). In turn, patients who are satisfied with their care are more prone to being compliant with provider's orders, which contributes to better outcomes (Berkhof, van Rijssen, Schellart, Anema, & van der Beek, 2011; Levinson, Lesser, & Epstein, 2010). By increasing patient control and engaging in shared decision-making, both patients and providers benefit. In essence, this can be a win-win situation. In addition to establishing trusting relationships and increasing patient control during high-risk pregnancy, providers can also engage in the feedback process with patients. Patient provider feedback can also increase patient compliance (Al-Abri & Balushi, 2014). I will discuss recommendations for incorporating feedback processes next.

In efforts to be transparent and to improve in the delivery of care, providers can ask their patients for feedback. Healthcare organizations do distribute formal surveys, but providers can solicit instant feedback during patient encounters. This focused feedback can occur within the context of providing and receiving care during high-risk pregnancy and may also aid in the process of establishing a trusting relationship. For example, during an initial encounter to

monitor high-risk pregnancy, a provider might ask the patient what her goals are for the pregnancy. In addition to discussing those goals with the patient, the provider can also document them in the clinic note. At the end of that visit and during subsequent visits, the provider can check in with the patient regarding her goals and ask about progress. A specific example of this might look something like, “Roxanne, I know that one of your goals has been to have a calm birthing experience, even though we know there might be some complications. Here are some ideas we can talk about...what else can I do to help you to meet this goal?” Providers could also ask direct questions of patients; “Patricia, how do you feel about the communication we are having? How can I make it better?” (Greco, Brownlea, & McGovern, 2001; Rowland, McMillan, McGillicuddy & Richard, 2017). Patient feedback can both affirm what providers are doing well and indicate areas for improvement. Now that I have identified implications at both the organizational and provider level, I will next discuss implications for patients.

Implications for Patients

The findings of this study support several implications for patients. These implications can be categorized into two parts: actively participating in care and patient advocacy. Patients in this study reported desiring a trusting relationship with their provider, which is consistent with existing literature (Mead & Bower, 2000; Pinto et al, 2012). Additionally, patients reported wanting to have control over decisions and pathways of care when possible. While organizations and providers bear a large portion of responsibility in these areas, patients can take actions while engaging in care during high-risk pregnancy.

Active participation in care. Patients experiencing high-risk pregnancy can benefit by actively participating in care throughout their pregnancy journey. Recommendations here are related to two main findings of this study: patients desiring a trusting relationship with

providers, and providers wanting patients to be active participants in the care process. First, there are actions patients can take to assist in establishing a trusting relationship with their pregnancy provider(s). Prior to meeting with a provider, patients can look up reviews and satisfaction scores online. Patients may also choose their provider (when possible) based on available reviews or even word-of-mouth recommendations from people they know.

Additionally, patients may find it helpful to consider what their goals and priorities are before each interaction with a provider. Writing these ideas down can remind patients to address them during visits. Lastly, patients can work to establish a positive relationship through direct and honest communication. Accurately reporting symptoms, concerns, and preferences for care assists both patients and providers during interactions. Patients can also participate by honestly responding to feedback requests from providers and healthcare organizations. If patients are comfortable with offering feedback to providers directly during encounters, they should do so. Patients should complete surveys sent by healthcare organizations; the anonymous nature of the survey may help patients to feel more comfortable with providing feedback on their care. Along with taking actions to help with building positive relationships with providers, patients can take steps to advocate for themselves.

Patients and advocacy. As discussed earlier in this chapter, many patients reported experiencing loss of control during high-risk pregnancy encounters. I have explained ways in which organizations and providers can help alleviate loss of control. Patients can also take measures to help them feel more in control via advocacy. When able to do so, patients can monitor their health record/electronic medical chart by signing up for a free account through the healthcare organization. Electronic medical charts are the legally mandated standard of care and contain information such as test results, upcoming appointments, summaries of past visits, and

messaging capabilities between patients and providers. Accessing information through their electronic chart can relieve anxiety about having to memorize everything discussed during an appointment. Patients might also choose to share their healthcare information with others such as partners and family members. In addition to accessing and monitoring information via electronic medical records, patients can engage in self-advocacy by asking questions about their care. Questioning may take a variety of forms depending on the comfort level of the patient: they might include asking general (non-emergent) questions via the electronic chart, during face-to-face encounters, or over the phone. If patients are concerned about care from a particular provider, they can seek out someone higher in the organizational structure who may be able to assist them. Depending on the severity, this might look like reporting concerns to a department manager, risk management division of the organization, or at the governmental regulation level. The action steps I have identified thus far are forms of self-advocacy. Patients may also benefit when others advocate on their behalf.

Partner advocates might be actualized in various ways. For example, this might be a support person (spouse, family member, friend, etc.) who is in attendance during care encounters (e.g. hospital stays, clinic visits). A support person may help patients to feel more at ease during interactions with providers, help to remember what transpired during encounters, and to advocate when the patient is unable to do so. If a patient is unable to advocate for themselves due to being incapacitated or ignored by providers, the advocacy partner can assist. It would be important for patients and their support persons to discuss potential concerns and desires with each other prior to encounters with providers in order to be in agreement with each other. Partner advocacy, self-advocacy, and active participation in care are actions patients can

engage during high-risk pregnancy. I have outlined implications for patients, providers, and organization this study has theoretical implications as well, which I will discuss next.

Theoretical Implications

This research contains important theoretical implications for communication scholars. Communication scholars have repeatedly called for additional research in the area of interactions between pregnant women and providers (Coxon, Scamell, & Alaszewski, 2012; Rothman, 2014; Coxon, 2016). This study responds to that call while focusing on a subsection of pregnant women: those experiencing high-risk pregnancy. By seeking to understand the ways in which patients and providers communicate during high-risk pregnancy, I build upon the previous work of others. Previous scholarship has traced the historical establishment of paternalistic, medicalized obstetric care (Barker, 1998; Seigel, 2014). As discussed in the beginning of this dissertation, the dynamics of power between providers and patients are closely linked with the enactment of gender and emphasize male privilege (Coxon, Scamell, & Alaszewski, 2017; Marshall, 1993; Mumby, 1993; Olesen, 2011). Research findings indicate that core feminist values such as cooperation, interdependence, receptivity, and acceptance (see Marshall, 1993) continue to be overlooked in the context of healthcare communication and high-risk pregnancy. The paternalistic model of maternity care continues to be problematic. My work in this study builds upon existing research by seeking to understand the experiences of patients and providers as they communicate during high-risk pregnancy. The insight gained through this research is the foundation for interventions. Based on the findings of this study, I am able to provide insight into positive and negative aspects of patients-provider communication, as well as to suggest avenues for practice change and further research. Additionally, this study extends the gap in existing literature related to patient-provider

communication in healthcare settings. I will next discuss how the findings of this study contribute to two theoretical components of patient-centered care: conflict theory and social constructionism.

Conflict Theory Perspective

As discussed in Chapter 2, the conflict theory approach to patient-centered care emphasizes the ways in which power dynamics are enacted within healthcare settings. In essence providers hold more power than patients and use their dominant position to direct patient care (Collins, 1994; Haug & Lavin, 1981; Ishikawa et al, 2013). Patients then attempt to wrest power from providers in order to meet their own needs and preferences for care (Ishikawa et al, 2013). The findings of this study suggest that these power dynamics are present in high-risk pregnancy encounters. Further, this research can provide impetus to continue to explore patient-provider communication as it relates to high-risk pregnancy and conflict theory. I suggest that examining potential connections between the enactment of conflict theory in high-risk pregnancy and the current crisis of poor maternal outcomes in the United States (discussed in Chapter 1) is critical avenue for research. This research may be fruitful in two ways: providing more complex insight and driving recommendations for practice change. This study has been largely exploratory in nature and additional work must be completed in order to more thoroughly address complex the complex nature of patient-provider communication during high-risk pregnancy. In addition to contributing to the conflict theory approach to healthcare communication, the findings of this study are connected to social constructionism. I will discuss this next.

Social Constructionism Implications

The social constructionist approach to patient-centered care emphasizes the mutual construction of reality during patient-provider interactions (Mead & Bower, 2000; Ishikawa et al, 2013; Stewart et al, 1995). Findings of this study support enactment of that theory in patient-provider communication during high-risk pregnancy. Each participant (e.g. patients and providers) enters the encounter with their own experiences, preferences, and desires. During the interaction, each individual is creating their own version of the narrative based on their perspective and what occurs during the encounter. For example. A patient may come to an appointment with concerns that they may have miscarried. The provider in this scenario may demonstrate caring through listening to the woman's concerns, using soft touch such as placing a hand on the patient's arm, checking for understanding, and ordering an ultrasound to assess the fetus. Regardless of the clinic outcome (i.e. if miscarriage has occurred), the patient may leave the encounter feeling that they have a trusting relationship with the provider, the provider is competent, and the patient is receiving excellent care. Similarly, the provider may believe the patient will be compliant with instructions to continue monitoring fetal movement at home or some other intervention. Each individual's interpretation of the healthcare encounter is based on what was mutually created during their interaction with each other. This social construction of reality can then drive further actions for each person, which may contribute to health outcomes for high-risk pregnancy patients. The theoretical contributions toward social construction theory are of significance, as they contribute to the larger body of knowledge regarding moving towards more effective patient-centered care for pregnant women (Epstein & Street, 2011; Ishikawa et al, 2013; Masse, Legare, Cole, & Dodin, 2001; Mead & Bower, 2000). It is important to note that conflict theory and social constructionism are not mutually exclusive; individuals can both enact elements of conflict and the mutual construction of reality.

Therefore, findings of this study contribute to each theoretical area as it relates to patient-centered care in general, and high-risk pregnancy care in specific. There are also broader implications in relation to the existing body of literature about patient-provider communication. I will discuss those next.

Healthcare researchers have produced numerous bodies of literature containing the woeful state of patient-provider communication, which is at the core of patient-centered care (Hall et al, 2002; Mercer et al, 2004; Pinto et al, 2012). In addition to responding to the call for additional research from the communication scholar camp, with this study I respond to the call for further research from the healthcare scholarship faction (Belasen & Belasen, 2018; Mead & Bower, 2002; Stewart et al, 1999; Venetis, Robinson, Turkiewicz, & Allen, 2009). My work pushes past the wall of accepted literature. While I agree with scholars about there being a lack in effective patient-provider communication, I seek to extend current literature. My work here contributes by exploring patient-provider experiences (through self-reported data) and by making recommendations for organizations, providers, and patients based on the findings. Results of this study are pertinent to understanding how some of the dynamics of patient-provider communication are enacted and are also directive for healthcare scholars in how they might proceed in both theory and practice. Additional research into patient-provider communication and potential interventions to improve communication can build further on my work in this study. While I have been able to gain insight and provide suggestions for both theory and praxis, the work in this study is not all-encompassing and there are several limitations. I will discuss the limitations of this study next.

Limitations

Several limitations were present in this study. The first limitation of this research is that time constraints were a factor. While I was able to conduct member checks of interview

transcriptions, due to the time constraints of concluding this study I was not able to follow up with participants to determine whether the results of the research were consistent with their experiences. Additionally, it would be helpful to conduct longitudinal research on this topic. Doing so would allow for gathering additional information from participants as they engaged in additional communication interactions and subsequent pregnancies might help to shed additional light on the topic at hand.

A related limitation is the number of providers participating in the study. A total of 6 providers, 3 physicians and 3 midwives, participated in the study. Research including a larger group of provider participants across a variety of practice settings and locations (e.g. small town and large city, different states, etc.) would be beneficial. Gaining more insight into provider experiences with communication during high-risk pregnancy might lead to the development of additional strategies and interventions.

Another limitation is that the majority of participants were Caucasian. There were 38 participants in total; 32 patients and 6 providers. Participants self-identified their race/ethnicity as 35 Caucasian Americans, 2 Asian Americans, and 1 African American. It would be useful to recruit an even more diverse pool of participants. Pregnancy-related outcomes for African American women in the United States are poor. As discussed in Chapter 1, the maternal mortality rate for African American women is four times that of Caucasian Americans. The explicit cause of such discrepancies is unknown but is suspected to be linked to racial disparity and socioeconomic factors (CDC, 2017; Martin, 2017). A larger, more diverse group of participants might provide additional insight into factors impacting patient-provider communication during high-risk pregnancy.

A related limitation is that the group of patients was well-educated. Twelve of the patients had a PhD, six had master's degrees, 11 had bachelor's degrees, one had an associate's degree, and two reported having some college education. It is possible that the way patients told their stories was impacted by their level of education. Participants with higher levels of education and income may have access to a greater variety of compliance tactics. For example, they may feel more comfortable in being assertive about agreeing with a provider or may be able to go on bed rest without fearing loss of income. It would be useful to recruit a more educationally diverse group of participants in order to more fully understand the ways in which patients and providers communicate during high-risk pregnancy.

Additionally, this study was composed of self-reported data gathered via interviews. While this was done to protect patient well-being due to the sensitive nature of the topic, a longitudinal diary study could help gain deeper insights into patient-provider communication during high-risk pregnancy.

Although there are limitations with this study the contributions outweigh these limitations. While this study makes contributions to the body of literature on patient-provider communication, there is still much work to be done. In addition to the areas of future research included in the discussion of practical and theoretical implications of this study there are additional opportunities for future research which I will discuss next.

Future Research

This exploratory study lays the groundwork for more in-depth research regarding patient-provider communication during high-risk pregnancy. I have several recommendations for future research related to this topic. The first recommendation for future research is to conduct a study in which pairs or groups of patients and providers are followed longitudinally. This type of study might involve paired patients and providers throughout the course of

pregnancy; gathering data from each of them before, during, and after interactions. A study of this nature might work particularly well if conducted by healthcare systems, as access to participants would be plentiful. Healthcare systems have an impetus to conduct ongoing research and to improve patient satisfaction results. Additionally, communication interventions could be introduced and assessed for effectiveness. For example, providers might undergo training related to communication regarding risk in pregnancy and the effectiveness of that training might be assessed by gathering data before and after the training. Scripting, through either an interview tool/worksheet, or via prompting by the electronic charting system might also be an intervention to assess.

The second recommendation for future research is for communication and medical scholars to collaborate. For purposes of this discussion, I consider communication scholars to be those working in communication-related fields, while medical researchers work within healthcare systems and are typically employed as providers and nurses. The two fields, communication and medicine, may be “talking past” each other in their approaches towards communication. Medical scholars bemoan the lack of consistent research on patient-centered care and patient-provider communication, while communication scholars criticize the quality of communication between pregnant women and providers. Collaboration between both fields of research could produce actionable work and contribute to each area of study. This collaborative scholarship could result in new knowledge about patient provider communication and perhaps more importantly could also present tangible tools for practice. Interventions improving communication between patients and providers during high-risk pregnancy are likely to benefit all of those involved: organizations, providers, patients, and the fetus or infant.

A related recommendation for future research is to explore patient-provider communication in other areas of healthcare. Numerous other health experiences are closely linked with risk, and strong communication between patients and providers may improve patient satisfaction as well as health outcomes. Particular areas for study might be organ transplant, diabetes, lung disorders, and cardiovascular disease. While each health area may require unique strategies for communication, it is likely that some core recommendations for practice may apply to all encounters involving patient-provider communication and risk. Additional research in this area is likely to benefit all stakeholders in healthcare. In addition to examining communication in various types of high-risk care settings, the organizational dynamics in which care is provided should be further researched.

Both general and condition-related constraints impact providers and patients encountering each other within healthcare organizations. For example, providers often report time constraints as a main concern to their delivery of care (Ishikawa et al, 2013; Mead & Bower, 2012). Practice settings vary by organization, but pregnancy providers typically juggle caring for patients admitted to the hospital, patients visiting clinics, and patients delivering babies on any given day. These time-related tensions may be particularly problematic for providers in high-risk pregnancy settings since delivering that type of care is even more complex. As discussed earlier, providers can take actions to improve their communication with high-risk pregnancy patients. However, providers' interactions are often mediated by organizational dynamics and power structures. Patient-provider interactions occur within healthcare organizations, and the hegemonic power structures currently in place impact the ways in which patients and providers communicate with each other. While some research has been conducted regarding patient empowerment and patient-provider communication (see, for

example Anderson, 1996; de Aguiar, 1998; Deveugele, 2015; Godolphin, 2003; Gore, 1992), additional research specifically focusing on power and communication in high-risk pregnancy would be beneficial.

Conclusion

This study contributed to the understanding of how patients and providers communicated with each other about high-risk pregnancy. In addition to greater awareness of how patients and providers experienced communication interactions and the need for more accountability of both organizations and individuals, this study also has important theoretical implications. In particular, scholars of communication and also of healthcare might continue building upon this study in order to enhance patient-provider communication and ultimately improve birth outcomes for high-risk pregnancy.

REFERENCES

- Agrawal, P. (2015). Maternal mortality and morbidity in the United States of America. *Bulletin of the World Health Organization*, 93: 135. <http://dx.doi.org/10.2471/BLT.14.148627>
- Ako-Arrey, D. E., Brouwers, M. C., Lavis, J. N., & Giacomini, M. K. (2015). Health systems guidance appraisal—a critical interpretive synthesis. *Implementation Science*, 11(1), 9. <https://doi.org/10.1186/s13012-016-0373-y>
- Al-Abri, R. & Balushi, A. A. (2014). Patient satisfaction survey as a tool towards quality improvement. *Oman Medical Journal*, 29(1), 3-7. doi: 10.5001/omj.2014.02
- American Academy of Pediatrics (2004). Age terminology during the perinatal period. *Pediatrics*, 115(5), 1362-1364. doi: 10.1542/peds.2004-1915
- American College of Obstetricians and Gynecologists (2013). Committee opinion: Definition of term pregnancy. *Society for Maternal-Fetal Medicine*, 20(5), 245–247. <http://doi.org/10.1097/SPV.0000000000000112>
- Anderson, J. M. (1991). Reflexivity in fieldwork: Toward a feminist epistemology. *Image: The Journal of Nursing*, 23(2), 115–118.
- Anderson, J. M. (1996). Empowering patients: Issues and strategies. *Social Science and Medicine*, 43(5), 697–705. [https://doi.org/10.1016/0277-9536\(96\)00153-0](https://doi.org/10.1016/0277-9536(96)00153-0)
- Anderson, R. M., & Funnell, M. M. (2005). Patient empowerment: Reflections on the challenge of fostering the adoption of a new paradigm. *Patient Education and Counseling*, 57(2), 153–157. <https://doi.org/10.1016/j.pec.2004.05.008>
- Apple, R.D. (1995). Constructing mothers: scientific motherhood in the nineteenth and twentieth centuries. *Social history of medicine*, 8 (2), 161–178.
- Arney, W.R. (1982). *Power and the profession of obstetrics*. Chicago: University of Chicago Press.
- Ashcraft, K. L. (2000). Empowering “professional” relationships: Organizational communication meets feminist practice. *Management Communication Quarterly*, 13(3), 347–392. <http://doi.org/10.1177/0893318900133001>
- Ball, L. (2018). The opioid crisis. *Nephrology Nursing Journal*, 45(6), 511-512.
- Barker, K. K. (1998). A ship upon a stormy sea: The medicalization of pregnancy. *Social Science and Medicine*, 47(8), 1067–1076. [http://doi.org/10.1016/S0277-9536\(98\)00155-5](http://doi.org/10.1016/S0277-9536(98)00155-5)
- Beck, R. S., Daughtridge, R., & Sloane, P. D. (2002). Physician-patient communication in the primary care office: a systematic review. *Journal of the American Board of Family Practice*, 15(1), 25–38. <https://doi.org/10.1002/pon>

- Beckman, H. B., & Frankel, R. M. (1984). The effect of physician behavior on the collection of data. *Annals of Internal Medicine*, *101*(5), 692-696.
- Bekker, H. (2010). The loss of reason in patient decision aid research: Do checklists damage the quality of informed choice interventions? *Patient Education and Counseling*, *78*(3), 357-364. doi: 10.1016/j.pec.2010.01.002
- Belasen, A. & Belasen, A.T. (2018). Doctor-patient communication: a review and a rationale for using an assessment framework. *Journal of Health Organization and Management*, *32*(7), 891-907. <https://doi.org/10.1108/JHOM-10-2017-0262>
- Bensing, J. (2000). Bridging the gap: The separate worlds of evidence-based medicine and patient-centered medicine. *Patient Education and Counseling* *39*(1), 17-25. Doi: 10.1016/S0738-3991(99)00087-7
- Bensing, J. & Dronkers, J. (1992). Instrumental and affective aspects of physician behavior. *Medical Care*, *30*(4), 283-298.
- Bensing, J. M., Verhaak, P. F., van Dulmen, A. M., & Visser, A. P. (2000). Communication: The royal pathway to patient-centered medicine. *Patient Education and Counseling*, *39*(1), 1-3.
- Berge, K. H., & Burkle, C. M. (2014). In reply—The contribution of patient satisfaction to the opiate abuse epidemic. In *Mayo Clinic Proceedings* (Vol. 89, p. 1168). Mayo Foundation for Medical Education and Research. <https://doi.org/10.1016/j.mayocp.2014.06.007>
- Berkhof, M., van Rijssen, H. J., Schellart, A. J. M., Anema, J. R., & van der Beek, A. J. (2011). Effective training strategies for teaching communication skills to physicians: An overview of systematic reviews. *Patient Education and Counseling*, *84*(2), 152–162. <https://doi.org/10.1016/j.pec.2010.06.010>
- Bernstein, M., Magill, M., Beaudoin, F., Becker, S., & Rich, J. (2018). Harnessing the placebo effect: A promising method for curbing the opioid crisis? *Addiction*, *113*(11), 2144-2145. <http://dx.doi.org/10.1111/add.14385>
- Björkman, I., Simrén, M., Ringström, G., & Ung, E. J. (2016). Patients' experiences of healthcare encounters in severe irritable bowel syndrome: an analysis based on narrative and feminist theory. *Journal of Clinical Nursing*, *25*(19–20), 2967–2978. <https://doi.org/10.1111/jocn.13400>
- Boston Women's Health Book Collective. (2011). *Our bodies, ourselves / Boston Women's Health Book Collective*. (40th anniversary Touchstone ed.). New York: Simon & Schuster.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in Psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>

- Braun, V., & Clarke, V. (2014). What can “thematic analysis” offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-Being*, 9, 9–10. <http://doi.org/10.3402/qhw.v9.26152>
- Brown, J.B., Boles, M., Mullooly, J.P., and Levinson, W. (1999). Effect of clinical communication skills training on patient satisfaction. *Annals of Internal Medicine*, 131(11), 822-829.
- Birkhäuer, J., Gaab, J., Kossowsky, J., Hasler, S., Krummenacher, P., Werner, C., & Gerger, H. (2017). Trust in the health care professional and health outcome: A meta-analysis. *PLOS One*. doi: 10.1371/journal.pone.0170988
- Burrell, G., & Morgan, G. (1979). *Sociological paradigms and organizational analysis*. London: Heinemann.
- Buzzanell, P. M. (1994). Gaining a voice: Feminist organizational communication theorizing. *Management Communication Quarterly*, 7(4), 339–383. <http://doi.org/10.1177/0893318994007004001>
- Byrne, P.S., & Long, B.E. (1976). *Doctors talking to patients: A study of the verbal behavior of general practitioners consulting in their surgeries*. London: Great Britain Department of Health and Social Security.
- Centers for Disease Control (2017). Births and natality. *National Center for Health Statistics*. Retrieved from <https://www.cdc.gov/nchs/fastats/births.htm>
- Centers for Disease Control (2018). Pregnancy mortality surveillance system. Retrieved from <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-mortality-surveillance-system.htm>
- Central Intelligence Agency (2011). World factbook. Retrieved from <https://www.cia.gov/library/publications/the-world-factbook/rankorder/2091rank.html>
- Chapman, A. L., Hadfield, M., & Chapman, C. J. (2015). Qualitative research in healthcare: An introduction to grounded theory using thematic analysis. *Journal of the Royal College of Physicians of Edinburgh*, 45(3), 201–205. <http://doi.org/10.4997/JRCPE.2015.305>
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine*, 49(5), 651-661.
- Charmel, P. A., & Frampton, S. B. (2008). Building the business case for patient-centered care. *Healthcare Financial Management*, 62(3), 80-5.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks: Sage Publications.

- Charmaz, K. (2009). Shifting the grounds: Constructivist grounded theory methods. In *Developing grounded theory: The second generation* (pp. 127–193).
- Charmaz, K., & Belgrave, L. (2012). Qualitative interviewing and grounded theory analysis. *The SAGE handbook of interview research: The complexity of the craft*, 2, 347-365.
- Clever, S.L., Jin, L., Levinson, W. and Meltzer, D.O. (2008). Does doctor-patient communication affect patient satisfaction with hospital care? Results of an analysis with a novel instrumental variable. *Health Services Research*, 43(5), 1505-1519. doi: 10.1111/j.1475-6773.2008.00849.x
- Collins, R. (1994). *Four sociological traditions*. New York: Oxford University Press.
- Conrad, P. (1992). Medicalization and social control. *Annual review of Sociology*, 13, 209–32.
- Coxon, K., Scamell, M., & Alaszewski, A. (2012). Risk, pregnancy and childbirth: What do we currently know and what do we need to know? *Health, Risk & Society*, 14(6), 503–510. <http://doi.org/http://dx.doi.org/10.1080/13698575.2012.709486>
- Coxon, K. (2016). Risk in pregnancy and birth: Are we talking to ourselves? In K. Coxon, M. Scamell, & A. Alaszewski's *Risk, pregnancy, and childbirth* (pp. 1-13). New York, NY: Routledge.
- Roland, M., Campbell, J. L., Swancutt, D. R., Abel, G. A., Roberts, M. J., & Croker, J. E. (2013). Factors affecting patients' trust and confidence in GPs: evidence from the English national GP patient survey. *BMJ Open*, 3(5), e002762. <https://doi.org/10.1136/bmjopen-2013-002762>
- Crossley, M. L. (2007). Childbirth, complications and the illusion of 'choice': A case study. *Feminism & Psychology*, 17(4), 543–563. <https://doi.org/10.1177/0959353507083103>
- Currie, D. H., & Wiesenber, S. E. (2003). Promoting women's health-seeking behavior: Research and the empowerment of women. *Health Care for Women International*, 24, 880–899. <https://doi.org/10.1080/07399330390244257>
- Dahlen, H. G., Jackson, M., & Stevens, J. (2011). Homebirth, freebirth and doulas: Casualty and consequences of a broken maternity system. *Women and Birth*, 24(1), 47–50. <https://doi.org/10.1016/j.wombi.2010.11.002>
- Davis-Floyd, R. (1988). Birth as an American rite of passage. In K. L. Michaelson (Ed.), *Childbirth in America: Anthropological perspectives* (pp. 153–172). South Hadley, MA: Bergin and Garvey.
- de Aguiar, A. C. (1998). Medicine and women's studies: Possibilities for enhancing women's health care. *NWSA Journal*, 10(1), 23-42.

- de Lauretis T. (1986) Feminist studies/critical studies: Issues, terms, and contexts. In: de Lauretis T. (Eds.) *Feminist Studies/Critical Studies: Language, Discourse, Society*, London: Palgrave Macmillan.
- Deetz, S., & Mumby, K. (1990). Power, discourse, and the workplaces: Reclaiming the critical tradition. *Annals of the International Communication Association*, 13(1), 18-47. doi: 10.1080/23808985.1990.11678743
- Deetz, S. (1996). Describing differences in approaches to organization science: Rethinking Burrell and Morgan and their legacy. *Organization Science*, 7(2), 191–207.
- Deveugele, M. (2015). Communication training: Skills and beyond. *Patient Education and Counseling*, 98(10), 1287–1291. <https://doi.org/10.1016/j.pec.2015.08.011>
- Dhalla, I., Persaud, N., & Juurlink, D. (2011). The prescription opioid crisis. *BMJ: British Medical Journal*, 343(7823), 569-571. <https://www.jstor.org/stable/23051386>
- Dunn, L. (2012). 6 characteristics of high-performing healthcare organizations. *Becker's Hospital Review*, 2012(7), 51-52.
- Eddy, D. M. (1990). Clinical decision making: From theory to practice. Anatomy of a decision. *Journal of the American Medical Association*, 263(3), 441-443.
- Edwards, A., & Elwyn, G. (1999). How should effectiveness of risk communication to aid patients' decisions be judged? A review of the literature. *Medical Decision Making*, 19(4), 428–434. <https://doi.org/10.1177/0272989X9901900411>
- Elwyn, G., Edwards, A., Wensing, M., Hood, K., Atwell, C., & Grol, R. (2003). Shared decision making: Developing the OPTION scale for measuring patient involvement. *Quality & Safety in Health Care*, 12(2), 93-99.
- Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *Journal of the American Medical Association*, 267(16), 2221-2226.
- Einstein, G., & Shildrick, M. (2009). The postconventional body: Retheorising women's health. *Social Science & Medicine*, 69(2), 293-300. Doi: 10.1016/j.socscimed.2009.04.027
- Epstein, R. M., Franks, P., Fiscella, K., Shields, C. G., Meldrum, S. C., Kravitz, R. L., & Duberstein, P.R. (2005). Measuring patient-centered communication in patient-physician consultations: Theoretical and practical issues. *Social Science & Medicine*, 61(7), 1516-1528. doi: 10.1016/j.socscimed.2005.02.001
- Epstein, R. M., Fagerlin, A., Zikmund-Fisher, B. J., & Ubel, P. A. (2011). Helping patients decide: Ten steps to better risk communication. *Journal of the National Cancer Institute*, 103(19), 1436–1443. <https://doi.org/10.1093/jnci/djr318>

- Epstein, R. M., & Peters, E. (2009). Beyond information: Exploring patients' preferences. *Journal of the American Medical Association*, 302(2), 195-197. doi:10.1001/jama.2009.984
- Epstein, R. M., & Street, R. L. (2011). Shared mind: Communication, decision making, and autonomy in serious illness. *Annals of Family Medicine*, 9(5), 454-461. Doi: 10.1370.afm.1301
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme Development. *International Journal of Qualitative Methods*, 5(1), 80-92. <https://doi.org/10.1177/160940690600500107>
- Fertl, K.I., Bergner, A., Beyer, R., Klapp, B.F., & Rauchfuss, M. (2009). Levels and effects of different forms of anxiety during pregnancy after a prior miscarriage. *European Journal of Obstetrics and Gynecology*, 142(1), 23-29. doi: 10.1016/j.ejogrb.2008.09.009
- Ford, S., Fallowfield, L., & Lewis, S. (1996). Doctor-patient interactions in oncology. *Social Science & Medicine*, 42(11), 1511-1519.
- Forrow, L., Wartman, S. A., & Brock, D. W. (1988). Science, ethics, and the making of clinical decisions: Implications for risk factor intervention. *Journal of the American Medical Association*, 259(21), 3161-3167.
- Friedman, C. F., & Wolchok, J. D. (2016). Patient-physician communication in the 21st Century. *Trends in Immunology*, 37(6), 347-349. <https://doi.org/10.1016/j.it.2016.04.005>
- Funnell, M. M. (2016). Patient empowerment: What does it really mean? *Patient Education and Counseling*, 99(12), 1921-1922. <https://doi.org/10.1016/j.pec.2016.10.010>
- Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20(9), 1408-1416. <https://nsuworks.nova.edu/tqr/vol20/iss9/3>
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research - Supplementary material: Illustrative example of the use of the Framework Method. *BMC Medical Research Methodology*, 13(1), 1-11. <https://doi.org/10.1186/1471-2288-13-117>
- Garro, L. (1988). The woman in the body: A cultural analysis of reproduction. *American Anthropologist*, 90(3), 771-772.
- Gatrell, C. J. (2013). Maternal body work: How women managers and professionals negotiate pregnancy and new motherhood at work. *Human Relations* 66(5): 621-644. <https://doi.org/10.1177/0018726712467380>
- Glaser, B. & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Abingdon, UK: Routledge.

- Godolphin, W. (2003). The role of risk communication in shared decision making: first lets get to choices. *British Medical Journal*, 327(7417), 692–696.
<https://doi.org/10.1136/bmj.327.7417.692>
- Goldman, R. (2016). A breakdown of miscarriage rates per week. *Healthline Media*. Retrieved from <https://www.healthline.com/health/pregnancy/miscarriage-rates-by-week#takeaway>
- Gore, J. (1992). What can we do for you! What can “we” do for “you”? Struggling over empowerment in critical and feminist pedagogy. In C. Luke & J. Gore (Eds.) *Feminisms and Critical Pedagogy* (pp. 54–74). New York: Routledge.
- Greco, M., Brownlear, A., & McGovern, J. (2001). Impact of patient feedback on the interpersonal skills of general practice registrars: A longitudinal study. *Medical Education*, 35(8), 748-756.
- Greiner, A. L., & Conklin, J. (2015). Breaking bad news to a pregnant woman with a fetal abnormality on ultrasound. *Obstetrical and Gynecological Survey*, 70(1), 39–44.
- Grohmann, B., Brazeau-Gravelle, P., Momoli, F., Moreau, K., Zhang, T., Keely, E. J., & Raymond, J. (2013). Obstetric health-care providers’ perceptions of communicating gestational weight gain recommendations to overweight/obese pregnant women. *MIDIRS Midwifery Digest*, 23(3), 315–317. <https://doi.org/10.1258/om.2012.120003>
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-92. doi: 10.1177/1525822X05279903
- Gurzick, M., & Kesten, K. S. (2010). The impact of clinical nurse specialists on clinical pathways in the application of evidence-based practice. *Journal of Professional Nursing*, 26(1), 42-48. doi: 10.1016/j.profnurs.2009.04.003
- Hall, M.A., Zheng, B., Dugan, E., Camacho, F., Kidd, K.E., Mishra, A., & Balkrishnan, R. (2001). Measuring patients’ trust in their primary care providers. *Medical Care Research and Review*, 59(3), 293-318. doi: 10.1177/1077558702059003004
- Hallgrimsdottir, H.K., & Benner, B.E. (2014). “Knowledge is power”: Risk and the moral responsibilities of the expectant mother at the turn of the twentieth century. *Health, Risk, & Society*, 15(1), 7-21.
- Halloran, S. M. (1982). Aristotle’s concept of ethos, or if not his somebody else’s. *Rhetoric Review*, 1(1), 58–63.
- Halpern, J. (2007). Empathy and patient-physician conflicts. *Journal of General Internal Medicine*, 22(5), 696-700. doi: 10.1007/s11606-006-0102-3
- Haug, M. R., & Lavin, B. (1981). Practitioner or patient-who’s in charge? *Journal of Health and Social Behavior*, 22(3), 212-229.

- Hawley, G., Jackson, C., Hepworth, J., & Wilkinson, S. A. (2014). Sharing of clinical data in a maternity setting: how do paper hand-held records and electronic health records compare for completeness? *BMC Health Services Research*, *14*, 650. <https://doi.org/10.1186/s12913-014-0650-x>
- Hermann, R. O., & Mayer, R. (1997). U.S. consumer movement: history and dynamics. In S. Brobeck (Ed.), *Encyclopedia of the consumer movement* (pp. 584-601). Santa Barbara, CA: ABC-Clio Inc.
- Hillemeier, M. M., Domino, M. E., Wells, R., Goyal, R. K., Kum, H. C., Cilenti, D.,... Basu, A. (2014). Effects of maternity care coordination on pregnancy outcomes: Propensity-weighted analyses. *Maternal and Child Health Journal*, 121–127. <http://doi.org/10.1007/s10995-014-1502-3>
- Hollway, W., & Jefferson, T. (2013). *Doing qualitative research differently: A psychosocial approach*. (2nd ed.). Los Angeles: SAGE.
- Huntington, B., & Kuhn, N. (2003). Communication gaffes: A root cause of malpractice claims. *Proceedings (Baylor University. Medical Center)*, *16*(2), 157-61.
- Institute of Medicine. (2001). Crossing the quality chasm: A new health system for the 21st century. *IOM*, (March), 1–8. <https://doi.org/10.17226/10027>
- Ishikawa, H., Hashimoto, H., & Kiuchi, T. (2013). The evolving concept of “patient-centeredness” in patient-physician communication research. *Social Science and Medicine*, *96*, 147–153. <https://doi.org/10.1016/j.socscimed.2013.07.026>
- Jasinski, J. (2001). *Sourcebook on rhetoric* (Vol. 4). Thousand Oaks: Sage Publications.
- Jefford, E., & Sundin, D. (2013). Post-structural feminist interpretive interactionism. *Nurse Researcher*, *21*(1), 14–22. Doi: 10.7748/nr2013.09.21.1.14.e303
- Joffe, H. (2012). Thematic analysis. In D. Harper & A. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 209–223). Chichester: Wiley-Blackwell.
- Johnson, G. L., & Ramaprasad, A. (2000). Patient-physician relationships in the information age. *Marketing Health Services*, *20*(1), 20–27.
- Johnson, M. (2015). Embodied understanding. *Frontiers in Psychology*, *6*, 875. doi: 10.3389/fpsyg.2015.00875
- Junewicz, A., & Youngner, S. J. (2015). Patient-satisfaction surveys on a scale of 0 to 10: Improving health care, or leading it astray? *Hastings Center Report*, *45*(3), 43–51. <https://doi.org/10.1002/hast.453>
- Katz, D., & Kahn, R. L. (1978). *The social psychology of organizations* (Vol. 2). New York: Wiley.

- Kee, J. W. Y., Khoo, H. S., Lim, I., & Koh, M. Y. H. (2017). Communication skills in patient-doctor interactions: Learning from patient complaints. *Health Professions Education, 4*(2), 97–106. <https://doi.org/10.1016/j.hpe.2017.03.006>
- Khan, Z.A., Sivakumar, S., Phillips, W., & Aslam, N. (2014). A new patient monitoring framework and Energy-aware Peering Routing Protocol (EPR) for body area network communication. *Journal of Ambient Intelligence and Humanized Computing, 5*(3), 409–423. <https://doi.org/10.1007/s12652-013-0195-6>
- Koschmann, M. A., & McDonald, J. (2015). Organizational rituals, communication, and the question of agency. *Management Communication Quarterly, 29*(2), 229–256. <https://doi.org/10.1177/0893318915572386>
- Krone, K. J., Jablin, F. M., & Putnam, L. L. (1987). Communication theory and organizational communication: Multiple perspectives. In *The Handbook of Organizational Communication: An interdisciplinary perspective* (pp. 18–40). Thousand Oaks: Sage Publications.
- Kuppermann, M., Little, M. O., Harris, L. H., Kukla, R., & Kuppermann, M. (2009). *Risk and the pregnant body. Hastings Center Report.*
- Lagerwey, M.D. (1999). Nursing, social contexts, and ideologies in the early United States birth control movement. *Nursing Inquiry, 6* (4), 250–258.
- Laine, C., & Davidoff, F. (1996). Patient-centered medicine: A professional evolution. *Journal of the American Medical Association, 275*, 152-156.
- Lambert, B.L., Street, R.L., Cegala, D.J., Smith, D.H., Kurtz, S., & Schofield, T. (1997). Provider-patient communication, patient-centered care, and the mangle of practice. *Health Communication, 9*(1), 27-43. https://doi.org/10.1207/s15327027hc0901_3
- Lay, M. (2000). *Body talk: Rhetoric, technology, reproduction / edited by Mary M. Lay ... [et al.]*. (Rhetoric of the human sciences). Madison: University of Wisconsin Press.
- Layne, L. L. (2003). Unhappy endings: A feminist reappraisal of the women's health movement from the vantage of pregnancy loss. *Social Science and Medicine, 56*(9), 1881–1891. [https://doi.org/10.1016/S0277-9536\(02\)00211-3](https://doi.org/10.1016/S0277-9536(02)00211-3)
- Layne, L. L. (2006). Pregnancy and infant loss support: A new, feminist, American, patient movement? *Social Science and Medicine, 62*(3), 602–613. <https://doi.org/10.1016/j.socscimed.2005.06.019>
- Lazar, M. (2005). *Feminist critical discourse analysis: Gender, power, and ideology in discourse*. London: Palgrave MacMillan.
- Leavitt, J. W. (1980). Birthing and anesthesia: The debate over twilight sleep. *Women: Sex and Sexuality, 6*(2), 147–164.

- Lee, E. J., MacVarish, J., & Bristow, J. (2010). Risk, health and parenting culture. *Health, Risk & Society*, 12(4), 293–300. <http://doi.org/10.1080/13698571003789732>
- Lee, S., Ayers, S., & Holden, D. (2012). Risk perception of women during high risk pregnancy: A systematic review. *Health, Risk & Society*, 14(6), 511–531. <http://doi.org/10.1080/13698575.2012.701277>
- Lee, S., Holden, D., & Ayers, S. (2016). How women with high risk pregnancies use lay information when considering place of birth: A qualitative study. *Women and Birth*, 29(1), e13–e17. <https://doi.org/10.1016/j.wombi.2015.07.010>
- Leeman, L., Dresang, L. T., & Fontaine, P. (2016). Hypertensive disorders of pregnancy. *American Family Physician*, 93(2), 121–127.
- Levinson, W. (1994). Physician-patient communication: A key to malpractice prevention. *JAMA*, 272(20), 1619–1620.
- Lindhardt, C. L., Rubak, S., Mogensen, O., Lamont, R. F., & Joergensen, J. S. (2013). The experience of pregnant women with a body mass index >30 kg/m² of their encounters with healthcare professionals. *Acta Obstetrica et Gynecologica Scandinavica*, 92(9), 1101–1107. <http://doi.org/10.1111/aogs.12186>
- Lines, L. M., & Lepore, M., & Weiner, J. (2015). Patient-centered, person-centered, and person-directed care: They are not the same. *Medical Care* 53(7), 561–563. doi: 10.1097/MLR.0000000000000387
- Link, E., Baumann, E., & Fruh, H. (2016). Online discourses about pregnancy : Privacy as a ‘price’ for supportive communication? *The International Journal of Communication and Health*, 8, 53–64.
- Lipkin, M., Quill, T., & Napodano, R. (1984). The medical interview: A core curriculum for residencies in internal medicine. *Annals of Internal Medicine*, 100, 277–284.
- Loftsdóttir, K. (2011). Feminist theory and that critical edge. *NORA - Nordic Journal of Feminist and Gender Research*, 19(3), 198–204. <https://doi.org/10.1080/08038740.2011.593556>
- Longest, B. B., & Darr, K. (2008). *Managing health services organizations and systems*. Baltimore: Health Professions Press.
- Lundgren, I., Karlsdóttir, S.I., & Bondas, T. (2009). Long-term memories and experiences of childbirth in a Nordic context: A secondary analysis. *International Journal of Qualitative Studies on Health and Well-being*, (4)2, 115–128. doi: 10.1080/17482620802423414
- Lupton, D. (2012). *Medicine as culture: Illness, disease, and the body*. London: Sage Publications.

- Luxford, K., Safron, D. G., & Deblanco, T. (2011). Promoting patient-centered care: A qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *International Journal for Quality in Health Care*, 23(5), 510–515. <https://doi.org/10.1093/intqhc/mzr024>
- MacDorman, M. F., & Mathews, T. J. (2010). Behind international rankings of infant mortality: How the United States compares with Europe. *International Journal of Health Services*, 40(4), 577–588. <https://doi.org/10.2190/HS.40.4.a>
- MacDorman, M. F., Mathews, T. J., & Declercq, E. (2014). Trends in out-of-hospital births in the United States, 1990-2012. *National Center for Health Statistics Data Brief* (Vol. 144).
- Marshall, J. (1993). Viewing organizational communication from a feminist perspective: A critique and some offerings. *Annals of the International Communication Association*, 16(1), 122-143. <https://doi.org/10.1080/23808985.1993.11678848>
- Martin, J. A., Hamilton, B. E., Osterman, M. J. K., Curtin, S. C., & Mathews, T. J. (2015). National vital statistics reports births : Final data for 2013. *National Vital Statistics Reports*, 64(1), 1–104.
- Martin, N. (2017). U.S. has the worst rate of maternal deaths in the developed world. Retrieved from <https://www.npr.org/2017/05/12/528098789/u-s-has-the-worst-rate-of-maternal-deaths-in-the-developed-world>
- Marvel, M. K., Epstein, R. M., Flowers, K., & Beckman, H. B. (1999). Soliciting the patient's agenda: Have we improved? *Journal of the American Medical Association*, 281(3), 283-287.
- Masse, R., Legare, F., Cote, L., & Dodin, S. (2001). The limitation of a negotiation model for perimenopausal women. *Sociology of Health & Illness*, 23(1), 44-64.
- Maxwell, J. A. (2013). *Qualitative research design: An interactive approach*. Los Angeles: SAGE.
- Mayo Clinic (2019). Preeclampsia. Retrieved from <https://www.mayoclinic.org/diseases-conditions/preeclampsia/symptoms-causes/syc-20355745>
- McCallum, C. (2005) Explaining caesarean section in Salvador da Bahia, Brazil. *Sociology of Health and Illness*, 27(2), 214–242.
- Mead, N., & Bower, P. (2000). Patient-centredness: A conceptual framework and review of the empirical literature. *Social Science and Medicine*, 51(7), 1087–1110. [https://doi.org/10.1016/S0277-9536\(00\)00098-8](https://doi.org/10.1016/S0277-9536(00)00098-8)
- Mead, N., & Bower, P. (2002). Patient-centred consultations and outcomes in primary care: A review of the literature. *Patient Education and Counseling*, 48(1), 51–61. [https://doi.org/10.1016/S0738-3991\(02\)00099-X](https://doi.org/10.1016/S0738-3991(02)00099-X)

- Mercer, S.W., Maxwell, M., Heaney, D., & Watt, G.C. (2004). The consultation and relational empathy (CARE) measure: Development and preliminary validation and reliability of an empathy-based consultation process measure. *Family Practice* 21(6), 699–705. Doi: 10.1093/fampra/cmh621
- Moore P, Meterko, M., Wright, S., Lin, H., Lowy, E., & Cleary, P. D. (2010). Mortality among patients with acute myocardial infarction: The influences of patient-centered care and evidence-based medicine. *Health Services Research*, 45(5 PART 1), 1188–1204. <https://doi.org/10.1111/j.1475-6773.2010.01138.x>
- Miller, J.B. (1988). Connections, disconnections and violations. (Working Paper No. 33). Wellesley, MA: Wellesley College.
- Mumby, D. K. (1993). Critical organizational communication studies: The next 10 years. *Communications Monographs*, 60(1), 18-25.
- Mumby, D. K. (1996). Feminism, postmodernism, and organizational communication studies. *Management Communication Quarterly*, 9(3), 259–295. <https://doi.org/10.1177/0893318996009003001>
- National Institutes of Health. (2017). What is a high-risk pregnancy? Retrieved from <https://www.nichd.nih.gov/health/topics/pregnancy/conditioninfo/Pages/high-risk.aspx>
- Ndiaye, K., Portillo, E., Ouedraogo, D., Mobley, A., & Babalola, S. (2018). High-risk advanced maternal age and high parity pregnancy : Tackling a neglected need through formative research and action. *Global Health: Science and Practice*, 6(2), 370–380. doi: 10.9745/GHSP-D-17-00417
- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1), 1–13. <https://doi.org/10.1177/1609406917733847>
- Oakley, A. (1981). Interviewing women: A contradiction in terms. In H. Roberts (Ed.), *Doing feminist research* (pp. 30-61). London: Routledge & Kegan Paul.
- Oberman, M. (2000). Mothers and doctors' orders: Unmasking the doctor's fiduciary role in maternal-fetal conflicts. *Northwestern Univ Law Review*, 94(2), 451–501.
- Olesen, V. (2011). Feminist qualitative research in the millennium's first decade: Developments, challenges, prospects. In N.K. Denzin & Y.S. Lincoln (Eds.) *The SAGE Handbook of Qualitative Research* (pp. 129–146). Thousand Oaks, CA: Sage Publications.
- O'Connor, A. M. (1995). Validation of a decisional conflict scale. *Medical Decision Making*, 15(1), 25-30.

- Oliveira, V. C., Ferreira, M. L., Pinto, R. Z., Filho, R. F., Refshauge, K., & Ferreira, P. H. (2015). Effectiveness of training clinicians' communication skills on patients' clinical outcomes: A systematic review. *Journal of Manipulative and Physiological Therapeutics*, 38(8), 601–616. <https://doi.org/10.1016/j.jmpt.2015.08.002>
- O'Malley, J.A., Zaslavsky, A.M., Hays, R.D., Hepner, K.A., Keller, S. and Cleary, P.D. (2005). Exploratory factor analyses of the HCAHPS hospital pilot survey responses across and within medical, surgical, and obstetric services. *Health Services Research*, 40(6), 2078-2095. doi: 10.1111/j.1475-6773.2005.00471.x
- Ong, L.M.L., De Haes, J. C. J. M., Hoos, A. M., & Lammes, F. B. (1995). Doctor-patient communication: a review of the literature. *Social Science & Medicine*, 40(7), 903–918. [https://doi.org/10.1016/0277-9536\(94\)00155-M](https://doi.org/10.1016/0277-9536(94)00155-M)
- O'Reilly, M., & Parker, N. (2012). Unsatisfactory saturation: A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research Journal*, 1-8. doi: 10.1177/1468794112446106
- Osterberg, L. and Blaschke, T. (2005). Adherence to medication. *New England Journal of Medicine*, 353(5), 487-497. doi: 10.1056/NEJMra050100
- Owens, K. H. (2015). *Writing childbirth: Women's rhetorical agency in labor and online*. Carbondale: SIU Press.
- Parsons, T. (1951). Illness and the role of the physician: a sociological perspective. *American Journal of Orthopsychiatry*, 21(3), 452-460.
- Pierce, J.B. (2008). Science, advocacy, and the sacred and intimate things of life: representing motherhood as a progressive era cause in women's magazines. *American Periodicals: A Journal of History, Criticism, and Bibliography*, 18(1), 69–95.
- Pinto, R. Z., Ferreira, M. L., Oliveira, V. C., Franco, M. R., Adams, R., Maher, C. G., & Ferreira, P. H. (2012). Patient-centered communication is associated with positive therapeutic alliance: A systematic review. *Journal of Physiotherapy*, 58(2), 77–87. [https://doi.org/10.1016/S1836-9553\(12\)70087-5](https://doi.org/10.1016/S1836-9553(12)70087-5)
- Putnam, L. L. (1982). Paradigms for organizational communication research: An overview and synthesis. *Western Journal of Speech Communication: WJSC*, 46(2), 192-206. doi: 10.1080/10570318209374077
- Putnam, L. L. (1983). The interpretive perspective: An alternative to functionalism. L. L. Putnam & M.E. Pacanowsky (Eds.) *Communication and organization: An interpretive approach*. Beverly Hills: Sage Publications.
- Raymond, K. M., Smith, P. C., Hopfer, C. J., Carrico, J. A., Sakai, J. T., Mims, L., ... Bartels, K. (2018). The association of patient satisfaction-based incentives with primary care physician opioid prescribing. *The Journal of the American Board of Family Medicine*, 31(6), 941–943. <https://doi.org/10.3122/jabfm.2018.06.180067>

- Redding, W. C. (1979). Organizational communication theory and ideology: An overview. *Annals of the International Communication Association*, 3(1), 309-342.
- Reeder, L. G. (1972). The patient-client as a consumer: Some observations on the changing professional-client relationship. *Journal of Health and Social Behavior*, 13(4), 406-412.
- Reszel, J. (2014). Young women's experiences of expected health behaviors during pregnancy: The importance of emotional support. *Journal of Community Health Nursing*, 70(1), 39-44.
- Riley, J. B. (2015). *Communication in nursing*. St. Louis: Elsevier Health Sciences.
- Robeznieks, A. (2015). U.S. has highest maternal death rate among developed countries. Retrieved from <http://www.modernhealthcare.com/article/20150506/NEWS/150509941>
- Roter, D. (2000). The enduring and evolving nature of the patient-physician relationship. *Patient Education and Counseling*, 39(1), 5-15.
- Roter, D. L., & Hall, J. A. (2006). *Doctors talking with patients/patients talking with doctors: Improving communication in medical visits* (2nd ed.). Westport, CT: Praeger Publishers.
- Rothman, B. K. (2014). Editorial: Pregnancy, birth, and risk: an introduction. *Health, Risk & Society* 16(1-2), 1-6. <https://doi.org/10.1080/13698575.2013.876191>
- Rowland, P., McMillan, S., McGillicuddy, P., & Richards, J. (2017). What is “the patient perspective” in patient engagement programs? Implicit logics and parallels to feminist theories. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 21(1), 76–92. <https://doi.org/10.1177/1363459316644494>
- Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data*. Thousand Oaks: SAGE.
- Rubinelli, S. (2013). Rational versus unreasonable persuasion in doctor-patient communication: A normative account. *Patient Education and Counseling*, 92(3), 296-301. <https://doi.org/10.1016/j.pec.2013.06.005>
- Ruhl, L. (1999). Liberal governance and prenatal care: risk and regulation in pregnancy. *Economy and Society*, 28(1), 95–117. <http://doi.org/10.1080/03085149900000026>
- Sadler, G.R., Lee, H.C., Lim, R.S., & Fullerton, J. (2010). Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. *Nursing and Health Sciences*, 12(3), 369–374. <https://doi.org/10.1111/j.1442-2018.2010.00541.x>
- Scamell, M., & Alaszewski, A. (2012). Fateful moments and the categorisation of risk: Midwifery practice and the ever-narrowing window of normality during childbirth. *Health, Risk & Society*, 14(2), 207–221. <https://doi.org/10.1080/13698575.2012.661041>

- Scamell, M., & Stewart, M. (2014). Time, risk and midwife practice: The vaginal examination. *Health, Risk & Society, 16*(1), 84-100. <https://doi.org/10.1080/13698575.2013.874549>
- Scherger, J. E. (2009). Future Vision: Is Family Medicine Ready for Patient-directed Care? *Family Medicine, 41*(4), 285–288.
- Scott, J. B., Segal, J. Z., & Keränen, L. (2013). The rhetorics of health and medicine: Inventional possibilities for scholarship and engaged practice. *Porio, 9*(1), 106. doi: 10.13008/2151-2957.1157
- Seigel, M. (2014). *The rhetoric of pregnancy*. Chicago: University of Chicago Press.
- Shapiro, J., & Ross, V. (2002). Applications of narrative theory and therapy to the practice of family medicine. *Family Medicine, 34*(2), 96-100.
- Shoebridge, A. (2015). Cohesion, collaboration, and communication in healthcare. *Healthcare, (June)*, 42–48.
- Smith, R. C. (2002). *Patient centered interviewing: An evidence-based method* (2nd ed.). Philadelphia, PA: Lippincott Williams & Wilkins.
- Smith, R.C., & Hoppe, R.B. (1991). The patient's story: Integrating the patient- and physician-centered approaches to interviewing. *Annals of Internal Medicine, 115*(6), 470-477.
- Spender, D. (1982). *Women of ideas: And what men have done to them: From Aphra Behn to Adrienne Rich*. London: Routledge & Kegan Paul, PLC.
- Steffensen, S. V. (2012). Care and conversing in dialogical systems. *Language Sciences, 34*(5), 513-531.
- Stewart, M., Brown, J. B., Boon, H., Galajda, J., Meredith, L., & Sangster, M. (1999). Evidence on patient-doctor communication. *Cancer Prevention & Control, 3*(1), 25-30.
- Stewart, M., Brown, J. B., Freeman, T., Weston, W., & McWilliam, C. (2009). A perfect fit. *Canadian Family Physician/Medecin de Famille Canadien, 55*(4), 351.
- Stoff, B. K., & Swerlick, R. A. (2013). Reframing risk part II: Methods for improving medical risk communication. *Journal of the American Academy of Dermatology, 69*(4), 637–639. <https://doi.org/10.1016/j.jaad.2013.02.026>
- Street, R. L. (2013). How clinician-patient communication contributes to health improvement: Modeling pathways from talk to outcome. *Patient Education and Counseling, 92*(3), 286–291. <https://doi.org/10.1016/j.pec.2013.05.004>
- Street, R. L., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counseling, 74*(3), 295-301.

- Strong, D. M., Johnson, S. A., Tulu, B., Trudel, J., Volkoff, O., Pelletier, L. R., ... & Garber, L. (2014). A theory of organization-EHR affordance actualization. *Journal of the Association for Information Systems*, 15(2), 53. <https://aisel.aisnet.org/jais/vol15/iss2/2>
- Swanson, K.M., Karmali, Z.A., Powell, S.H., Pulvermakher, F. (2003). Miscarriage effects on couples' interpersonal and sexual relationships during the first year after loss: Women's perceptions. *Psychosomatic Medicine*, 65(5), 902-910.
- Tabatabaei, S. M., Moakhar, Z.S., Pour, F.B., Mollashahi, S.S., & Zaboli, M. (2015). Hospitalized pregnant women who leave against medical advice: Attributes and reasons. *Maternal and Child Health Journal*, 20(1), 128–138. <http://doi.org/10.1007/s10995-015-1811-1>
- Taylor, J. R., Flanagin, A. J., Cheney, G., & Seibold, D. R. (2001). Organizational communication research: Key moments, central concerns, and future challenges *Annals of the International Communication Association*, 24(1), 99-137. <https://doi.org/10.1080/23808985.2001.11678983>
- Tinetti, M.E., Naik, A.D., & Dodson, J.A. (2016). Moving from disease-centered to patient goals-directed care for patients with multiple chronic conditions: Patient value-based care. *JAMA Cardiology*, 1(1), 9-10. doi: 10.1001/jamacardio.2015.0248
- Toller, P. (2011). Bereaved parents' experiences of supportive and unsupportive communication. *Southern Communication Journal*, 76(1), 17–34. <http://doi.org/10.1080/10417940903159393>
- Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10), 837–851. <http://doi.org/10.1177/1077800410383121>
- Tracy, S. J. (2013). *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact*. Malden, MA: Wiley-Blackwell.
- Tucker, W.H., (1998). Keeping America sane: Psychiatry and eugenics in the United States and Canada, 1880–1940. *Journal of the American Medical Association*, 279 (6), 477–478.
- Turner, P. K. (2003). Telling the story of birth. In R.P. Clair (Ed.) *Expressions of ethnography: Novel approaches to qualitative methods* (pp. 153–158). New York: SUNY Press.
- Turner, P. K. (2011). You are doing it wrong: Voicing child/research birthing choices. *Qualitative Inquiry*, 17(9), 763–768. <http://doi.org/10.1177/1077800411423191>
- Turner, P. K., & Norwood, K. (2013). Unbounded motherhood. *Management Communication Quarterly*, 27(3), 396–424. <https://doi.org/10.1177/0893318913491461>
- University of California San Francisco. (2017). High-risk pregnancy. Retrieved from https://www.ucsfhealth.org/conditions/high-risk_pregnancy/

- Venetis, M. K., Robinson, J. D., Turkiewicz, K. L., & Allen, M. (2009). An evidence base for patient-centered cancer care: A meta-analysis of studies of observed communication between cancer specialists and their patients. *Patient Education and Counseling*, 77(3), 379-383.
- Walker, J.L. (2012). The use of saturation in qualitative research. *Canadian Journal of Cardiovascular Nursing*, 22(2), 37-46.
- Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. New York: Routledge.
- Wensing, M. (2000). Modern measurement for a modern health service. *Quality in Health Care*, 9, 199–202. <https://doi.org/10.1136/qhc.9.4.200>
- Wertz, F. J., Charmaz, K., McMullen, L., Josselson, R., Anderson, R., McSpadden, E. (2011). *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry*. New York: Guilford Press.
- What is a high-risk pregnancy? (2017). Retrieved from <https://www.nichd.nih.gov/health/topics/pregnancy/conditioninfo/high-risk>
- Wieringa, S. E. (1994). Women's interests and empowerment: Gender planning reconsidered. *Development and Change*, 25(4), 829–848.
- Wieringa, S. E. (1998). Rethinking gender planning : A critical discussion of the use of the concept of gender. *Gender, Technology and Development* 1(2), 349–371.
- Willis, J.W. (2007). *Foundations of qualitative research: Interpretive and critical approaches*. Thousand Oaks: Sage Publications.
- Winefield, H., Murrell, T., Clifford, J., & Farmer, E. (1996). The search for reliable and valid measures of patient-centredness. *Psychology and Health*, 11(6), 811-824. <https://doi.org/10.1080/08870449608400277>
- Witz, A. (2000). Whose body matters? Feminist sociology and the corporeal turn in sociology and feminism. *Body and Society* 6(2): 1–24.
- World Health Organization. (2000). Health systems: Improving performance. Retrieved from: <http://www.who.int/whr/2000/en/>
- World Health Organization. (2019). Maternal Health. Retrieved from <https://www.who.int/maternal-health/en/>
- Yasin, M. M., Meacham, K. A., & Alavi, J. (1998). The status of TQM in healthcare. *Health Marketing Quarterly*, 15(3), 61-84.

APPENDIX A. DEMOGRAPHIC SURVEYS**Patient Demographic Survey**

DIRECTIONS: Please circle or fill in the appropriate response to each question.

1. What is your age? _____

3. What is the highest level of education you have completed?
 Some high school
 High school
 Associates degree, diploma, certificate, etc.
 Some college
 Bachelors degree
 Masters degree
 PhD/or other advanced professional degree (e.g., DDS, JD, MD)

4. What is your ethnicity? Please check all that apply.
 African American/Black
 Latino/Latina
 White/Caucasian
 Native American or Alaskan Native
 Pacific Islander/Hawaiian Native
 Asian/Asian American
 Other (Please Specify): _____

4. What is your marital status?
 Single, never married
 Married
 Legally separated
 Divorced
 Widowed

5. What is your employment status?

- Work Part Time
 Work Full-Time
 Work in the home/homemaker
 Unemployed

6. What is the range of annual income for your household?

- Less than \$30,000
 \$30,000 to \$50,000
 \$51,000 to \$75,000
 \$75,000 to \$100,000
 \$101,000 to \$150,000
 Greater than \$150,000

7. How many pregnancies have you experienced? _____

8. For each pregnancy, please identify the outcome. Use the additional space below if needed.

Pregnancy #1.

- Termination/Abortion
 Spontaneous abortion/miscarriage (Fewer than 20 weeks)
 Stillbirth (greater than 20 weeks)
 Live birth with complications
 Healthy live birth

Pregnancy #2.

- Termination/Abortion
 Spontaneous abortion/miscarriage (Fewer than 20 weeks)
 Stillbirth (greater than 20 weeks)
 Live birth with complications
 Healthy live birth

Pregnancy #3.

- Termination/Abortion
 Spontaneous abortion/miscarriage (Fewer than 20 weeks)

- Stillbirth (greater than 20 weeks)
- Live birth with complications
- Healthy live birth

Pregnancy #4.

- Termination/Abortion
- Spontaneous abortion/miscarriage (Fewer than 20 weeks)
- Stillbirth (greater than 20 weeks)
- Live birth with complications
- Healthy live birth

Pregnancy #5.

- Termination/Abortion
- Spontaneous abortion/miscarriage (Fewer than 20 weeks)
- Stillbirth (greater than 20 weeks)
- Live birth with complications
- Healthy live birth

Pregnancy #6.

- Termination/Abortion
- Spontaneous abortion/miscarriage (Fewer than 20 weeks)
- Stillbirth (greater than 20 weeks)
- Live birth with complications
- Healthy live birth

Pregnancy #7.

- Termination/Abortion
- Spontaneous abortion/miscarriage (Fewer than 20 weeks)
- Stillbirth (greater than 20 weeks)
- Live birth with complications
- Healthy live birth

Pregnancy #8.

- Termination/Abortion
- Spontaneous abortion/miscarriage (Fewer than 20 weeks)
- Stillbirth (greater than 20 weeks)
- Live birth with complications
- Healthy live birth

Pregnancy #9.

- Termination/Abortion
- Spontaneous abortion/miscarriage (Fewer than 20 weeks)
- Stillbirth (greater than 20 weeks)
- Live birth with complications
- Healthy live birth

Pregnancy #10.

- Termination/Abortion
- Spontaneous abortion/miscarriage (Fewer than 20 weeks)
- Stillbirth (greater than 20 weeks)
- Live birth with complications
- Healthy live birth

NOTE: Of the pregnancies listed above, please circle which ones, if any, were identified as a “high-risk pregnancy” by a healthcare provider.

Provider Demographic Survey

DIRECTIONS: Please circle or fill in the appropriate response to each question.

1. What is your age? _____
2. What is your gender? (Circle)
 Male Female Other (please specify):
3. What is your ethnicity? Please check all that apply.
 African American/Black
 Latino/Latina
 White/Caucasian
 Native American or Alaskan Native
 Pacific Islander/Hawaiian Native
 Asian/Asian American
 Other (Please Specify): _____
4. What is your job title or occupation?
 Physician
 Nurse Practitioner
 Certified Nurse-Midwife
 Physician Assistant
 Other (Please Specify): _____
5. How long have you been practicing medicine? _____
6. How frequently do you work with patients experiencing high-risk pregnancies?
 Never
 Rarely (5-10% annually)
 Sometimes (10-30% annually)
 Often (30-50% annually)
 Frequently (greater than 50% annually)
7. How many children do you have? _____
8. Have you or a significant other experienced a high-risk pregnancy? YES NO

APPENDIX B. INTERVIEW PROTOCOLS

Patient Interview Protocol

1. Can you share with me your story about your high-risk pregnancy?
 - a. When did you first become aware that you were experiencing a high-risk pregnancy?
2. What type of healthcare provider did you work with? How did that change and your pregnancy progressed?
3. Regarding delivery options and choices, how did knowing about potential risks impact your decisions?
4. When you met with your healthcare provider, what was most important to you to discuss?
5. Please share with me your understanding of risk factors in your pregnancy
 - a. How did you know about this?
 - b. Where did you go to find out information?
6. What do you wish your provider would have discussed with you?
7. Is there anything you wish your provider would not have discussed with you?
8. Did you experience any problems or stresses based on what you and your provider talked about during your high-risk pregnancy? If so, would you please share those with me?
9. Do you feel you were in control of pregnancy related decisions? If so, please explain. If not, please explain.
10. How much power did you have regarding decisions during your pregnancy?
 - a. Who do you think held the most power?
11. In your ideal world, how would you and your provider have worked together during your pregnancy?
12. What are your overall feelings about how your healthcare provider communicated with you during your pregnancy and delivery (if applicable)?
13. We are coming to a close. Is there anything else you'd like to share with me at this time?

Provider Interview Protocol

1. How would you define a high-risk pregnancy?
2. How frequently do you work with high-risk pregnancy patients?
 - a. What role do you typically fill?
 - b. What types of interactions do you have with high-risk pregnancy patients? (e.g. phone, office visits, MyChart, etc.)
3. When you think about communicating about pregnancy risk with a patient, what do you think of?
4. What types/sources of information do you think patients should have? Not have?
5. What kinds of training related to communicating about high-risk pregnancy did you receive?
6. Can you tell me about a time when communication with a high-risk pregnant patient went well? What happened?
7. Can you tell me about a time when communication with a high-risk pregnant patient did not go so well? What happened?
8. What do you think is the biggest barrier to communicating with these patients?
9. What factors (e.g. liability, personal experiences, etc.) impact how you discuss risk with patients?
10. Did you experience any problems or stresses based on what you and patients talked about regarding high-risk pregnancy?
 - a. If so, would you please share those with me?
11. How much power did you have regarding decisions during your patients' pregnancy?
 - a. Who do you think held the most power?
12. In your ideal world, how would you and your patients work together in high-risk pregnancy situations?
13. We are coming to a close. Is there anything else you'd like to share with me at this time?

APPENDIX C. PROFILES OF RESEARCH PARTICIPANTS

Profiles of Research Participants: Patients

| Name | Age | Education | Ethnicity | Marital Status | Employ | Income | # of Preg |
|-----------|-----|--------------|------------------|----------------|-----------|---------|-----------|
| Emma | 35 | PhD | Caucasian | Married | Full-Time | 30-50 | 1 |
| Olivia | 32 | Masters | Caucasian | Married | Full-Time | 75-100 | 1 |
| Ava | 35 | PhD | Caucasian | Married | Full-Time | 101-150 | 4 |
| Lily | 30 | Associate | Caucasian | Married | Homemaker | 51-75 | 1 |
| Mia | 32 | Bachelors | Caucasian | Married | Full-Time | 101-150 | 2 |
| Sophie | 38 | PhD | Caucasian | Married | Full-Time | 51-75 | 2 |
| Charlotte | 31 | PhD | Caucasian | Married | Full-Time | 101-150 | 4 |
| Paisley | 32 | PhD | Caucasian | Married | Full-Time | 51-75 | 2 |
| Madison | 34 | Bachelors | Caucasian | Married | Full-Time | 75-100 | 2 |
| Morgan | 45 | Some college | Caucasian | Married | Homemaker | 101-150 | 7 |
| Patty | 31 | Masters | Caucasian | Married | Full-Time | 51-75 | 2 |
| Evelyn | 32 | Bachelors | Caucasian | Divorced | Full-Time | 51-75 | 6 |
| Scarlett | 38 | Bachelors | Caucasian | Married | Part-Time | 51-75 | 2 |
| Victoria | 36 | Some college | Caucasian | Married | Homemaker | 150 + | 3 |
| Grace | 34 | Bachelors | Caucasian | Married | Full-Time | 75-100 | 3 |
| Esmerelda | 42 | Bachelors | Asian American | Married | Full-Time | 150 + | 4 |
| Camila | 32 | Masters | Caucasian | Married | Full-time | 101-150 | 2 |
| Penelope | 39 | Bachelors | Caucasian | Married | Full-time | 75-100 | 2 |
| Layla | 36 | PhD | Caucasian | Married | Full-Time | 75-100 | 3 |
| Nora | 34 | PhD | Caucasian | Married | Part-time | 51-75 | 3 |
| Zoey | 42 | PhD | African American | Married | Full-Time | 101-150 | 4 |

| Name | Age | Education | Ethnicity | Marital Status | Employ | Income | # of Preg |
|---------|-----|-----------|-------------------|----------------|-----------|---------|-----------|
| Hannah | 37 | PhD | Caucasian | Married | Full-time | 75-100 | 1 |
| Kim | 40 | Bachelors | Caucasian | Married | Homemaker | 75-100 | 5 |
| Addison | 34 | Masters | Caucasian | Married | Full-Time | 101-150 | 1 |
| Luna | 38 | Bachelors | Caucasian | Married | Full-Time | 75-100 | 3 |
| Hazel | 33 | Masters | Caucasian | Married | Full-Time | 75-100 | 7 |
| Violet | 34 | PhD | Caucasian | Married | Part-time | 51-75 | 3 |
| Allison | 44 | PhD | Caucasian | Separated | Full-Time | 150+ | 1 |
| Quinn | 36 | PhD | Caucasian | Married | Full-Time | 75-100 | 3 |
| Ruby | 36 | Bachelors | Asian American | Divorced | Full-time | 51-75 | 4 |
| Sadie | 28 | Bachelors | Caucasian | Married | Full-Time | 75-100 | 2 |
| Lydia | 35 | Masters | Caucasian | Married | Full-Time | 101-150 | 3 |

* To protect participants' confidentiality, pseudonyms are used.

Profiles of Research Participants: Providers

| Name | Age | Gender | Provider Type | Ethnicity | Years of Practice | # of Children | History of HRP? |
|-----------|-----|--------|---------------|-----------|-------------------|---------------|-----------------|
| Isabella | 48 | Female | Midwife/NP | Caucasian | 32 | 1 | No |
| Dr. Mayn | 62 | Female | Physician | Caucasian | 38 | 2 | No |
| Dr. Fern | 75 | Female | Physician | Caucasian | 50 | 1 | No |
| Dr. Smith | 46 | Male | Physician | Caucasian | 22 | 2 | No |
| Mary | 54 | Female | Midwife/NP | Caucasian | 26 | 2 | No |
| Logan | 38 | Female | Midwife/NP | Caucasian | 12 | 2 | No |

* To protect participants' confidentiality, pseudonyms are used.

APPENDIX D. INFORMED CONSENT DOCUMENTS

Informed Consent Document: Patients

- Title of Study:** Patient-Provider Communication During High-Risk Pregnancy
- Investigator:** Laura Jackman is a PhD student in the Rhetorical and Professional Communication program at Iowa State University.
This is a research study. Please take your time in deciding if you would like to participate.
- Introduction:** The purpose of this study is to explore the ways in which patients and healthcare providers communicate with each other regarding high-risk pregnancy. Specifically, we aim to identify what priorities each group places upon student assessment to determine how the business communication curriculum can be improved. You are being invited to participate in this study because you have experienced at least one high-risk pregnancy.
- Description of Procedures:** If you agree to participate, you will be asked to participate in an interview with the primary investigator. You will be asked demographic information about you such as age, number of pregnancies, pregnancy outcomes and education level. Then you will be asked a series of open-ended questions about your experiences communicating with healthcare providers about high-risk pregnancy.
- Duration:** The interviews should take approximately 45 minutes to complete.
- Risk:** Some of the questions asked may be upsetting, or you may feel uncomfortable answering them. If you do not wish to answer a question, you may skip it and go to the next question. Some of the questions asked may make you angry, emotionally upset, or stressed out now or at a later time. If this occurs, you can contact your primary care provider, a qualified mental health professional, or the Health and Human Services hotline at 800-273-8255.
- Benefits:** There may be no personal benefit to your participation in the study but the knowledge received may be valuable to improving healthcare communication for future patients and healthcare providers.
- Costs and compensation:** You will not have any costs from participating in this study.
You will be eligible for a raffle to win a \$20 Amazon.com gift card. Five people among the participants of this study will receive a gift card.
- Participant Rights:** Your participation in this study is completely voluntary. You are free to stop your participation at any point. If you decide not to participate in the study or leave the study early, it will not result in any penalty or loss of benefits to which you are otherwise entitled.
- Anonymity:** Your responses will remain confidential and a pseudonym will be used in place of their real name. Additionally, details such as location or name of the care facility will be replaced with more generic, unidentifiable information. Your data and

consent form will be kept separate. Your consent form will be stored in a locked location on Iowa State University property and will not be disclosed to third parties. Each participant will be assigned a pseudonym/fake name and no additional personally identifiable information will be stored with your responses. Data will be collected on a secure server and then downloaded to a password protected computer. Data will be stored electronically while in use.

Questions or problems:

If you have any questions about this study, feel free to contact Laura Jackman at ljackman@iastate.edu. You may also contact supervising faculty member for this research study, Dr. Stacy Tye-Williams, at styewill@iastate.edu .

If you have any questions about your rights as a research participant, please contact the Campus IRB (Institutional Review Board) Administrator, (515) 294-4566, IRB@iastate.edu, or Director, (515) 294-3115, Office of Responsible Research, Iowa State University, Ames Iowa 50011.

Verbal Consent:

Do you have any questions about this research? Do you agree to participate and may I record our discussion?

Informed Consent Document: Providers

- Title of Study:** Patient-Provider Communication During High-Risk Pregnancy
- Investigator:** Laura Jackman is a PhD student in the Rhetorical and Professional Communication program at Iowa State University.
This is a research study. Please take your time in deciding if you would like to participate.
- Introduction:** The purpose of this study is to explore the ways in which patients and healthcare providers communicate with each other regarding high-risk pregnancy. Specifically, we aim to identify what priorities each group places upon student assessment to determine how the business communication curriculum can be improved. You are being invited to participate in this study because you have provided healthcare to patients experiencing high-risk pregnancy.
- Description of Procedures:** If you agree to participate, you will be asked to participate in an interview with the primary investigator. You will be asked demographic information about yourself such as age, the type and length of medical practice you provide, and if you have personal experience with high-risk pregnancy. Then you will be asked a series of open-ended questions about your experiences communicating with patients about high-risk pregnancy. Only members of the research team will have access to any identifying information. If a transcriptionist is used, a confidentiality agreement will be in place to protect your identity. If you would like to read the final research report, you may provide your email address to the research team during the study.
- Duration:** The interviews should take approximately 45 minutes to complete.
- Risk:** The risks and discomfort associated with participation in this study are no greater than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.
- Benefits:** There may be no personal benefit to your participation in the study but the knowledge received may be valuable to improving healthcare communication for future patients and healthcare providers.
- Costs and compensation:** You will not have any costs from participating in this study.
You will be eligible for entry into a drawing to win a \$20 Amazon.com gift card. Five people among the participants of this study will receive a gift card.
- Participant Rights:** Your participation in this study is completely voluntary. You are free to stop your participation at any point. If you decide not to participate in the study or leave the study early, it will not result in any penalty or loss of benefits to which you are otherwise entitled.
- Anonymity:** Your responses will remain confidential and a pseudonym will be used in place of your real name. If you choose to provide the research team with your email address so you can read the final research report, your email address will be stored in a secure location along with your name. Additionally, details such as location or

name of the care facility will be replaced with more generic, unidentifiable information. Each participant will be assigned a pseudonym/fake name and no additional personally identifiable information will be stored with your responses. Data will be collected on a secure server and then downloaded to a password-protected computer. Data will be stored electronically while in use. Although all these measures are taken to protect your identity, someone familiar with your specific case may be able to identify you.

De-identified information collected about you during this study may be shared with other researchers or used for future research studies. We will not obtain additional informed consent from you before sharing the de-identified data.

Questions or problems:

If you have any questions about this study, feel free to contact Laura Jackman at ljackman@iastate.edu. You may also contact supervising faculty member for this research study, Dr. Stacy Tye-Williams, at styewill@iastate.edu.

If you have any questions about your rights as a research participant, please contact the Campus IRB (Institutional Review Board) Administrator, (515) 294-4566, IRB@iastate.edu, or Director, (515) 294-3115, Office of Responsible Research, Iowa State University, Ames Iowa 50011.

Verbal Consent:

Do you have any questions about this research? Do you agree to participate and may I record our discussion?

APPENDIX E. IRB APPROVAL MEMO

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Institutional Review Board
Office for Responsible Research
Vice President for Research
2420 Lincoln Way, Suite 202
Ames, Iowa 50014
515 294-4566

Date: 3/14/2018

To: Laura Jackman
206 Ross Hall

CC: Dr. Stacy Tye-Williams
364 Carver Hall
Dr. Tina Coffelt
348 Carver Hall

From: Office for Responsible Research

Title: Patient-Provider Communication During High-Risk Pregnancy

IRB ID: 17-607

Approval Date: 3/14/2018 **Date for Continuing Review:** 3/13/2020

Submission Type: New **Review Type:** Expedited

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University according to the dates shown above. Please refer to the IRB ID number shown above in all correspondence regarding this study.

To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- **Use only the approved study materials** in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.
- **Retain signed informed consent documents for 3 years after the close of the study**, when documented consent is required.
- **Obtain IRB approval prior to implementing any changes** to the study by submitting a Modification Form for Non-Exempt Research or Amendment for Personnel Changes form, as necessary.
- **Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences** involving risks to subjects or others; and (2) **any other unanticipated problems involving risks** to subjects or others.
- **Stop all research activity if IRB approval lapses**, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.
- **Complete a new continuing review form** at least three to four weeks prior to the **date for continuing review** as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

Please be aware that IRB approval means that you have met the requirements of federal regulations and ISU policies governing human subjects research. **Approval from other entities may also be needed.** For example, access to data from private records (e.g. student, medical, or employment records, etc.) that are protected by FERPA, HIPAA, or other confidentiality policies requires permission from the holders of those records. Similarly, for research conducted in institutions other than ISU (e.g., schools, other colleges or universities, medical facilities, companies, etc.), investigators must obtain permission from the institution(s) as required by their policies. **IRB approval in no way implies or guarantees that permission from these other entities will be granted.**

Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 202 Kingland, to officially close the project.

Please don't hesitate to contact us if you have questions or concerns at 515-294-4566 or IRB@iastate.edu.