COMMUNICATIVE NEEDS OF PATIENTS WHO EXPERIENCE MISCARRIAGE: UNDERSTANDING HEALTHCARE COMMUNICATION AND REPRODUCTIVE SELF-EFFICACY

by

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Note: We sometimes use “women” and “mothers” when referring to people who are or were pregnant or who gave birth. We acknowledge that not all people who become pregnant or give birth identify as “woman” or “female.”

ABSTRACT

KANDICE LACCI-REILLY. Communicative Needs of Patients who Experience Miscarriage: Understanding Healthcare Communication and Reproductive Self-efficacy (Under the direction of DR. LARISSA R. BRUNNER HUBER and DR. MARGARET M. QUINLAN)

Miscarriage, defined as pregnancy loss in the first 20 weeks of gestation, is a profound and individualized experience. It is estimated to occur in up to one in four pregnancies, resulting in approximately one million miscarriages annually in the US alone. Consequences of miscarriage include poor psychological health outcomes, such as depression and anxiety, and physiological effects, such as recurrent miscarriage and other complications for subsequent pregnancies. Experiencing a miscarriage may also hinder one's ability to try to conceive again by undermining their reproductive confidence.

The literature on miscarriage is increasing; however, studies concerning patients' communicative needs are limited. The following research aimed at understanding the context around communication from one's healthcare team during a miscarriage and perceptions of grief and self-efficacy related to reproductive goals. This three-manuscript dissertation project contributes to efforts to improve miscarriage care throughout the entirety of healthcare interactions.

My first manuscript produced a scoping review of original, peer-reviewed research on healthcare communication and miscarriage conducted in the US. This synthesis provided an overview of the relationship between healthcare communication and miscarriage experiences and identified the potential knowledge gaps for future miscarriage studies. Data were charted according to Arksey and O'Malley's Scoping Review Framework. Three primary themes emerged relating to patient-centered care, the overmedicalization of miscarriage, and informed

decision-making. This manuscript presented a foundational understanding of these concepts, which informs my second two manuscripts.

In my second manuscript, I used semi-structured individual interviews to understand the perceptions and experiences of healthcare communication by women who have had a miscarriage. A phenomenological approach was used to recognize and comprehend how participants reflect on their individualized experiences of miscarriage in the healthcare setting. Interviews with 12 participants revealed valuable context regarding the care received during and after a miscarriage and a patient’s sense of reproductive self-efficacy (RSE). Findings from this study point to three ways that providers can optimize a patient’s sense of RSE: (1) reassure patients of their long-term reproductive goals and discuss implications of miscarriage; (2) provide guidance for a patient’s next steps; and (3) provide patient-centered care that is empathetic to a patient’s pregnancy history.

The semi-structured interviews for manuscript two were also used to inform my final manuscript, which sought to explore how knowledge, expectations, and perceptions of miscarriage change throughout the pregnancy experience as impacted by the healthcare team. We mapped our findings onto a journey map, emphasizing four opportunities for healthcare teams to improve miscarriage management: (1) engage in conversations about miscarriage and missed miscarriage with patients before they get pregnant and in early pregnancy; (2) avoid potentially triggering contexts such as waiting rooms full of pregnant people or exam rooms where miscarriages were diagnosed; (3) acknowledge the emotional impacts of miscarriage in subsequent care; and (4) be aware of pregnancy-related anxiety and allow for additional screening and/or appointments in subsequent pregnancies.

ACKNOWLEDGEMENTS

I want to express my appreciation to my dissertation committee and co-chairs who have provided invaluable support and feedback throughout this process. This research would also not have been possible without support from the UNC Charlotte Department of Public Health Sciences, who financed my research.

Further, words cannot express how grateful I am for the participants who shared their stories with me for this dissertation project. There is no progress without proper reflection and evaluation of current practices. I am honored to be a keeper of your stories.

DEDICATION

This dissertation is dedicated to the following:

To Dr. Huber, who has kept me afloat along this journey and
has always been much more than an advisor,

To my husband, who never stops reminding me of
all the great things I will do one day,

To the women whose stories I will hold in my heart
and that fill these pages,

And to the five heaven babies who inspired this work.

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List of Abbreviations

ACOG	American College of Obstetrics & Gynecology
IDM	Informed decision-making
IPA	Interpretive phenomenological analysis
OB/GYN	Obstetrician/gynecologist
PCC	Patient-centered communication
PGITF	Perinatal Grief Intensity Theoretical Framework
PI	Primary investigator
RADaR	Rigorous and Accelerated Data Reduction
RSE	Reproductive self-efficacy

Chapter 1: Introduction

Miscarriage is a profound and individualized loss in which a woman mourns not only her child but also a future for which she was planning and, potentially, her identity as a mother (Van Aerde, 2001). Miscarriage is defined by the American College of Obstetricians and Gynecologists (ACOG) as the involuntary loss of an intrauterine pregnancy prior to 20 weeks of gestation (Prager et al., 2018). It is estimated that between 10-25% of pregnancies end in miscarriage (Farren et al., 2016; Prager et al., 2018) and approximately 80% of pregnancy losses occur within the first 20 weeks, making it the most common type of pregnancy loss (ACOG, 2018; World Health Organization [WHO], 2021). Approximately 23 million miscarriages occur annually, though this number may be underestimated due to lack of reporting (Quenby et al., 2021). In addition, individuals may also mistake early miscarriages for late or unusually heavy periods (Bellhouse et al., 2018).

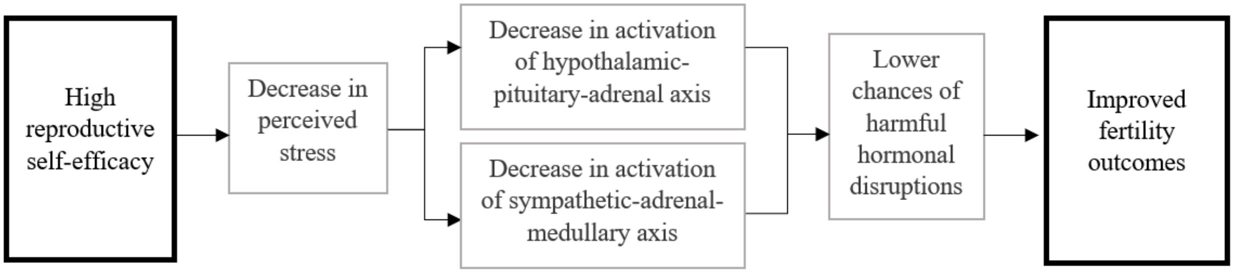
Women who experience miscarriage are at greater risk for poor mental health outcomes following a loss, including post-traumatic stress disorder, anxiety, and depression (Farren et al., 2016). These consequences can be detrimental to subsequent pregnancies. Research has indicated that anxiety, depression, and stress experienced during pregnancy are risk factors for adverse health outcomes for mothers and infants, such as shorter gestations and poor fetal neurodevelopment (Dunkel Schetter & Tanner, 2012). Additionally, women who have a miscarriage are likely to have multiple and consecutive pregnancy losses (Larsen et al., 2013). The risk of miscarriage increases from 20% after one miscarriage to 43% after three or more consecutive losses (Dugas & Slane, 2021). There are also unexpected and, in some cases, significant healthcare costs associated with miscarriage management, including prescriptions, surgical procedures, and follow-up visits (Dalton et al., 2015). In the US, individual cost estimates for miscarriage treatment range from $388 to $1,543, but these estimates fail to include any indirect costs associated with lost productivity (Dalton et al., 2014; Graziosi et al., 2005).

In addition to the psychological and physiological consequences of early pregnancy loss, a miscarriage can also undermine a couple's confidence in their ability to reproduce successfully (Bhattacharya & Bhattacharya, 2009). Reproductive self-efficacy (RSE) is a term I will use throughout my dissertation project to refer to a woman's confidence in her ability to get pregnant and carry a pregnancy to full term, resulting in a live birth. With its foundations in Bandura's studies of self-efficacy mechanisms, RSE examines thought patterns, individual actions and emotional influences related to reproduction efforts. Bandura (1982) conceptualizes self-efficacy as influential in changing behaviors, such as coping or psychological processing behaviors. He suggests that having a higher sense of self-efficacy promotes higher rates of achieving a desired physical or psychological outcome (Bandura, 1982). His studies have evidenced robust outcomes in health promotion, indicating a potentially critical construct in reproduction processes (Cousineau et al., 2006).

While the relationship between reproductive self-efficacy and fertility has yet to be examined, reproductive self-efficacy may help reduce the harmful physiological responses to stress while trying to conceive. Moreover, reductions in perceived stress may decrease activation of the hypothalamic-pituitary-adrenal axis and the sympathetic-adrenal-medullary axis (Palomba et al., 2018). When activated, these axes may result in abnormal, prolonged, and/or excessive stress-induced states of the body, which can produce long-term neuroendocrine changes (i.e., impacting fertility) (Palomba et al., 2018). This hypothesis is summarized in the figure below (see figure 1).

Figure 1

Reproductive self-efficacy and fertility relational model



Similar constructs have been explored and measured. For instance, the Infertility Self-Efficacy (ISE) scale is a validated data collection tool that seeks to estimate perceived abilities and confidence in engaging in health-promoting activities related to infertility practices (Cousineau et al., 2006). This tool has shown great promise in predicting psychological and behavioral health outcomes in patients seeking fertility assistance (Cousineau et al., 2006). Findings from this dissertation project may be used to inform RSE scale development and validation studies.

Miscarriage is a complex outcome with many contributing factors, and often the cause cannot be determined without extensive testing. Pregnancy loss can occur even with a history of wellness, proper prenatal and medical care, and healthy behaviors (Fonagy, 2001). Some known risk factors include advanced maternal age, previous miscarriage, chronic conditions, uterine or cervical issues, drug/alcohol use, being overweight or underweight, and invasive prenatal testing (Mayo Clinic, 2021).

Despite the pervasiveness of miscarriage and its associated adverse health effects, women often report negative experiences with healthcare providers following a perinatal loss, indicating a potential lack of soft skills training in medical education (Radford & Hughes, 2015; Sanchez, 2001). Miscarriage is often treated as all other forms of loss in the healthcare setting, despite the unique nature of the event. Women who experience a miscarriage report an enhanced sense of guilt or self-blame compared to those experiencing other forms of loss. Moreover, losses that occur early in pregnancy are often marked with a sense of disenfranchisement and little is done clinically to encourage an improved bereavement process (Kersting & Wagner, 2012).

Reports of negative experiences with healthcare teams following a perinatal loss and during the bereavement process are abundant, notwithstanding existing guidelines that outline the need for supportive and empathetic treatment. Women report dissatisfaction with the timing of the disclosure of a miscarriage, the duration of the conversation, and the period they were left alone once the news was delivered (Sanchez, 2001). Recent qualitative evidence suggests that women prefer patient-centered care and that miscarriage experiences differ drastically, requiring an individualized approach (Brann et al., 2020).

Additionally, the siloed nature of the US healthcare system can leave room for women to fall in between the cracks of care and without access to methods for addressing their loss (Wool & Catlin, 2019). Women experiencing miscarriage come into contact with the healthcare system at many different entry points. Thus, empathetic and respectful caregiving from providers that addresses the psychological and physiological needs of the patient should be a standard across care. Wool and Catlin (2019) summarize the need to address perinatal loss and the bereavement process over the entirety of healthcare delivery:

> Physicians, nurses, and administrators must encourage pregnancy loss support so that regardless of where in the facility the contact is made, when in the pregnancy the loss occurs, or whatever the conditions contributing to the pregnancy ending, trained

> caregivers are there to provide bereavement support for the family and palliative symptom management to the fetus born with a life limiting condition. (p. S28)

Finally, awareness of miscarriage and its associated risk factors is lacking. Over 55% of surveyed adults in the US, both men and women, inaccurately believe miscarriage to be a rare occurrence (Bardos et al., 2015).

In sum, many women in the US are affected by miscarriage, and evidence suggests that poor clinical management can worsen these experiences. Yet, research specific to healthcare communication during a miscarriage is limited. Research highlighting the gaps in care is crucial for improving the experiences of those who have a miscarriage. Relevant studies can inform future guidelines for healthcare practitioners and administrators, emphasizing patient preferences for communication during a miscarriage. Additionally, medical school curricula may improve teaching methods for delivering bad news to patients by boosting soft skills training, such as using empathy in the office.

Theoretical & Philosophical Foundations

Research relating to the communicative needs of patients who experienced a miscarriage is limited, yet several theoretical approaches are used to describe mechanisms related to miscarriage and psychological health. For instance, the perinatal grief intensity theoretical framework, developed and validated by Marianne Hutti (1992), contributed substantially to perinatal loss research. Hutti’s framework suggests that increasing congruence between perceptions of one’s pregnancy loss and the reality of the experience may help to reduce the intensity of grieving (Hutti, 1992; Hutti & Limbo, 2019). This theory is further described below.

Ambiguous loss theory, another central concept within miscarriage research, asserts that unclear loss can be more challenging to manage than more definitive, normative forms of loss (Boss, 2007). Other conceptual theories, such as emotional cushioning, describe the impacts of miscarriage on behaviors following pregnancy loss. Emotional cushioning denotes a resistance to acknowledge or embrace psychological changes in pregnancies after a previous loss to protect oneself from potential future losses (Côté-Arsenault & Donato, 2011). The following frameworks were used heavily in the formation and execution of this dissertation: Patient-centered Communication, Post-structural Feminism, and the Perinatal Grief Intensity Theoretical Framework.

Patient-centered communication

This three-paper dissertation provides insight into the experiences of healthcare communication during a miscarriage using a patient-centered communication (PCC) framework. PCC can help healthcare providers acknowledge the complexities of perinatal loss and improve care during and following a miscarriage. PCC theory describes strategies and behaviors that providers are encouraged to promote mutuality, shared understandings, and shared decision-making through the healthcare process (Brown, 1999; Hashim, 2017). When PCC is employed correctly, the outcome is often a highly individualized clinical discourse (Brown, 1999). PCC comprises verbal and non-verbal communication (Hashim, 2017).

The healthcare team plays an important role in the process of grieving and has the potential to assist couples who experience pregnancy loss in various capacities. Clinicians and medical staff must acknowledge the complexities of perinatal loss and the associated mechanisms that drive outcomes. Frameworks like PCC were developed to enhance patient experiences within the healthcare setting and improve health outcomes (King & Hoppe, 2013; Naughton, 2018). According to Epstein and Street (2007), the core tenets of PCC include:

> (1) eliciting and understanding patient perspectives (e.g., concerns, ideas, expectations, needs, feelings, and functioning), (2) understanding the patient within his or her unique psychosocial and cultural contexts, and (3) reaching a shared understanding of patient problems and the treatments that are concordant with patient values. (p. 2)

Evidence suggests that when patients are more involved in their care, they are better equipped to manage complicated health conditions and reduce anxiety and stress (Naughton, 2018). Further, an observational study of patient-physician encounters from internal medicine clinics within the Veteran's Association found that 71% (n= 68, P=0.002) of the patients who received care that involved patient-centered decision-making had improved outcomes, compared to only 46% (n=28, P=0.002) of patients who did not receive care with patient-centered decision making (Weiner et al., 2013). While the observed physicians in this study were equally representative of males and females, the patients in the study were 98% male (Weiner et al., 2013). A recent cross-sectional study also revealed a potential association between PCC and decreased symptom burden in individuals with ovarian cancer (Pozzar et al., 2021). The 176 participants reported on communication received from their treating physicians, which were made up primarily of gynecological oncologists (81%), surgical oncologists (7%), general gynecologists (3%), among others (Pozzar et al., 2021). PCC was measured using the Patient-Centered Communication in Cancer Care-36 (PCC-Ca-36) and symptom burden was measured using the Functional Assessment of Cancer Therapy Ovarian Symptom Index (FOSI-18). Patients with higher PCC-Ca-36 scores had higher FOSI-18 scores (P=0.003), indicating decreased perceptions of symptom burden (Pozzar et al., 2021). In addition to physiological outcomes, PCC is important to patient recall and adherence. Communication that helps patients retain important information (i.e., uncomplicated, specific, uses repetition, minimizes jargon, and checks for patient understanding) has been associated with greater adherence to medical recommendations (King & Hoppe, 2013). PCC methods can engage the patient in shared decision-making regarding their treatment, thus incorporating patient desires, exploring perceived barriers, and tailoring treatment interventions to the patient's requirements, which can boost clinical adherence rates (Hahn, 2009).

PCC should be used to address both the informational and emotional needs of the patient (King & Hoppe, 2013). Since perinatal loss can invoke various responses, clinicians and staff must take the time to assess each situation accurately and effectively communicate through PCC. In a national survey of couples who had experienced a miscarriage (N= 1,147), only 45% of respondents reported receiving adequate emotional support from the medical community, with another 25% reporting inadequate support (Bardos et al., 2015). Yeh and Nagel (2010) argue that aspects of PCC should be implemented to an even greater extent within obstetrics and gynecology practice, given the often-intimate nature of gynecological health issues and diversity in experiences of these issues. Delaney and Singleton's (2020) qualitative research with 21 pregnant women confirmed the need for more individualized care within obstetrics and gynecology. It revealed important communication functions in the healthcare setting. The findings from this study suggest that in the context of pregnancy, essential informational functions of communication included monitoring the pregnancy and normalizing the patient's experiences (Delaney & Singleton, 2020). Table 1 outlines the best practices for achieving PCC based on six essential communication functions.

Table 1

Best Practices for PCC according to six key functions of communication

Functions of the Medical Interview	Roles and Responsibilities of the Physician	Skills
Fostering the relationship	• Build rapport and connection • Appear open and honest • Discuss mutual roles and responsibilities • Respect patient statements, privacy, autonomy • Engage in partnership building • Express caring and commitment • Acknowledge and express sorrow for mistakes	• Greet patient appropriately • Maintain eye contact • Listen actively • Use appropriate language • Encourage patient participation • Show interest in the patient as a person
Gathering information	• Attempt to understand the patient's needs for the encounter • Elicit full description of major reason for visit from biologic and psychosocial perspectives	• Ask open-ended questions • Allow patients to complete responses • Listen actively • Elicit patient's full set of concerns • Elicit patient's perspective on the problem/illness • Explore full effect of the illness • Clarify and summarize information • Inquire about additional concerns
Providing information	• Seek to understand patient's informational needs • Share information • Overcome barriers to patient understanding (language, health literacy, hearing, numeracy) • Facilitate understanding • Provide information resources and help patient evaluate and use them	• Explain nature of problem and approach to diagnosis, treatment • Give uncomplicated explanations and instructions • Avoid jargon and complexity • Encourage questions and check understanding • Emphasize key messages
Decision making	• Prepare patient for deliberation and enable decision making • Outline collaborative action plan	• Encourage patient to participate in decision making • Outline choices • Explore patient's preferences and understanding • Reach agreement • Identify and enlist resources and support • Discuss follow-up and plan for unexpected outcomes
Enabling disease- and treatment-	• Assess patient's interest in and capacity for self-management	• Assess patient's readiness to change health behaviors

related behavior	- Provide advice (information needs, coping skills, strategies for success) - Agree on next steps - Assist patient to optimize autonomy and self-management of his or her problem - Arrange for needed support - Advocate for, and assist patient with, health system	- Elicit patient's goals, ideas, and decisions
Responding to emotions	- Facilitate patient expression of emotional consequences of illness	- Acknowledge and explore emotions - Express empathy, sympathy, and reassurance - Provide help in dealing with emotions - Assess psychological distress

Note: Table sourced from King and Hoppe (2013)

As denoted in figure 1, PCC skills involve both verbal and non-verbal components. Key verbal actions can include continuers, such as "go on"; legitimation, such as "that makes sense"; open-ended questions; checking for understanding and rephrasing; and exploration, such as, "I wonder if you…" (Hashim, 2017 p. 31). Nonverbal communication can be an effective way to achieve PCC. These methods include showing attention through eye contact, reacting with facial expressions, attentiveness and active listening through motions like nodding, displaying openness with body language, and spending sufficient time with a patient (Hashim, 2017; King & Hoppe, 2013).

The application of PCC to improve outcomes among patients who experience a miscarriage is a relatively recent effort. Given the multiple treatment options available for managing a miscarriage, Shorter, Atrio, and Schreiber (2019) call for PCC use when making decisions with patients regarding their miscarriage care. Individualized patient counseling improves patient satisfaction (Shorter et al., 2019). A recent qualitative study by Brann, Bute & Foxworthy (2020) had focus groups of women who had experienced a miscarriage to watch medical intern training videos for miscarriage disclosures. The participants were then asked to identify aspects of the training videos that aligned with their communication preferences and highlight areas for improvement. The results emphasized four key themes related to PCC: empathy, creating space for the patients to process, checking for understanding, and avoiding medical jargon or emotionally charged language (Brann et al., 2020). The Miscarriage Care Initiative (MCI) was introduced in 2013 to expand the education of patient-centered miscarriage management to primary care clinicians across the US (Srinivasulu et al., 2020). An evaluation of the program's first four years suggests a successful integration of miscarriage care into the primary care setting and expanding the availability of miscarriage management options (Srinivasulu et al., 2020). Of the 13 sites that completed the MCI, 100% (n=13) of the programs included comprehensive miscarriage management into their didactic curricula, and 92.3% (n=12) now offered medical treatment options for miscarriage management (Srinivasulu et al., 2020).

I selected PCC as a guiding framework for my dissertation based on its ability to impact patient outcomes and comprehensiveness. The thematic elements of my scoping review for manuscript #1 and the interview guide for manuscripts #2 and 3 were influenced by the fundamental factors of PCC with a focus on both informational and emotional support.

Post-structural Feminism

Post-structural feminism was the guiding philosophy for my dissertation research. This philosophy highlights the relationship between language, gender, knowledge, and power regarding the research participants and experiences (Alspaugh et al., 2021; Quinlan & Bute, 2012). A distinct insight from a post-structural feminist approach is understanding power in relationships (Cannon et al., 2015). Thus, applying this approach allowed me to be cognizant of the power differentials between patients and medical personnel and between men and women. The post-structural feminist sense of these relationships compels us to look beyond traditional power dynamics and deconstruct social binaries (Cannon et al., 2015). Post-structural feminist theorists argue “taking the discursively constructed category of women as always already socially constituted by a sense of shared oppression risks overlooking women as material subjects with their own histories and experiences” (Cannon et al., 2015, pp. 671-672).

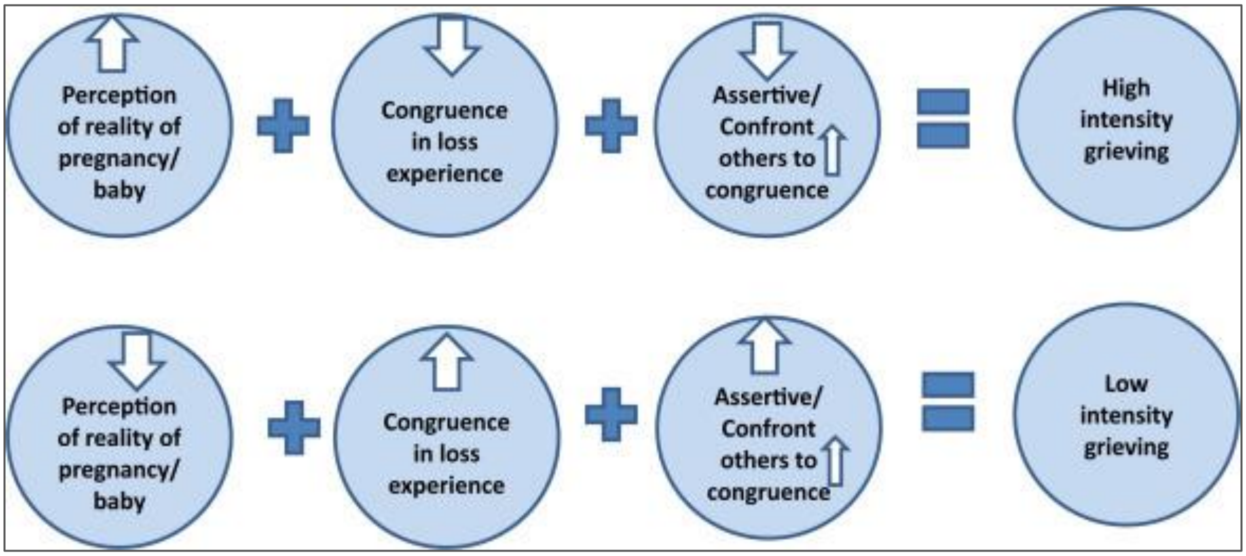
Research employing a post-structural feminist approach to miscarriage research is lacking. However, some pregnancy loss studies have employed a more traditional feminist theoretical perspective. For instance, Carolan and Wright (2016) used feminism to assert that the medicalization of miscarriage has created a means of disparaging women by desensitizing and minimizing emotional responses. They also discussed the role of feminism in the social silencing of miscarriage, suggesting that the belittling of the miscarriage experience in the medical setting may prevent women from discussing their experiences with their friends and family (Carolan & Wright, 2016). Parsons (2010) also uses a feminist approach to navigate the experiences of miscarriage in a socio-political world where pro-forced birth/pro-choice debates may influence how a woman perceives her miscarriage. As these studies are the first to examine miscarriage through a post-structural feminist lens, the potential impact is substantial. This novel approach may enlighten new ways that gender and power influence miscarriage discourse in healthcare.

Perinatal Grief Intensity Theoretical Framework

The Perinatal Grief Intensity Theoretical Framework (PGITF) stemmed from a 1992 study revealing that parents had little to no experiences or awareness of miscarriage and thus, were not prepared with the expectations needed to address grief levels in the event of pregnancy loss (Hutti, 1992). The theory focuses balancing reality and expectations, emphasizing congruence between the two. Hutti’s results evidenced the factors impacting grief levels, which equate to the theory’s central constructs are: (a) the perceived reality of the pregnancy or the baby, (b) the congruence between the actual loss experience and the parents' perception regarding the loss, and (c) the parents' ability to make decisions or act in ways that increase this congruence (Hutti, 1992). Figure 2 displays the hypotheses formed in the PGITF.

Figure 2.

Effects of the Perinatal Grief Intensity Theoretical Framework on Grieving Levels, 2013



Note. Lower intensity grieving results from a decrease in the perception of the pregnancy as a baby, the increase in the congruence of loss experience and expectations, and the increase of actions needed to increase congruence.

While the study sample was small (N = 12), results indicated that the process or presence of grief might depend on how real the pregnancy and baby are to the parent, as well as what their expectations were for the pregnancy and the possibility of loss.

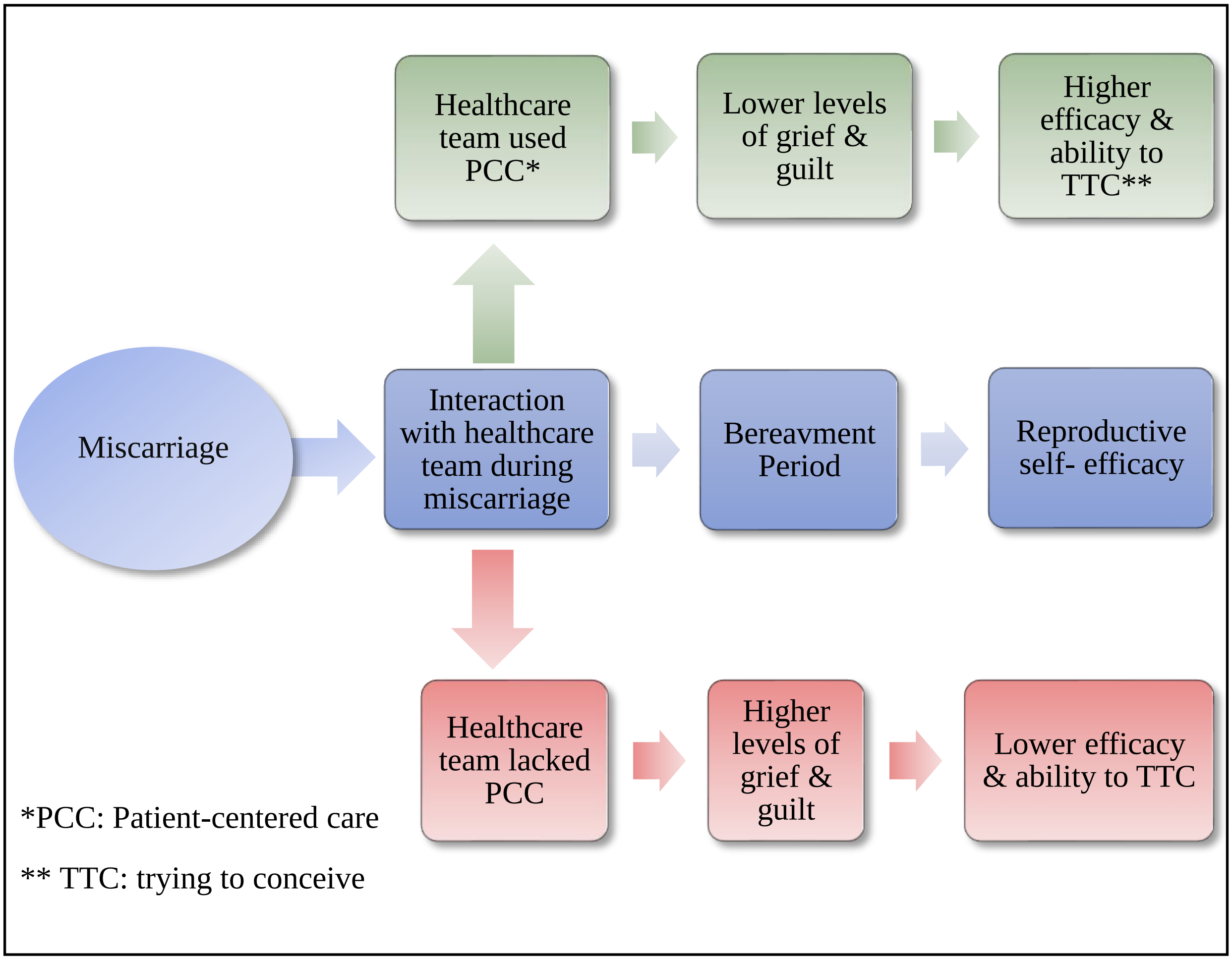
The PGITF has subsequently been applied to perinatal grief research and evaluated. In 2013, Hutti, Armstrong, and Myers (2013) further validated the framework and subsequent grief intensity scale, developed in a study with a larger sample (N = 227). Cronbach's alpha was used to establish reliability (range for constructs: 0.75 – 0.82), and factor analysis was used to confirm validity and accounted for 66.9% of the total variance (Hutti et al., 2013). Hutti and Limbo (2019) used the PGTIF to inform a study on perinatal bereavement care; the framework helped identify parents who are likely to experience highly intense grief and may require professional follow-up after loss.

Conceptual Model

PCC is a driving framework for my dissertation and a key factor in my conceptual model (See figure 3). This model denotes the posited relationship between PCC and RSE. I believe that one's interactions with their healthcare team can influence how their miscarriage is perceived and thus impact the type of bereavement period that follows. In turn, the feelings experienced during this bereavement period may be consequential to a woman's sense of self-efficacy when trying to conceive again. For instance, if a patient who has had a miscarriage receives care representative of PCC, she may experience lower levels of grief and guilt and higher RSE. On the other hand, if a patient having a miscarriage receives care that is not patient-centered, she may experience higher levels of grief and guilt and lower RSE. This model was developed based on existing relationships evidenced by research detailed in the following literature review.

Figure 3

Conceptual Model of PCC and Reproductive self-efficacy



*PCC: Patient-centered care

** TTC: trying to conceive

Review of the Relevant Literature

Conceptualizing Miscarriage

Miscarriage and the subsequent bereavement period is a complex social and psychological phenomenon. Just as experiences of miscarriage vary, so do definitions. While ACOG defines miscarriage as a pregnancy loss before 20 weeks of gestation, others, such as the WHO, use 28 weeks as the cut point (Prager et al., 2018; WHO, 2021). I chose to use ACOG's definition of a miscarriage as my research is being conducted in and about the US. Miscarriage affects as many as 1 in 4 (10-25%) pregnancies and is the most common pregnancy complication (ACOG, 2018; Farren et al., 2016; Prager et al., 2018). Evidence shows that miscarriage can be a traumatic event due to the shocking nature of the loss. Bardos and colleagues (2015) revealed that over half of surveyed adults (55%) falsely believed miscarriage to be an uncommon event. The odds of male respondents reporting this misconception were 2.5 times (95% confidence interval (CI)= 1.87-3.15) that of female respondents (Bardos et al., 2015).

When a miscarriage is diagnosed, there are three treatment options: expectant management (waiting for the body to miscarry naturally); medical management (using medication to induce the miscarriage); and surgical evacuation (the miscarriage is completed surgically via sharp or suction curettage) (Dugas & Slane, 2021). Expectant management can take up to eight weeks and is typically limited to earlier miscarriages (Dugas & Slane, 2021). Medical management usually results in complete expulsion within 3 days of treatment, and surgery allows for complete evacuation during the procedure. Treatment decisions depend on several factors, including risk for hemorrhage, length of gestation, other comorbidities, the risk for infection, and patient preference in many cases. All three treatment options are equally safe and effective for women with no comorbidities and a low risk for hemorrhage and infection (Dugas & Slane, 2021).

There are many identified risk factors associated with miscarriage. Maternal age, for instance, is a significant predictor of risk. The risk for miscarriage increases from 8.9% to 74.7% when comparing women ages 20-30 with women over 40 (Dugas & Slane, 2021). Additionally, miscarriage is a predictor of subsequent losses; after one miscarriage, the risk is approximately 20%. After two consecutive losses the risk increases to 28%. After three or more consecutive losses, it is 43% (Dugas & Slane, 2021). Women with recurrent miscarriage, which are classified as obese (BMI ≥ 30) experience an estimated 70% increase in risk for spontaneous abortion (odds ratio [OR]= 1.73; 95% CI= 1.06, 2.83) (Lo et al., 2012). Underweight women (BMI ≤ 18.5) also have nearly a 4-fold increase in odds of miscarriage in a subsequent pregnancy (OR = 3.98; 95% CI= 1.06-14.92) (Metwally et al., 2010). The risk for miscarriage is also greater among Black women than white women after adjusting for age and alcohol use (adjusted hazard ratio = 1.57; 95% CI= 1.27, 1.93) (Mukherjee et al., 2013). This difference in risk is even more significant for miscarriage within the first 10 weeks (adjusted hazard ratio = 1.93; 95% CI= 1.48, 2.51) (Mukherjee et al., 2013). Miscarriage risk increases in a stepwise fashion with the number of chronic conditions a woman has before getting pregnant; compared to women with no chronic conditions, women with three or more pre-existing conditions have 1.49 times the odds (AOR= 1.49; 95% CI= 1.25, 1.78) of having a miscarriage (Magnus et al., 2021). Other risk factors include cigarette smoking, excessive caffeine consumption, trauma, and malnutrition (Dugas & Slane, 2021; Mayo Clinic, 2021).

Consequences of Miscarriage

Many complex emotions can accompany miscarriage. Bereavement, emotional distress and/or grief are common and expected outcomes after such an event. Still, when these psychological morbidities become prolonged or intensified, they can interfere with a couple's life and have lasting effects. Distinguishing between typical grief after a miscarriage and clinical diagnoses such as depression or anxiety can be challenging thus, the psychosocial consequences of miscarriage are thought to be underestimated (Nynas et al., 2015). Further, there may be no outward physical manifestations of grief, so accompanying psychological effects like depression or anxiety may go unrecognized by providers, friends, or family (Quenby et al., 2021).

Prolonged or highly intense complicated grief occurs in about 25-30% of women who experience a perinatal loss (Hutti et al., 2017). In a prospective study of women, psychological morbidity was higher among those who had experienced an early pregnancy loss compared to those who were still pregnant, with 28% meeting the criteria for PTSD, 32% for anxiety, and 16% for depression at one month-post loss (Farren et al., 2016). No women from the control group met the criteria for PTSD, and 10% met the criteria for anxiety and depression (Farren et al., 2016).

Several factors predict greater emotional distress in women who experience a miscarriage. These factors include whether the pregnancy was planned, a history of infertility/inability to conceive, no symptoms of the loss (i.e., bleeding or cramping), prior pregnancy losses, advanced gestational age, no living children, loneliness, relationship strain with one's partner, and a history of poor coping skills (Nynas et al., 2015). An experimental study in Oman explored the use of brief supportive psychotherapy (BSP) intervention with miscarriage patients (Barat et al., 2020). The experimental group received a two-hour psychotherapy session with a trained BSP therapist, while the control group received a placebo two-hour counseling session with a midwife. The results indicate that anxiety (13.5% vs. 60.5%), depression (32.4% vs. 71.1%), and high perinatal grief symptoms (10.8% vs. 65.8%) were all lower in the experimental group compared with the control group at four months post-loss (Barat et al., 2020). These findings highlight a potential method that can be employed in obstetric settings to reduce the impact of psychological distress following a miscarriage; however, the mechanisms behind the study are unclear, and BSP needs to be further investigated in these settings (Barat et al., 2020). Moreover, women in the US are not typically hospitalized for a miscarriage; thus, the application of a similar study would need to occur in a different setting.

In addition to the potential for psychological distress, miscarriage can also be associated with physiological consequences. Typical bodily side effects include moderate-to-heavy bleeding, cramping, diarrhea, vomiting, or nausea (ACOG, 2018; Dugas & Slane, 2021). In a few cases, miscarriage or the management of a miscarriage can result in hemorrhaging, infection, need for analgesia, or blood transfusions (ACOG, 2018; Al Wattar et al., 2019). These concerns are more significant in later miscarriages and often dictate the treatment option (ACOG, 2018). Intrauterine adhesion formation, or scarring between the inner walls of the uterus, can also occur after surgical treatment of a miscarriage but is considered a rare complication (ACOG, 2018). A systematic review of treatment options and risk for adverse outcomes indicated a decreased risk in infection rates among those who use expectant management, compared to those undergoing surgical treatment (risk ratio (RR)= 0.29; 95% CI= 0.09-0.97); however, overall rates of infection remained very low (1-2%) (Nanda et al., 2012). Additionally, 1.4% of the expectant care group required blood transfusions, compared to no one in the surgical management group (Nanda et al., 2012).

Perhaps the most common physiological outcome related to miscarriage, and recurrent miscarriage, in particular, is the impact on subsequent pregnancies. Recurrent miscarriage is associated with increased incidence of preterm birth (<37 weeks gestation) (adjusted OR (AOR)= 1.54; 95% CI= 1.29-1.84), very preterm birth (<32 weeks gestation) (AOR= 1.80; 95% CI= 1.28-2.53) and perinatal death in subsequent pregnancies (AOR= 2.66; 95% CI= 1.70-4.14) (Field & Murphy, 2015).

The costs of miscarriage impact patients directly and contribute to increasing healthcare expenditures nationwide. Economic data for the US regarding miscarriage costs is unavailable. However, in the UK, the short-term national economic costs of miscarriage (including estimates of the expenses of hospital and community health and social services, costs to patients, and broader societal costs associated with lost productivity) are estimated to be $633.6 million USD (Quenby et al., 2021). This comparison should be taken with precaution given the difference in healthcare expenditures between the US and the UK (16.9% of gross domestic product vs. less than 10%, respectively) (Tikkanen & Abrams, 2020). According to a recent literature review, cost estimates of miscarriage vary by the nature of the treatment, the location of care (inpatient vs. outpatient), and the cost accounting methodology and jurisdiction (Quenby et al., 2021). In nearly all studies, surgical evacuation of miscarriage remains the most expensive option, mainly when performed inpatient (ACOG, 2018; Dalton et al., 2014; Quenby et al., 2021). In the US, cost estimates for miscarriage treatment range from $388 (for medication) to $1,543 (for surgical evacuation), according to Dalton and colleagues (2014). Non-healthcare costs associated with a miscarriage should also be considered. For instance, among women who received medical treatment for their miscarriage in the Netherlands, the mean value of lost productivity was more significant than the mean direct costs of the treatment ($546 USD vs. $486 USD, respectively) (Graziosi et al., 2005). Moreover, these direct and indirect costs of miscarriage may not be experienced equally. Though the literature assessing these costs in various populations is lacking, the disparate rates of miscarriage among Black women compared to white women may indicate higher costs in that population.

Miscarriage & Healthcare Communication

The literature on early pregnancy loss suggests a strong relationship between miscarriage experiences and the care one receives from their healthcare team. Patients and their partners desire accurate and updated information from their clinicians regarding their miscarriage, and inaccurate or missing information is considered highly distressing (Meaney et al., 2017). A recent qualitative study asserted that "although distressing, parents felt relief when healthcare professionals spoke openly to them about their diagnoses…Good communication with healthcare professionals meant an appropriate plan for the pregnancy could be put in place" (Meaney et al., 2017, p. 291). Discontinuity of information regarding healthcare or miscommunication among the healthcare team resonated as a source of patient mistrust (Meaney et al., 2017; Sereshti et al., 2016). Some qualitative research indicates that when healthcare teams fail to properly acknowledge the loss and spend appropriate time with the patient to answer questions, the overall experience worsens, and women are left feeling lost (Meaney et al., 2017; Sereshti et al., 2016). Sereshti and colleagues (2016) attribute this lapse in communication to the overexposure to miscarriage that healthcare providers can have as well as the medicalization of pregnancy loss. Patients are more likely to view their miscarriage as an emotional, symbolic phenomenon rather than an ailment (Sereshti et al., 2016).

Medical team members who display emotional or social support efforts are praised among miscarriage patients and their partners (Brann et al., 2020; MacWilliams et al., 2016; Meaney et al., 2017). Compassion and empathy, specifically, help validate a patient's experiences and are considered beneficial in helping couples cope with this difficult loss (MacWilliams et al., 2016). Displays of empathy varied among qualitative reports. One method for demonstrating empathy was sharing a personal experience or anecdote with patients (MacWilliams et al., 2016). A miscarriage patient from one qualitative study expressed,

> Here, where this physician's instincts of training may have led him to attempt to protect the patient from his emotional reaction, the patient instead found the reaction to be deeply human and a sign of shared grief over a terrible loss. (Kelley & Trinidad, 2012, p. 7)

Other displays of compassion included more non-verbal cues, such as maintaining eye contact, devoting sufficient time to the patient, and providing nurturing physical touch (Kavanaugh & Hershberger, 2006; Kelley & Trinidad, 2012).

Healthcare Communication and Bereavement

Qualitative evidence suggests that the care and communication one receives from their healthcare team can impact the perceived severity of grief and, thus, the duration and intensity of their bereavement period. For instance, when a patient's healthcare team fails to use strategies from PCC to interact with their patients, such as checking for understanding and allotting time for questions, the patients report a sense of unpreparedness for what comes next, leaving them to feel more in the dark during a critical time (MacWilliams et al., 2016). This unpreparedness relates to both the physiological symptoms to come as well as the emotional responses. One patient recalled,

> […] there was no sort of the stuff that you start having questions about after you leave. You know, like when am I going to expect to start bleeding? Or does that happen? Or you know, how do I get rid of what's inside? (MacWilliams et al., 2016, p. 508)

Having a positive experience with one's healthcare team can be influential in reducing perceptions of self-blame or guilt regarding miscarriage. When patients receive accurate information about the pregnancy loss when they can process it, which emphasizes the potential role of chromosomal abnormalities, parents report a lower sense of guilt (Sereshti et al., 2016). In a qualitative study of miscarriage patients who received care from an emergency department, three out of eight participants expressed a better coping period because of the compassion and empathy they received from their provider (MacWilliams et al., 2016). Experiences of insensitivity from healthcare providers can result in low patient satisfaction, poor coping with the loss, and a resistance to seeking health care (MacWilliams et al., 2016).

Stress, Grief, & Trying Again

Psychological comorbidities associated with miscarriage can be specifically problematic for women intending to conceive again. Pregnancy loss instills distress for couples, but it may also undermine their confidence in attaining future reproductive success, or their sense of RSE, despite studies showing that 75-98% of women who experience a miscarriage will conceive naturally again (Bhattacharya & Bhattacharya, 2009). For those patients who do conceive again, lasting psychological impacts from their miscarriage, if not appropriately managed, can physiologically affect the subsequent pregnancy. Anxiety, depression, and stress experienced during pregnancy are risk factors for adverse pregnancy outcomes, such as shorter gestations and poor fetal neurodevelopment (Dunkel Schetter & Tanner, 2012). For example, women who experience stressful life events, such as the death of a family member, have a 1.4-1.8 times greater risk for preterm birth than those without stressful events (Dunkel Schetter & Tanner, 2012). Moreover, women who are classified as having pregnancy anxiety have an 80% increase in odds (AOR= 1.8; 95% CI= 1.3-2.4) of preterm birth compared to those without pregnancy anxiety (Kramer et al., 2009). Depressive symptoms during pregnancy are also associated with a 10% increase in low birth weight in the US (RR= 1.10; 95% CI= 1.01-1.21) (Grote et al., 2010).

A history of miscarriage also influences behaviors during pregnancy. Compared to women with no history of miscarriage or one miscarriage, women with multiple early pregnancy losses are more than twice as likely to have visited an emergency department during the third trimester (AOR= 2.21; 95% CI= 1.24-3.94) and 1.66 times as likely (95% CI= 1.01-2.73) to be hospitalized during pregnancy (Kinsey et al., 2015).

Given the heightened sense of uncertainty, pregnant women following a miscarriage may look for ways to feel more in control during this new pregnancy (Kinsey et al., 2015). Many couples recall that they focused on gestational weeks as goals rather than the end of the pregnancy as a coping mechanism in subsequent pregnancies, diluting some of the joys of the process of pregnancy (Meaney et al., 2017). Patients and their partners are also likely to seek additional services in early pregnancy and appreciate when these services are offered because of their reproductive history. A participant from a recent qualitative study expressed gratitude when she received similar support even before getting pregnant again, stating:

> I went up to the [early pregnancy clinic] and they said, ‘the next time you get pregnant, call us here and come in and we will do a scan, we will do an early scan, we will give you that reassurance.’ That made a huge difference, because […] someone is actually saying ‘we care about you, we know this is hard and the next time you get pregnant we know it’s going to be distressful for the first few weeks so come in and we will give you scans.’ (Meaney et al., 2017, p. 5)

However, such support is not always offered or available. Additional services or testing can be costly and are often restricted by policies requiring a diagnosis of three or more miscarriages (Bhattacharya & Bhattacharya, 2009; Meaney et al., 2017). Policies like these are especially problematic as they do not consider maternal age, previous infertility, or other risk factors (Bhattacharya & Bhattacharya, 2009), making it more difficult for at-risk women to advocate for themselves.

In light of the health risks to future pregnancies, healthcare teams must be comprehensively aware of the psychosocial complexities of miscarriage and sensitive to patient grief responses. The use of grief detection tools, such as the perinatal grief intensity scale, should be incorporated into miscarriage and post-miscarriage obstetric care (Hutti et al., 2017). As indicated in the literature, proper management of a miscarriage by a healthcare team, including thorough information-based care that employs elements of PCC, can significantly influence a patient's experience of pregnancy loss. Reduction of psychosocial comorbidities is possible through appropriate healthcare communication, which can decrease the impacts of pregnancy anxiety on subsequent pregnancies, thus improving reproductive self-efficacy. As mentioned previously, reproductive self-efficacy is a new concept; therefore, there is little in the literature relating to it. However, I posit that literature related to pregnancy-related anxiety may be revealing for relationships between miscarriage and RSE, such that goals of interventions to reduce pregnancy-related anxiety may, in turn, improve perceptions of RSE.

Dissertation Overview

Research Questions

The level of general knowledge regarding miscarriage in the US population and the complex and siloed nature of the US healthcare system introduces the need to understand better the experiences of miscarriage and interactions with healthcare teams. The following three-manuscript dissertation provides evidence for improving communication from one's healthcare team during a miscarriage by synthesizing the existing literature and collecting qualitative data related to healthcare communication. The individualized nature of pregnancy loss and the varying degrees to which women associate miscarriage with the loss of life called for a qualitative approach. Qualitative methodological techniques allowed for a more in-depth insight into the unique perspectives of loss and communication patterns. The three manuscripts were guided by the research questions (RQs) listed below.

Manuscript #1

RQ 1: What is known in the literature about experiences of healthcare communication during a miscarriage in the US?

RQ 2: What gaps exist in the literature related to health communication and miscarriage in the US?

Manuscript #2

RQ 1: What role does communication from a healthcare team during a miscarriage play in a woman's perceptions of RSE?

RQ 2: What aspects of miscarriage management enhance or worsen a patient's sense of RSE?

Manuscript #3

RQ 1: How do knowledge, expectations, and perceptions of miscarriage change from preconception through post-miscarriage, as impacted by the healthcare team?

The first manuscript aims to synthesize the existing literature on healthcare communication and miscarriage through a scoping review. This review established a foundational understanding of these relationships and highlighted gaps in the extant knowledge. This manuscript also helped to identify needs for future research beyond my dissertation project within the perinatal health realm. In addition to a number of maternal health journals, I would also consider publishing this scoping review in a journal dedicated to reviews, such as *Systematic Reviews.* The second manuscript used qualitative semi-structured interviews to explore patient experiences of healthcare communication during a miscarriage. This manuscript was prepared for submission to *Qualitative Health Research*. Lastly, the third manuscript translated data from the semi-structured interviews into a journey map using narrative analysis to summarize critical recommendations for healthcare professionals. The target audience of this final manuscript is practitioners. Thus, the manuscript was prepared for submission to a perinatal health practice journal, such as the *American Journal of Perinatology*.

Significance

These studies contribute to the knowledge base of early perinatal loss research to improve future healthcare communication experiences of those having a miscarriage in the US. Most of the existing research does not explicitly address the communicative needs of miscarriage patients, and little is known about how healthcare communication may influence health outcomes, such as RSE, following a miscarriage. Furthermore, as the data related to this topic are scarce, a scoping review was needed to summarize what has been evidenced by other researchers, whose primary focus may not have been on the communication surrounding the perinatal loss. To the author's knowledge, no existing studies have assessed the style and content of the communication that patients receive from their healthcare team during their miscarriage, and any literature that does mention communication experiences focuses solely on nurses or physicians. The qualitative manuscripts (i.e., manuscripts #2 and 3) include questions about interactions with healthcare team members, including reception staff, technicians, anesthesiologists, etc.

Possible benefits of this research include building a better understanding of the complexities of miscarriage and establishing methods that can be used to lessen the psychological damage that can accompany pregnancy loss. Findings from these studies may also be used to guide future training materials/ policies for healthcare staff and inform legislation on a greater scale. For instance, communication preferences identified through manuscripts #2 and 3 may inform recommendations presented in the journey map, which can be enlightening for healthcare team members who do not obtain professional educational training from medical school curricula. Additionally, recommendations from the journey map may be helpful for medical school training, particularly for those who do not intend to work in obstetrics/gynecology but who may still encounter a miscarriage at a different entry point, such as an emergency department. Collectively, these findings can inform a model of miscarriage communication and care built upon the voices and experiences of patients who have a miscarriage. By amplifying patient voices, we can hope to reduce paternalistic medical practices and create more equitable and comprehensive, patient-centered care models.

This research places critical value on healthcare providers as a source of support to women struggling with fertility. By seeking to reduce emotional harm following a miscarriage and improve RSE for those trying to conceive, our findings may alleviate some of these patients' stresses. The communication and clinical practice suggestions may also enhance patient-provider relationships, resulting in more effective care.

Researcher statement

I have a personal connection with miscarriage as a research topic. As a researcher and interviewer, my emotional proximity to the subject allows me to speak and act with greater empathy for the women I interact with throughout these studies. As a woman in my late twenties and someone who would like to have children of my own one day, I feel particularly connected to pregnancy's embodied and emotional processes. I have witnessed in my relationships how beliefs associated with motherhood and pressures relating to that identity have shaped decision-making and psychological responses to pregnancy and loss. I have been researching perinatal and early pregnancy loss for over four years, so my knowledge and familiarity with the subject have also aided me in the interviewing, analyzing, and writing.

Chapter 2: A scoping review of miscarriage and healthcare communication in the US

Abstract

Background*:* Miscarriage is a pervasive and socioemotionally complex pregnancy complication. Evidence suggests that poor clinical management can worsen these experiences. Yet, assessments of healthcare communication during a miscarriage are limited and a systematic review of the literature is needed.

Methods*:* This scoping review identified and synthesized original research on miscarriage and healthcare communication in the US from the past 20 years to identify existing knowledge gaps for future miscarriage research. The following databases were searched: PubMed, PsychINFO, and ERIC Database. Data were charted according to Arksey and O'Malley's Scoping Review Framework.

Results*:* Eleven articles were included in the review and three primary themes emerged: (a) patients overwhelmingly prefer patient-centered care; (b) miscarriage is often overmedicalized, which leads to poor communication; and (c) informed decision-making related to one's miscarriage can improve patient experiences. Several gaps were also identified, including studies seeking physician perspectives on miscarriage communication, evaluation of standard care guidelines, and studies evaluating diverse patients' perspectives.

Discussion*:* This review highlights the need for patient-centered care that utilizes compassionate and accessible language and promotes informed decision-making. Future research should use quantitative methodologies and longitudinal designs to build upon these findings and improve patient experiences of miscarriage.

Introduction

Miscarriage and the subsequent bereavement period can be a painful yet common process. Miscarriage, or early pregnancy loss, is defined as the naturally occurring termination of pregnancy prior to 20 weeks of gestation (Prager, Dalton, & Allen, 2018). It is a fairly common complication estimated to occur in between 10-25% of pregnancies (Farren, Jalmbrant, Ameye et al., 2016; Prager et al., 2018). Approximately 23 million miscarriages occur annually worldwide, though this number may be underestimated due to a lack of reporting (Quenby, Gallow, Dhillon-Smith, et al., 2021).

Symptoms of miscarriage include vaginal spotting or bleeding, pain or cramping in the abdominal region, and fluid/tissue passing from the vagina (Mayo Clinic, 2021A). However, these symptoms do not necessitate a diagnosis of miscarriage as many healthy pregnancies can incur early-term spotting and cramping, and not all miscarriages are symptomatic (i.e., missed or silent miscarriages) (Chu, Devall, Beeson, et al., 2020). A miscarriage is diagnosed with a pelvic exam, ultrasound, or blood, tissue or chromosomal testing (Mayo Clinic, 2021B).

Pregnancy loss can often be accompanied by both psychological and physiological consequences, including but not limited to post-traumatic stress disorder, anxiety, depression, scarring or adhesions, and recurrent miscarriage (Farren et al., 2016; Hooker, Lemmers, Thurkow et al., 2014; Larsen, Christiansen, Kolte, et al., 2013). The risk for subsequent miscarriage increases from 20% after one miscarriage to 43% after three or more consecutive losses (Dugas & Slane, 2021). Experiencing pregnancy loss can also undermine a couple's confidence in their ability to reproduce successfully or their reproductive self-efficacy (Bhattacharya & Bhattacharya, 2009). Those who are at higher risk for miscarriage are women older than 35 years, with partners over 40 years old, with very low or very high body-mass index, of Black ethnicity, and those who engage in risky health behaviors such as smoking, excessive alcohol consumption, or who are exposed to air pollutants or pesticides (Quenby et al., 2021).

Problem statement

Women frequently report negative experiences with providers following pregnancy losses, indicating a potential lack of soft skills training among medical professionals (Radford & Hughes, 2015; Sanchez, 2001). Moreover, losses that occur early in pregnancy are often marked with a sense of disenfranchisement and little is done clinically to encourage an improved bereavement process (Kersting & Wagner, 2012).

In sum, many women in the US are affected by miscarriage, and evidence suggests that poor clinical management can worsen these experiences. For instance, physician communication that is unclear or unsettling may act as an additional source of stress or anxiety for women, particularly when it comes to making decisions about one's miscarriage management (Brann, Bute, & Foxworthy Scott, 2020; Wallace, DiLaura & Dehlendorf, 2017). Yet, assessments of healthcare communication during a miscarriage in the US are limited, and the few existing studies fail to evaluate healthcare interactions. A review of the existing literature is needed to synthesize what evidence has been developed and to identify what still needs to be explored.

Findings from this study will inform researchers of the work that needs to be done to enhance healthcare communication during a miscarriage. By synthesizing this literature, we are shedding light on the overlooked public health focus of miscarriage management in the US.

Theoretical influences in miscarriage research

Several theoretical approaches have informed miscarriage research and healthcare practice around miscarriage diagnoses. For instance, Patient-centered communication (PCC) has long been considered a standard in care, particularly for potentially sensitive healthcare issues, such as miscarriage (Brown, 1999; Hashim, 2017). PCC describes strategies and behaviors providers are encouraged to use to promote mutuality, shared understandings, and shared decision-making with the patient (Brown, 1999). PCC often results in highly individualized care, pivotal to pregnancy loss care. PCC has been used to study patient care satisfaction during early pregnancy care, bad news delivery in miscarriage management, and outpatient programs for early pregnancy loss (Brann, Bute & Foxworthy Scott, 2020; Grégoire-Briard, Horwood, Berger et al., 2022; van den Berg, Dancet, Erklikh et al., 2018).

Similarly, frameworks related to informed decision-making have also been prominent in miscarriage research (Towle & Godolphin, 1999). Informed decision-making (IDM) requires informed patients (i.e., patients with information, expectations and preferences), informed physicians (i.e., physicians who find and evaluate current evidence), and constructing a decision together in an agreed-upon way (Towle & Godolphin, 1999). IDM is used to “promote quality interactions with physicians, better knowledge about health conditions, trust of physicians, satisfaction with treatment decisions, and ultimately better treatment adherence and clinical outcomes” (Brann & Bute, 2017, p. 2269). It is beneficial in situations where one course of treatment is not inherently superior to another; such is the case with miscarriage management (i.e., expectant, medication or surgical management) (Brann & Bute, 2017). Informed and shared decision-making models have been used to assess miscarriage treatment options from patient and provider perspectives (Ankum, 2001; Linnet, Graungaard & Husted, 2014).

Significance

To the best of our knowledge, this is the first study to appraise healthcare communication in the field of miscarriage management using a scoping review. To improve miscarriage care in the healthcare setting, we need to identify the role of healthcare communication in this process. This study provides additional insight into the relevance of specific healthcare communication strategies, particularly those related to PCC. Furthermore, we identify existing gaps in the literature related to healthcare communication and pregnancy loss. Our results are expected to enhance communication in a healthcare setting during and after a miscarriage by synthesizing patient experiences from various miscarriage studies. For women at risk of having adverse downstream outcomes related to their miscarriage management, it is important to understand their experiences and how these healthcare interactions impact their life so we can tailor intervention and treatment resources using a meaningful approach.

Research Questions

The present study aims to review the literature on healthcare communication and miscarriage. This scoping review will identify and synthesize evidence relating to patient and provider perceptions of miscarriage communication and will identify gaps in the literature where research is still needed. We sought to answer the following research questions:

1. What is known in the literature about experiences of healthcare communication during a miscarriage in the US?
2. What gaps exist in the literature related to healthcare communication and miscarriage in the US?

Methods

Design

A scoping review was conducted to review the recent literature related to communication and miscarriage in the US and identify existing knowledge gaps for future miscarriage research. A scoping review was selected because of its broader search strategy, which is efficient for understudied content (Munn, Peters, Stern, et al., 2018). The Arksey and O'Malley (2002) scoping review framework guided this study, which promotes reproducibility, transparency, and reliability. Ethical concerns for the study are limited as it did not require the participation of human subjects. Thus, IRB approval was not needed.

Search strategy & Eligibility criteria

A systematic search of the following databases was conducted to gather original peer-reviewed research articles on communication and miscarriage: PubMed, PsychINFO, and ERIC Database (via EBSCOhost). All identified articles from the search were downloaded and transferred to a systematic review management software, Covidence, and all duplicates were removed. The following search terms, including MeSH terms, were used to identify the relevant articles: [Miscarriage OR "Perinatal Loss" OR "Early Pregnancy Loss" OR "Pregnancy Loss" OR "spontaneous abortion"] for miscarriage, [Communication OR "Communication patterns" OR "Patient-Provider Communication" OR "Healthcare Communication" OR "Physician-Patient Relations"] for communication experiences related to one's healthcare treatment, and ["Professional support" OR "Provider support"] to capture relevant content about communication needs.

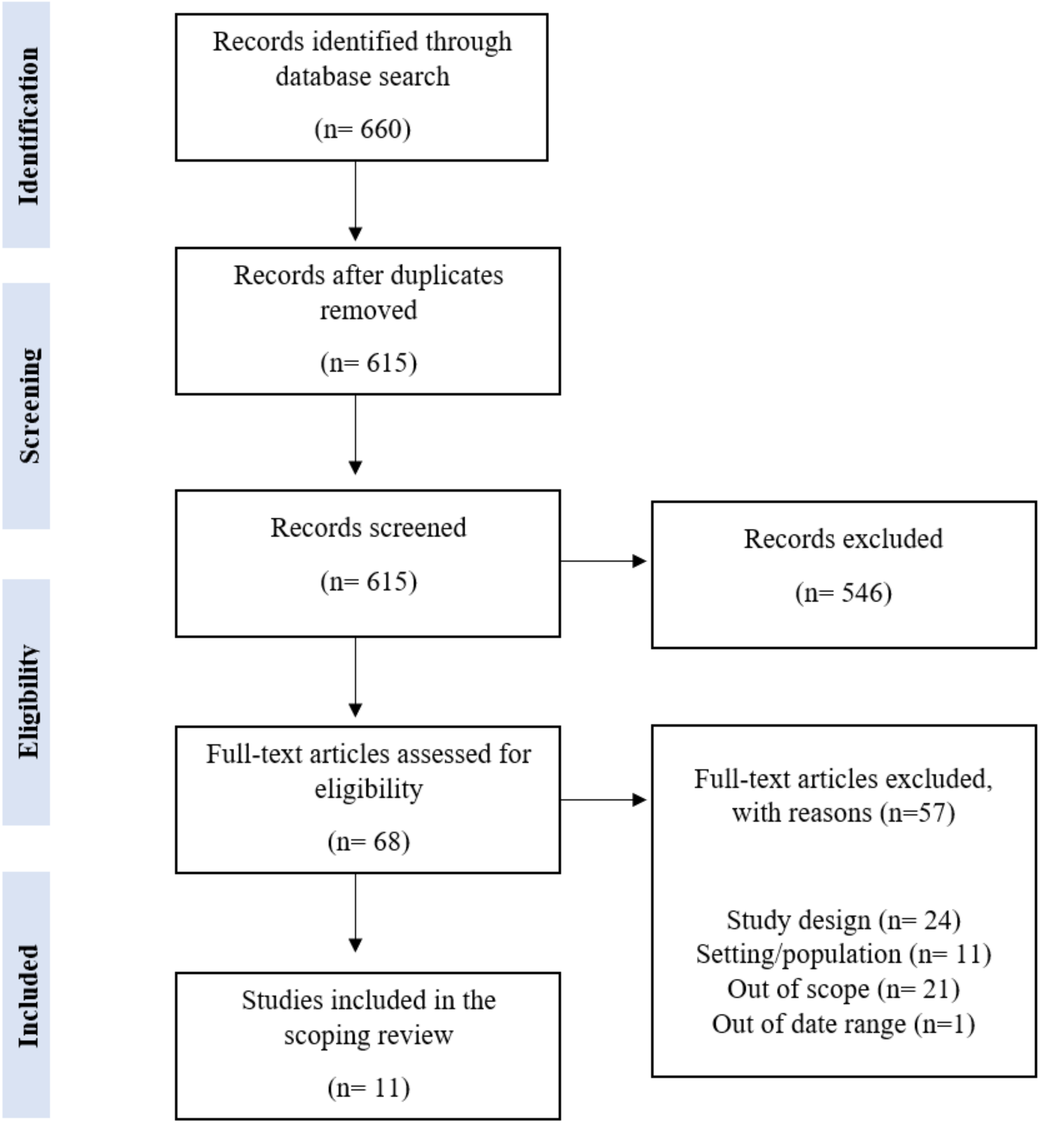
Selection criteria

Articles were included in the review if they were original, peer-reviewed research conducted between January 2002 and June 2022 and met the following criteria: 1) the primary focus of the research was broadly related to experiences of miscarriage; 2) the research also measured/described outcomes related to communication; 3) the research utilized original quantitative, qualitative, or mixed methods methodology; and 4) the research was conducted in the US. Studies were excluded if they were not written or made available in English. Clinical drug trials, cellular biology studies, and book reviews were excluded.

A two-stage screening process was used to evaluate the relevance of the identified studies in the search. The first phase consisted of a title and abstract screening to preclude wasting resources on acquiring articles that did not meet the eligibility criteria. A second reviewer screened 5% of the articles by their abstract/title to validate the eligibility screening performed by the primary investigator. No conflicts were reported. The second phase included a full-text review of each study. Figure 1 outlines the study identification and selection process.

Figure 1.

PRISMA diagram for selecting the empirical articles related to healthcare communication and miscarriage



Data extraction

The data were charted in Excel according to Arksey and O'Malley's (2002) scoping review framework. The following data points were extracted from each included study: author(s), title, publication year, summary, research setting, participant demographics, research methods, measures/interventions, key findings, and limitations. An abbreviated version of this chart is provided in the appendices (Appendix 2-A).

Data analysis

The data were compiled into a single spreadsheet in Excel for validation and coding. Following the charting of the data, a narrative account of the included studies was established to present any patterns in the literature. Using thematic analysis, studies were classified by emerging themes (Barnett-Page & Thomas, 2009; Vaismoradi, Turenen & Bondas, 2013). Table 1 summarizes the key findings related to these themes.

Table 1

Key findings from the thematic analysis

Theme	Key Findings
Patient-Centered Communication	Patients overwhelmingly prefer patient-centered care (PCC); when PCC is not employed, patients are left feeling invalidated.
Terminology/Phrases	Miscarriage can be overmedicalized, which can lead to perceptions of poor communication.
Informed Decision-making	Informed decision-making related to one's miscarriage can improve patient experiences.

Results

Narrative summary

Eleven articles were included in the scoping review analysis. Of these 11, a qualitative approach was used in 9 studies, quantitative methods were used in one, and one study employed a mixed methods approach. The articles were published from February 2005 to September 2021. Six studies recruited only female patients who had experienced a miscarriage; two assessed male partners of women who had a miscarriage, and three evaluated healthcare practitioners.

The introductions, sampling and analysis methods, and results were adequately explained in each of the 11 articles, and ethical or human subjects' concerns were also mentioned in all included studies. However, five articles did not address the study limitations within their discussions.

To answer our first research question, we categorized studies as pertaining to one of three themes that emerged in the literature. Below are the findings related to the themes: patient-centered communication, terminology/phrases, informed decision-making, male partner role, privacy 'rules,' and communicated sense-making. Table 2 provides exemplary quotes from the literature in support of each theme.

Table 2

Exemplary quotes supporting thematic findings

Theme	Exemplary quote
Patients overwhelmingly prefer patient-centered communication (PCC); when PCC is not employed, patients are left feeling invalidated.	"[participants] recommended providers be empathetic, allow patients the opportunity to process the information, and actively check patient understanding…Even with these consistent suggestions for interactions, participants recommend that providers be mindful of the uniqueness of the situation to each patient" (Brann, Bute & Foxworthy Scott, 2020, p.264)
Miscarriage can be overmedicalized, which can lead to perceptions of poor communication	"[participants] adamantly recommended that providers be mindful of the language they use and specifically suggested avoiding medical jargon and emotionally charged language" (Brann, Bute & Foxworthy Scott, 2020, p. 261) "Take out contents; remove all the parts. I'm not an assembly. Like this isn't a factory" (Brann, Bute & Foxworthy Scott, 2020, p. 264)
Informed decision-making related to one's miscarriage can improve patient experiences.	"Women in our study strongly favored the ability to choose from among all treatment options—expectant care, medication management, and uterine aspiration—when faced with [early pregnancy loss]. They valued having options for this preference-sensitive decision, but also being supported by their provider in selecting the option that was best for them" (Wallace et al., 2017, p.460)

Patient-centered communication

The central principles of PCC were prominently featured in much of the literature on miscarriage and healthcare communication. These studies demonstrate patient-centered, individualized, and empathetic care is highly beneficial to miscarriage experiences and may lessen grief following an early pregnancy loss (Brann, Bute & Foxworthy Scott, 2020). PCC may play such an impactful role in this process that evidence shows that when communication regarding miscarriage lacks aspects of PCC, patients report feeling invalidated and distressed (Meluch, 2021). Moreover, if the provider is unclear in their communication of what happened or if they are dismissive of emotional aspects of the experience, patients are left with unanswered questions or misassigned guilt or shame (Brann, Bute & Foxworthy Scott, 2020; Meluch, 2021). Meluch (2021) summarizes, "when the way a traumatic diagnosis is communicated feels invalidating, it can make the entire medical experience feel undermined […] the way healthcare providers frame bad news is critical to how patients respond."

Additionally, providing PCC may also mean trying to include a patient's partner in the conversation. While miscarriage is often regarded as a women's health issue, male partners to women who have miscarriages report varying socioemotional effects following a pregnancy loss (Horstman et al., 2021; O'Leary & Thorwick, 2005). A study of male partners to pregnancy loss found that,

> When a baby dies, the anguish of the mother is visible to the world because she has the physical experience of pregnancy and child birth. This does not happen for fathers. They describe feeling overlooked… 'I felt even doctors or whatever seemed to worry about [my wife] and not so much about me. But it was there, it was hard because you felt left out. (O'Leary et al., 2006, p. 80)

Primary elements of PCC include demonstrating empathy, creating space for patients to process, checking for understanding, and avoiding medical jargon and emotionally charged language (Brann, Bute, & Foxworthy Scott, 2020). Empathetic care was emphasized and described in multiple articles from the review. For instance, Meluch (2021) suggests that healthcare providers do not have enough training to acknowledge *both* the physical and emotional pain of miscarriage. This is also evidenced in Miller and colleagues' (2019) study of miscarriage care in emergency settings. The study found that patients who were treated in the emergency department at a northeastern university hospital were more likely to report a lack of clarity surrounding their diagnosis, inefficient care, and a varied experience with provider sensitivity compared to those who sought care in an ambulatory-only setting (Miller et al., 2019).

Roehrs and colleagues (2008) used open-ended questionnaires and semi-structured interviews with nurses (n=10) from a birthing unit at a university hospital in the Rocky Mountain region to explore methods for addressing these concerns among healthcare providers,. The nurses indicated that healthcare providers must "be calm, but accessible [and] be sensitive to family needs" (Roehrs et al., 2008, p 634). Some participants also suggested that all providers take turns treating miscarriage patients in order to promote experience-based training and that orientations specific to miscarriage communication and conduct may be useful for improving care (Roehrs et al., 2008).

Finally, Brann and Bute (2017) used PCC concepts to guide their evaluation of medical interns (n= 40) discussing miscarriage with standardized patients (portrayed by training actors). Out of the 40 patient encounters assessed, only 8 (20%) interns properly explored patient concerns surrounding decision-making about their miscarriage (Brann & Bute, 2017).

Additionally, only 8 (20%) interns provided complete support to their ‘patients’ with comforting statements about their decision-making. Such statements included phrases like “one choice isn’t any better or worse than another” and “I think you have made a good choice” (Brann & Bute, 2017, p. 2272).

Terminology/phrases

Specificity with language and the ability to express empathy through words is crucial for achieving patient-centered care. The examined literature highlights how terminology and phrases used around miscarriage can impact how an individual processes their pregnancy loss (Brann, Bute & Foxworthy Scott, 2020; Bute & Brann, 2020; Meluch, 2021; Meyer, 2016; Wallace et al., 2017). For example, the use of ambiguous terms/diagnoses and medical jargon were both considered to have negatively affected the patients (Brann, Bute, & Foxworthy Scott, 2020; Meluch, 2021; Wallace et al., 2017). Ambiguity from one’s provider acted as a barrier to decision-making around miscarriage treatment, resulting in uncertainty influencing patients’ ability to cope (Wallace et al., 2017). In a study of women who have had a miscarriage responding to pre-recorded videos of medical interns delivering the news of a lost pregnancy, participants discussed their common dislike for medical terms like ‘fetal tissue, contents or parts’ when referencing the miscarried baby (Brann, Bute & Foxworthy Scott, 2020). One participant stated, “Take out contents; remove all the parts. I’m not an assembly. Like this isn’t a factory” (Brann, Bute & Foxworthy Scott, 2020, p. 264). Additionally, several studies have demonstrated that women who have a miscarriage strongly prefer the terms ‘miscarriage’ or ‘early pregnancy loss’ compared to ‘abortion’ (Brann, Bute & Foxworthy Scott, 2020; Clement al., 2019).

The language used in the healthcare setting around pregnancy loss has led to the discursive medicalization of miscarriage. Further, physicians’ communication about miscarriage unavoidably invokes expectations that pregnancy, and thus, pregnancy loss, are medical events that require medical solutions (Bute & Brann, 2020). Bute and Brann (2020) evaluated medical interns' ability to communicate a miscarriage diagnosis to trained medical actors. Their findings revealed several contradictory terms or phrases that can cause tension and confusion for patients experiencing a pregnancy loss (i.e., referring to miscarriage as a natural event in attempt to comfort women while also sometimes describing miscarriage as an abnormality in pregnancy; or explaining to patients that the miscarriage is not their fault, while also stating that the cause cannot be determined) (Bute & Brann, 2020).

While providers should strive to improve miscarriage communication according to the findings in the literature, they must also acknowledge that pregnancy loss is highly individualized, and thus, comforting messages may vary depending on the value assigned to the miscarriage (Horstman et al., 2021; Meyer, 2016). For instance, Horstman and colleagues (2021) found that some memorable messages can be both helpful and hurtful depending on the context of the loss. Common phrases like, 'this happens a lot' can be interpreted as being just another statistic *and* as validating because others are going through it too (Horstman et al., 2021).

Informed decision-making

Findings also suggest that practicing informed decision-making (IDM) can positively impact one's miscarriage experience (Brann & Bute, 2017; Wallace et al., 2017). When interviewed about their miscarriage healthcare and treatment options, women overwhelmingly prefer having management options available (Wallace et al., 2017). In other words, "women preferred direct communication about their treatment options with honest and clear explanations about what to expect from each method" (Wallace et al., 2017, p. 460). Moreover, while women report the need to choose which option seems best suited, they also desire their provider's advice and support in that decision (Wallace et al., 2017). Overall, participants valued the experience that their healthcare providers had with women in similar situations and their knowledge about the patients' individual needs and histories (Wallace et al., 2017).

Brann and Bute (2017) describe the critical aspects of IDM, including discussing the advantages and disadvantages of each option, the uncertainties associated with treatments, the patient's role in making the decision, and the patient's concerns and preferences, among several other elements. In a study evaluating the use of IDM among 40 medical interns in a Midwestern hospital, not one intern engaged in complete IDM (i.e., the highest score was a 13 out of 18 possible points using the IDM-18), indicating that a fully comprehensive discussion never transpired (Brann & Bute, 2017). The aspects of IDM that were most frequently lacking were assessing the patient's understanding, exploring patient concerns, and exploring the effect of the decision on the context (Brann & Bute, 2017). Though this study suggests that interns are engaged in somewhat effective IDM behaviors, the findings indicate more comprehensive training may be required.

Gaps in the Literature

To answer our second research question, we compiled a short list of topics and methodologies that remain unexplored in the miscarriage and healthcare communication research field in the US. Among other subjects, the primary aspects of research missing in the current literature include experienced physicians' perspectives of communication, evaluations of care guidelines and implementation of these guidelines, and studies evaluating diverse patient preferences and perspectives of PCC. The extant research on miscarriage communication in the US offers perspectives from women who have experienced miscarriage, their partners, and nurses. Additionally, as discussed earlier, several studies assessed interactions between medical interns and trained actors; however, miscarriage care would benefit from collecting direct perspectives of physician experiences with miscarriage patients via interviews or surveys, both in their training (i.e., internships/fellowships) and beyond.

A lack of care evaluation studies was apparent from our search. Professional guidelines and training for miscarriage communication among healthcare providers are inconsistent, and thus require systematic evaluation. Evaluations of the training materials and implementation of training programs are needed to assess communication standards across the healthcare sector.

Finally, research on patient preferences and miscarriage experiences has been conducted with primarily homogeneous groups. Moreover, existing studies are composed mainly of non-Hispanic white, highly educated participants who were trying to conceive (Brann, Bute & Foxworthy Scott, 2020; Horstman et al., 2021; Roehrs et al., 2008).

We also identified several gaps in the methodologies used to study miscarriage and healthcare communication. For instance, it was overwhelmingly clear that longitudinal studies are missing in miscarriage research in the US. Studies within our review pointed out the limitations in their cross-sectional study designs and called for longitudinal studies to explore any potential causal pathways. The literature is also largely qualitative and lacks in the generalizability of results. Therefore, miscarriage care and communication would likely benefit from more quantitative research studies with more extensive and diverse samples.

Discussion

This scoping review synthesized original peer-reviewed research on miscarriage and healthcare communication in the US. Three primary themes emerged from the eleven articles related to patient-centered care, terminology and phrases, and informed decision-making.

According to the literature, patients overwhelmingly prefer PCC and indicate that when their care lacks critical aspects of PCC, they are left feeling invalidated. Also, terminology used to describe miscarriage by medical professionals can lead to overmedicalized and less fulfilling interactions. This often results in patient perceptions of poor communication from their healthcare providers. Lastly, when providers promote informed decision-making related to miscarriage treatment, patient experiences improve.

Several gaps in the literature were also identified, which provides a roadmap for future research. Topics that remain unexplored in the US include physician perspectives of communication, evaluations of care guidelines, and studies representing diverse patient populations and their preferences for miscarriage care. Further, longitudinal studies are needed to assess healthcare communication during a miscarriage and grief periods following these interactions and more quantitative studies with larger and more diverse samples are needed to identify statistical relationships and establish generalizable results.

Limitations and strengths

There are limitations to consider with this study. While scoping reviews can offer a broad synthesis of existing literature, they cannot formally evaluate the quality of evidence as they often gather information from a wide range of methodologies (Sucharew & Macaluso, 2019). Additionally, our sample size of included articles was relatively small given the understudied nature of miscarriage communication research. We also limited our study to peer-reviewed, original research that omitted work in the grey literature. Moreover, the use of only specific databases available through the institutional affiliation may have resulted in a narrower literature search. Finally, the search was limited to publications available in English, potentially leading to a language bias and an exclusion of relevant content published in another language. However, this possibility was considerably small given that the study assessed US healthcare communication.

Our scoping review design did have several strengths. Primarily, the systematic scoping review is good for broadly synthesizing unexplored topics (Pham et al., 2014). Further, using two systematic frameworks (i.e., Arksey and O’Malley’s scoping review framework and PRISMA-ScR) helped to establish rigorous methodology and reporting/reproducibility of the results. Additionally, a second reviewer was used to perform the first phase of sorting articles by their title and abstract for 5% of the total articles to validate the eligibility categorizing performed by the primary investigator. Both reviewers used a citation management software, which further standardized the process.

Conclusions

This study highlights the need for individualized, patient-centered care that promotes informed decision-making and utilizes compassionate and accessible language when discussing miscarriages with patients. Though the literature in this review was largely qualitative, the emerging themes were supported by numerous studies. Future research should use quantitative methodologies and longitudinal designs to build upon these findings and further assess healthcare communication around a miscarriage.

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Appendix 2-A. *Abbreviated version of the extraction chart for sample of 11 articles*

Citation	**Topic**	**Design**	**Sample**
Brann & Bute, 2017	Informed decision-making	Observational	Patient encounters between OB/GYN interns & standardized patients [actors] (N=40)
Brann, Bute & Foxworthy Scott, 2020	Patient communication preferences	Focus groups	Patient encounters between OB/GYN interns & standardized patients [actors] (N=40)
Bute & Brann, 2020	Contradictions in miscarriage care	Observational	Patient encounters between OB/GYN interns & standardized patients [actors] (N=40)
Clement et al., 2019	Language preferences	Cross-sectional survey	Women with nonviable pregnancy between 5 and 12 weeks (N=145)
Horstman et al., 2021	Communicated sense-making	Phenomenology	Cis-gender heterosexual men (N= 45)
Meluch, 2021	Provider-patient communication in the ER	Autoethnography	Female with pregnancy loss (N=1)
Meyer, 2016	Commonly used social support phrases	Autoethnography	Female with pregnancy loss (N= 1)
Miller et al., 2019	Miscarriage in the emergency and ambulatory settings	Mixed methods	Women with first trimester fetal demise (N= 54)
Roehrs et al., 2008	Caring for families	Descriptive naturalistic	Nurses (N= 10)
Wallace et al., 2017	Counseling	Grounded theory	Women with early pregnancy loss (N= 21)
O’Leary & Thorwick, 2005	Father’s perspectives	Phenomenology	Fathers with pregnancy loss (N= 10)

Chapter 3: “You're kind of just left to figure it out on your own": A qualitative exploration of miscarriage communication and reproductive self-efficacy

Abstract

Miscarriage affects as many as one in four pregnancies and can have health and social consequences, including diminishing a couple’s sense of reproductive self-efficacy (RSE). While a miscarriage itself does not typically dictate a woman’s ability to get pregnant again, how her miscarriage is managed may play a role in this process. Research suggests that women prefer patient-centered communication during a miscarriage; however, research on the relationship between healthcare communication and RSE is limited. This study aimed to explore the role of healthcare communication during a miscarriage on one’s sense of RSE and to identify aspects of care that improve or worsen RSE. We conducted semi-structured virtual interviews with 12 women who had experienced miscarriage. Our findings revealed important context regarding the care received during and after one’s miscarriage and a patient’s sense of RSE following that loss. RSE was optimized when patients received care that reassured them of their long-term reproductive goals, provided guidance for their next steps, and was patient-centered and empathetic to their pregnancy history. Our study acts as an important step in introducing the concept of RSE, opening up various directions for future research regarding miscarriage management and fertility outcomes. The findings also echo previous research on patient-centeredness and miscarriage care while offering new insights into post-miscarriage management and the process of trying to conceive.

Introduction

Miscarriage affects as many as one in four pregnancies equating to approximately one million losses per year in the US alone (Clement et al., 2019; Farren et al., 2016). Though the true rate of miscarriage may be much higher, many women experience early miscarriage before they know they're pregnant and may assume it to be a late or heavy period (Bellhouse et al., 2018). Miscarriage, defined as a spontaneous loss of a pregnancy prior to 20 weeks of gestation, is the most common form of pregnancy loss (Prager et al., 2018; World Health Organization, 2021). Patients who experience miscarriage are at increased risk for subsequent losses and adverse psychological effects (i.e., post-traumatic stress disorder, anxiety, depression, etc.) (Farren et al., 2016; Larsen et al., 2013). Unexpected and considerable healthcare costs may also accompany miscarriage management when expectant treatment is not an option (i.e., medical and/or surgical management is required) (Dalton et al., 2015). Unfortunately, miscarriage can affect anyone of child-bearing age, though individuals over 35 are at greater risk for pregnancy loss (American Pregnancy Association [APA], 2017).

The miscarriage itself often does not incur long-term health consequences or affect a couple's ability to get pregnant again (APA, 2017). Management of the miscarriage, however, may affect the couple's coping and daily life (Brann & Bute, 2017). Psychological and social consequences can be mitigated if healthcare providers engage in patient-centered communication (PCC) and informed-decision making (Bellhouse et al., 2018; Brann, Bute, & Foxworthy Scott, 2020). PCC during a miscarriage helps patients to process their loss more effectively and assist in creating a plan for moving forward with their reproductive journey (Brann, Bute & Foxworthy Scott, 2020; King & Hoppe, 2013). Evidence suggests that despite existing training models and hospital policies, some healthcare providers still fail to engage in these practices (Bellhouse et al., 2018). This failure can harm a patient's mental and emotional state after receiving heartbreaking and often shocking news.

Patient-centered Communication

Brann and colleagues (2020) outlined preferred communication strategies by patients who experience a miscarriage and called upon the medical community to incorporate patient's voices and preferences in training and practice. For instance, women from their study desired empathetic care, which creates space for patients to process their losses, checks for patient understanding, and avoids medical jargon and emotionally charged language (Brann, Bute & Foxworthy Scott, 2020). However, these strategies of PCC have not yet been directly assessed in the healthcare setting.

As such, we used a PCC framework to inform this phenomenological study which was used in developing the interview guide and throughout the analysis. PCC may help healthcare providers to acknowledge the complexities of pregnancy loss and to improve care for miscarriage patients. The framework describes strategies and behaviors providers are encouraged to use to promote mutuality, shared understandings, and shared decision-making through the healthcare process (Brown, 1999; Hashim, 2017). PCC care is often highly individualized and addresses a patient's informational and emotional needs (Brown, 1999; King & Hoppe, 2013).

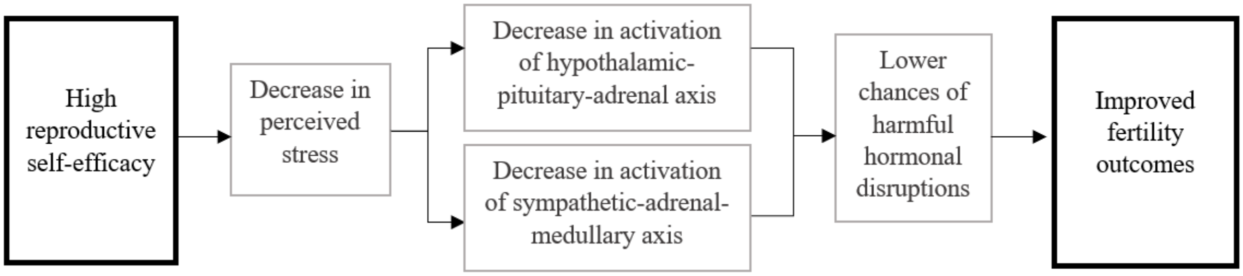
Reproductive Self-efficacy

In addition to the psychological and physiological consequences of early pregnancy loss, a miscarriage can also undermine a couple's confidence in their ability to reproduce successfully (Bhattacharya & Bhattacharya, 2009). We describe this sense of confidence in one's ability to get pregnant and to carry a pregnancy to full term resulting in a live birth as reproductive self-efficacy (RSE). Grounded in Bandura’s studies of self-efficacy mechanism, RSE relates thought patterns, individual actions, and emotional influences related to reproduction efforts. Bandura (1982) suggests that perceptions of self-efficacy influence changes in coping behaviors and psychological health processes, producing higher rates of performance accomplishments (i.e., achieving the desired outcome). Self-efficacy has evidenced robust outcomes in health promotion in many health topics and may be a critical construct in relationships involving reproduction processes (Cousineau et al., 2006).

The relationship between RSE and fertility has yet to be examined; however, there may be a crucial beneficial nature to RSE by means of reducing harmful physiological responses to stress while trying to conceive. Moreover, reductions in perceived stress may decrease activation of the hypothalamic-pituitary-adrenal axis and the sympathetic-adrenal-medullary axis (Palomba et al., 2018). When activated, these axes may result in abnormal, prolonged, and/or excessive stress-induced states of the body, which can produce long-term neuroendocrine changes (i.e., impacting fertility) (Palomba et al., 2018). This relationship is summarized in the model below (see figure 1).

Figure 1

Reproductive self-efficacy and fertility relational model



The Infertility Self-Efficacy scale (ISE), a validated data collection tool, has shown similar promise in predicting psychological and behavioral health outcomes in patients seeking fertility assistance (Cousineau et al., 2006). This scale is used to estimate perceived abilities and confidence to engage in particular health-promoting activities related to infertility practices (Cousineau et al., 2006). Findings from the present study may be used to inform RSE scale development comparable to the ISE in hopes of addressing self-efficacy in patients prior to seeking fertility assistance treatments.

Significance

RSE remains unexplored, particularly in its association with fertility and miscarriage management. This study will contribute to the existing research on early pregnancy loss in hopes of improving the healthcare communication experiences of those having a miscarriage in the US. While patient preferences for healthcare communication during a miscarriage have been identified via focus group studies, research and clinical practice would benefit from directly analyzing the use of PCC in miscarriage management and its effects on RSE and fertility. Additionally, little is known about how healthcare communication influences health outcomes, such as RSE, following a miscarriage.

Further, this study explores beyond the initial disclosure of a miscarriage and encapsulates the entire management of a patient’s miscarriage(s) from trying to conceive through treatment and post-miscarriage care. Unlike previous studies, this study also examines miscarriage communication from both the clinical (i.e., physicians, nurses, radiologists, laboratory and ultrasound technicians, etc.) and administrative (i.e., receptionists, billing departments, office staff, etc.) employees as to paint a holistic picture of the healthcare communication received during a miscarriage.

This work will enhance miscarriage management by addressing these research needs, resulting in improved health outcomes for women and families. Establishing standardized care that boosts RSE will benefit all individuals trying to conceive and may augment the reproduction process. Healthcare teams may also benefit from these findings as they seek to provide holistic and beneficial care for their patient's best interests.

Research Questions

This study explores the contexts in which miscarriage communication and RSE interact. Using a qualitative approach, we conducted semi-structured interviews with women who have experienced miscarriage(s) to better understand this relationship. The following research questions guided our study:

1. What role does communication from a healthcare team during a miscarriage play in a patient's sense of RSE?
2. What aspects of miscarriage management enhance or worsen a patient's sense of RSE?

Methods

Design

Phenomenology was used to explore the experiences of communication from a healthcare team by women who have had a miscarriage and perceptions of RSE. Phenomenology allows the researcher to understand how individuals reflect on their experiences, what they perceive as significant and how that impacts their lives and decision-making going forward (Meaney et al., 2017). Women were recruited from social media support groups and informed consent as obtained upon recruitment. Semi-structured, individual, in-depth interviews were conducted via webcam (i.e., Zoom). A semi-structured interview format was selected due to the sensitive nature of the research subject. This approach enables the exploration of in-depth experiences when little is known about a sensitive topic without deviation (Adams, 2010). Interviews were audio-recorded, transcribed in full and analyzed using Smith's interpretive phenomenological analysis (IPA) and the RADaR (rigorous and accelerated data reduction) technique (Smith et al., 2009; Watkins, 2017). Detail on these techniques are further described below. Demographic information on all participants was also collected.

Sample

The study population comprised women with one or more miscarriages within the last five years. For this study, a miscarriage was defined as an unintentional pregnancy loss before 20 weeks of gestation (Centers for Disease Control and Prevention [CDC], 2020). Women were included in the study if they lived in the US, spoke English, and were between 18 and 45. Participation also required a medical diagnosis of a miscarriage, meaning that the participant was told by a healthcare provider that they had miscarried. Purposive sampling was used to identify women who met the criteria and sampling continued with maximum variation regarding age, educational attainment, race/ethnicity, parity/gravidity, and location of diagnosis (i.e., obstetric office, hospital, emergency department, etc.). Data were collected until saturation within the findings was met and 12 women were included in the study. Participants ranged from 25 to 38 years, with an average age of 31.4 years. Approximately half of the women had experienced one miscarriage (n=7, 58.3%), and the rest experienced multiple miscarriages (range=3-6). Most women (n=10, 83.3%) were actively trying to conceive and over half (n=7, 58.3%) had successfully carried at least one pregnancy to term resulting in a live child (see Table 1 for additional participant demographics).

Table 1

Participant demographics, N=12

	Frequency (N)	Percent (%)
Age		
18-24	0	0.0
25-29	3	25.0
30-34	7	58.3
35-45	2	16.7
Number of miscarriages		
1	7	58.3
2-3	1	8.3
≥ 4	4	33.3
Intentionality of pregnancy		
Trying to conceive	10	83.3
Not actively trying	2	16.7
Parity		
0	5	41.7
≥ 1	7	58.3
Treatment Location		
OB/GYN office	6	50.0
Hospital/Emergency Department	4	33.3
Both	2	16.7
Marital Status		
Married	11	91.7
Unmarried	1	8.3
Race/Ethnicity		
Non-Hispanic White	10	83.3
Non-Hispanic Asian	1	8.3
Multiple races	1	8.3
Educational level		
High school degree/GED	1	8.3
4-year college degree	4	33.3
Graduate degree	7	58.3

Recruitment

Women were invited to participate in the study through miscarriage bereavement groups and women-based groups on the social media sites Facebook and Reddit. The following Facebook pages were used for recruitment: Miscarriage Support-Pink Elephants, Pregnancy and

Infant Loss Support Page, Miscarriage Support Group, New Moms in NYC, and Moms and Mommies to be—Charlotte, NC area. The Facebook population is considered fairly representative of the general population given the significant number of users and growing utilization rates (Kosinski et al., 2016). The following Reddit subforums were used: r/Miscarriage, r/WomensHealth, r/ttcafterloss, and r/Pregnancyafterloss. Reddit's subforums allowed us to target specific populations, enhancing recruitment (Shatz, 2017). Additionally, US Reddit users' demographics are considered fairly representative of the general adults' US population, particularly when controlling for age (Shatz, 2017).

An initial post with a digital flyer (see Appendix 3-A) was created to seek participants, who were then asked to complete a brief Qualtrics eligibility survey. If the participants were determined to be eligible, they completed an electronic demographic survey via Qualtrics and were scheduled for an interview by the primary investigator (PI). None of the participants were known to the PI. Upon completing an interview, all participants received a $25 electronic gift card to Amazon as a thank you for their participation.

Data collection

One-to-one interviews were conducted from June through August of 2022 and lasted between 26-74 minutes (mean time = 48 minutes). The PI conducted all interviews to ensure consistency. Interviews were audio-recorded, and digital audio files were stored in a restricted-access university Dropbox folder to ensure the participants' privacy was protected. The audio files were transcribed verbatim using the transcription software, Rev.com and transcripts were reviewed by the PI for accuracy. All field notes, audio files, transcriptions and analyses were preserved in the restricted-access folder.

The interviews were driven by an interview guide (see appendix 3-B) to ensure that certain topics were discussed. The questions were developed using the researcher's reflections on practice and the existing literature on communication and perinatal loss. Some questions from the interview guide mirrored definitions of PCC, such as asking about vague or unsettling language, whether a healthcare provider checked for understanding, or if the healthcare team took steps to mitigate a distressful response. We also asked questions related to RSE (i.e., After your miscarriage(s), how confident were you in your ability to get pregnant again, if this was something you wanted?). The PI did divert from the interview guide when probing for more information or asking clarifying questions, resulting in a semi-structured format.

Analysis

A combination of manual and digital coding was used. Interview transcripts were read once through for transcription accuracy. The PI then annotated the transcripts by hand, followed by digital coding using Microsoft Excel and the RADaR (rigorous and accelerated data reduction) technique (Watkins, 2017). This technique uses tables and spreadsheets to create several rounds of data reduction to arrive at synthesized themes. Thus, inductive analysis was used to create a codebook driven by the data. Some of the relevant codes included, intentionality of pregnancy, parity, disclosure of miscarriage, the role of the partner, etc. Three rounds of deduction were completed to arrive at a final codebook of themes and subthemes.

IPA was used to pull themes and subthemes from the data. IPA relies on the participants making sense of their personal and social realities and will help understand how they recognize and share their experiences (Smith et al., 2009). Further details of IPA are described by Smith and colleagues (2009). All authors confirmed emergent themes.

Ethical Concerns

The study was approved by the UNC Charlotte Institutional Review Board (Protocol #: IRB-22-1046) (see Appendix 3-C). All members of the research team operated in compliance with the Health Insurance Portability and Accountability Act to ensure the protection of the participants' sensitive and medical data. In addition, the data were de-identified using pseudonyms during all stages of analysis and reporting. Lastly, informed consent was collected upon recruitment, where participants were informed about the study requirements, the purpose of the study, and the risks or benefits of participation (see Appendix 3-D). The participants were also made aware of their ability to withdraw from the study at any point. During the interviews, they were allowed to refuse to answer if they were uncomfortable sharing certain information. Evidence suggests that the benefits of conducting interviews on sensitive topics may outweigh the risks of harm, mainly when the research team takes the appropriate steps to mitigate those risks (Muraglia et al., 2020).

Rigor

Credibility was achieved using member checks after digital coding. Several participants were asked to validate transcription and analysis aspects and to confirm or correct the information provided. This process was in place to verify the accurate representation of the participants' realities in the analysis and final report and to establish authenticity (Goldblatt et al., 2011). Particular attention was paid to the description of the context, settings, and participants using a reflexivity journal throughout the study to boost transferability; detailed notetaking and description helped to limit the likelihood of missing data as well as to enhance the dependability of the data that are collected (Lincoln & Guba, 1985). The reflexivity journal was also used to enhance credibility and deepen the PI's understanding of the work.

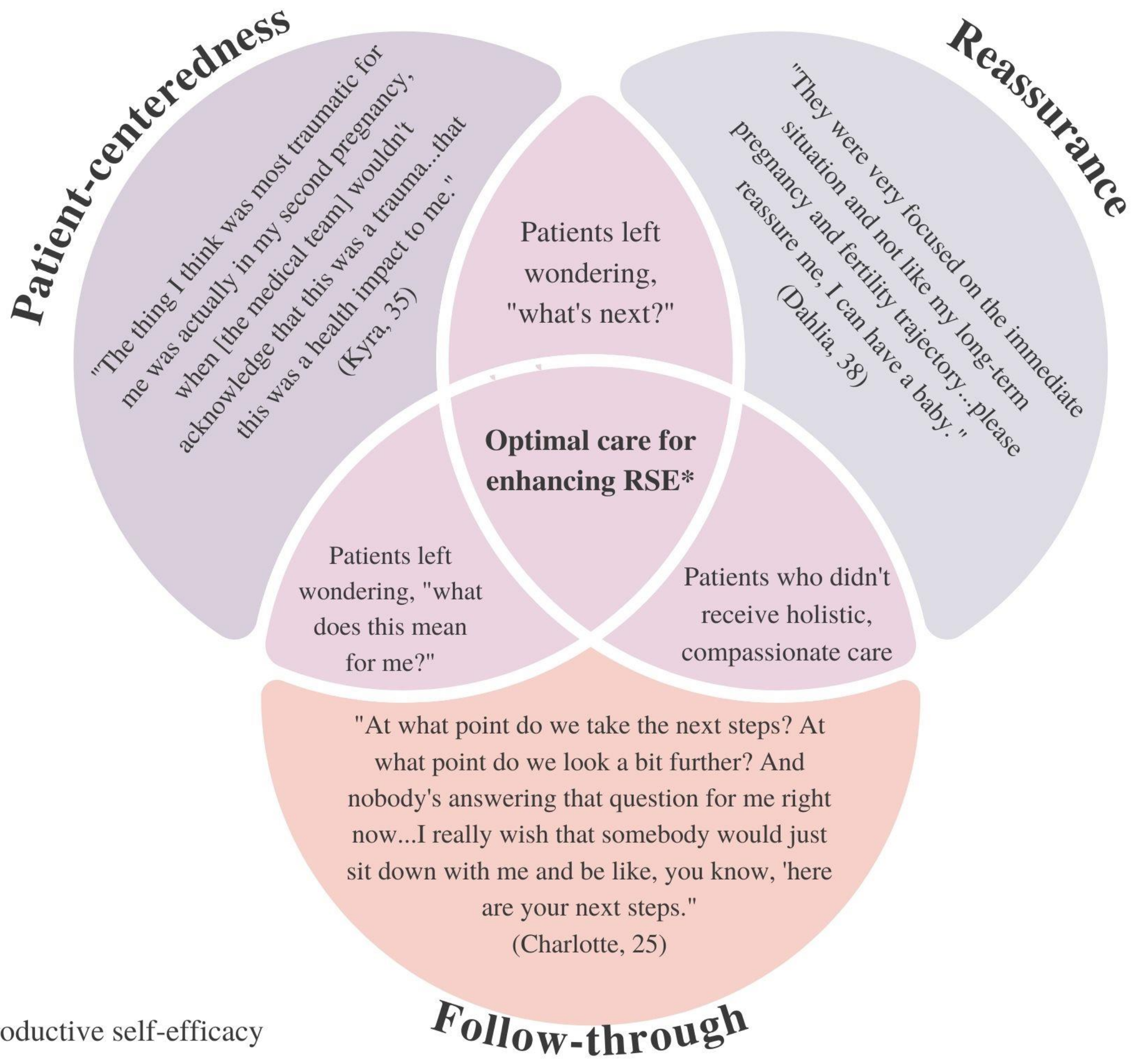
Findings

The interviews gave some context to the potential relationship between miscarriage management/ healthcare communication and RSE. Each of the participants who reported feelings of somewhat high RSE (i.e., their confidence in their ability to have a baby was not impacted greatly by their experience of miscarriage) also expressed supportive and reassuring care (i.e., providers who spoke positively about future pregnancies and who discussed implications of pregnancy loss on fertility). Three themes emerged to support this finding: (a) reproductive implications of miscarriage, (b) guidance and resources for navigating fertility issues; and (c) patient-centeredness.

Figure 2 outlines the relationship between these themes and RSE. Findings related to the implications of miscarriage are displayed as desiring reassurance and findings related to guidance and resources are displayed as follow-through. Patients who receive patient-centered care that is reassuring of future pregnancies and helpful in navigating fertility issues by providing follow-through is optimal for enhancing a patient’s sense of RSE.

Figure 2

Optimizing miscarriage care for improving reproductive self-efficacy



*Reproductive self-efficacy

Reproductive Implications of Miscarriage

Participants overwhelmingly desired reassurance from their healthcare teams. Patients who did not receive care that reassured them of their goal of having a baby were left wondering, ‘what does this mean for me?’. Scarlett, a 31-year-old woman who miscarried before even knowing she was pregnant, equated informative care about the implications of miscarriage with an empathic response.

In many circumstances, women received overall effective care for treating their miscarriage but noted a lack of discussion about the future implications of miscarriage on getting pregnant again. Dahlia, a 38-year-old woman who had experienced recurrent miscarriages, expressed:

> It kept getting scarier and scarier and I wanted and needed reassurance, but [my doctors] weren’t really giving that to me. They were very focused on the immediate situation and not like my long-term pregnancy and fertility trajectory…Please reassure me [that] I can have a baby and I can have a successful pregnancy.

Others noted that their provider’s attempt at comforting them with blame-reducing language was less helpful when it was not followed by the reassurance that they really wanted. Thirty-five-year-old Kyra, who experienced one miscarriage before successfully giving birth to her daughter, recalled,

> There was a lot of, ‘it’s not your fault’ but there wasn’t a lot of, ‘it’s going to be okay.’ Like there wasn’t a lot of ‘this doesn’t mean you can’t have a baby.’…And like, I get that they can’t give you assurances necessarily, but they can give you statistics if it’s unlikely…this isn’t your whole story, this moment isn’t everything.

Another implication of miscarriage that was often dismissed in the healthcare setting was the psychological and emotional impacts on pregnancies after loss.

Further, Kyra felt that her medical team invalidated her experiences of miscarriage in her subsequent pregnancy. She said, “it sort of doesn’t matter how well [the healthcare team] communicate the first time around if it, it just feels like lip service at that point” (Kyra, 35).

Maggie (32) requested an additional follow-up appointment after her miscarriage when she was left with many unanswered questions about what this experience meant for her reproductive journey. She described her initial miscarriage care saying, “I know it’s not my fault, but at the same time at that moment, I just wanted data to say, ‘hey, what’s happened here? And how can we prevent it in the future?...What if this happens again, like what do I do then? Or how long should we realistically wait?” (Maggie). Though it was not part of the healthcare system’s protocol, the follow-up appointment proved to be quite helpful in Maggie’s situation. Her experience lends itself to receiving both the reassurance that she desired and the guidance in navigating the next steps, our second thematic finding.

Guidance and Resources for Navigating Fertility Issues

Participants shared experiences of difficulties navigating their reproductive journey once they had a miscarriage. Participants who did not receive care that included follow-ups and guidance were left wondering, ‘what happens next?’. This frustration was about both navigating the healthcare system (i.e., when to see an infertility specialist, using the patient portals, interacting with insurers and administrative staff, etc.) and navigating their own fertility issues (i.e., what happens if I continue to miscarry? When can I receive extra ultrasounds for my subsequent pregnancies? How do I advocate for fertility testing? etc.). Dahlia (38) described the experience of recurrent miscarriages, expressing that these frustrations at times outweighed the grief she felt from her losses:

> Disjointed care is really annoying for anybody, but it can definitely be retraumatizing, um, when you're experiencing a loss and you have to go seek out information from different sources… Probably more difficult than the experience of the loss, the losses themselves, it was having to interface with the medical system hundreds of times…and every potential interaction or step into the medical system or phone call, or, or my chart message, like sending your doctor a message was another vulnerability. It was opening yourself up to be triggered or retraumatized or made to feel bad.

This vulnerability went hand-in-hand with the experiences of invalidation of the psychosocial impacts of miscarriage previously mentioned. Participants desired immediate information for what to expect next and assistance in following through with managing their reproductive journeys. Twenty-five-year-old Charlotte, a mother of two who had experienced five pregnancy losses, wished that her healthcare team had sat down with her and laid out the next steps in her attempt to have a baby. Participants were often left to advocate for themselves regarding care in subsequent pregnancies and trying to find the root cause of their miscarriages. Everly (34) recalled:

> None of my doctors seemed very concerned about figuring out the cause [of my miscarriages] until I started seeing my reproductive endocrinologist… if my healthcare team had been more interested in investigating the miscarriages, and if I didn't have to advocate so strongly for myself for testing and referrals, that would have helped.

Another woman faced barriers to investigating the cause of her miscarriage when her insurance company refused to cover the costs. She expressed, "Part of me was convinced that the reason why I had miscarried was because of my first [medically necessary] termination…And no one did or said anything to try to confirm or look into that" (Sadie, 26).

Providing resources to patients following their miscarriage also was described as very helpful in this navigation. Participants who received resources of any kind more positively described their care and post-miscarriage periods, and participants who struggled after their miscarriages said they wished someone had given them more resources. Kate, a 28-year-old mother who experienced a missed miscarriage, explained, "I think maybe like even just giving resources to people…it would've been nice for my [OB/GYN] office to give me support. Yeah, or like support groups or like tips or just anything. You're kind of just like left to figure it out on your own." This also heightened the loneliness and stress felt by participants, who often took to Google or Reddit for help when their medical provider failed to guide them through the experience. Kyra (35) much preferred to have been told important medical information from her provider rather than searching online for answers, stating that having receiving that information would have lessened some of her anxiety.

Similarly, Lily, a 34-year-old mother of one, said she had heard of other hospitals providing pamphlets about miscarrying at home that guide for when to seek medical help and how to manage your miscarriage, which she suggested should be a commonplace practice for pregnancy loss care. Another participant expressed gratitude for a pregnancy-loss grieving support group she joined following her miscarriage, saying, "I feel like organizations like [Return to Zero] have been really helpful. Um, and if more medical professionals know about stuff like that, then I think that would be good."

Patient-centeredness

The final supporting theme was related to patient-centeredness. When patients received care not grounded in PCC, they were left feeling like they did not receive compassionate care that acknowledged them as whole people. Care that lacked PCC included being dismissive of anxiety and other psychological and emotional factors, using unclear or unsettling language (i.e., medical jargon), and being ignorant of the emotional impacts of the OB/GYN setting for women who have experienced a miscarriage. Everly (34), who experienced recurrent miscarriage, felt something was wrong with her pregnancy when she was experiencing continual bleeding and cramping. Her healthcare team repeatedly advised to 'not worry about it,' only to be told she had miscarried at her next appointment. She expressed, "I really wish, um, that [my doctor] would've just like validated my concerns instead of writing me off as this like, anxious, crazy person."

Some language used, specifically in medical documents and portals, was upsetting for participants. For example, seeing the term 'habitual aborter' or 'spontaneous abortion' in their medical chart was mentioned when participants were asked if their provider used any unclear or unsettling language. Dahlia (38) reflected, "there's a lot of language…used in general that makes you feel not great, things about your age and advanced maternal age, habitual aborter, it does feel very 'blame the woman.'" On the other hand, efforts to remove guilt or blame (i.e., "this is not your fault," "you did nothing wrong," etc.) were most often well-received, apart from one woman who felt these efforts were "cliché" and unhelpful.

The healthcare setting in itself can be full of potentially triggering conditions. Healthcare teams should be aware of these factors and act to protect women who may be grieving a pregnancy. For instance, Kate (28), Kamryn (33), Lily (34), Morgan (30), and Everly (30) all mentioned being in the waiting room full of pregnant people while either communicating with the administrative staff or when waiting for their procedure or appointment. Thirty-three-year-old Kamryn, a mother of one who experienced recurrent miscarriages, recalled, “Just waiting a long time for doctor’s appointments was really hard…So I would…like this recent time [with miscarriage], I faced myself towards a wall just cause I knew it would give me a lot of anxiety.” Morgan (30) recalled feeling “trapped” in the waiting room while surrounded by “happy-go-lucky” pregnant people. Others were fortunate to have a nurse or doctor walk them out of the office an alternative way so that they would not have to encounter other pregnant people. This empathetic act was appreciated greatly by the participants.

Putting patients at the center of your care requires acknowledging the potential impacts of their pregnancy histories. As previously discussed, when a provider takes the time to acknowledge the effects of miscarriage, patients perceive better care. When they fail to do so, it may have devastating effects. Kyra (35) said, “The thing I think was most traumatic for me was actually in my second pregnancy, when [the medical team] wouldn’t acknowledge that this was a trauma…that this was a health impact to me and so, that’s not okay.” Conversely, Dahlia explained that her healthcare team acted with appropriate compassion for the situation:

> It’s not even just words, it’s that they’re gentle with you…they meet the moment. They acknowledge the gravity of the situation, and they are not acting like that you’re in there for like a UTI…You wanna act like you’ve done it a hundred times if you’re doing a colonoscopy, but acknowledge what I’m there for, if it’s something like [pregnancy loss] and they did.

Similarly, Charlotte (25) felt that her healthcare team acted proactively by anticipating her needs and being able to read how Charlotte felt once they disclosed the news of her pregnancy loss.

Discussion

Research on RSE is limited, yet it may have affect fertility and pregnancy health. Studying healthcare communication during a miscarriage, particularly in improving RSE and subsequent pregnancy outcomes is critical given the association of PCC and psychological and emotional outcomes following a miscarriage (Bellhouse et al., 2018; Brann, Bute & Foxworthy Scott, 2020). Our study revealed findings that suggest multiple avenues for improving RSE through healthcare communication and management. Participants from our study emphasized their desire for reassurance of long-term pregnancy goals, guidance through the navigation beyond a miscarriage, and care that is patient-centered and empathetic to their loss(es).

These findings may indicate an area of needed improvement for training medical professionals (including administrative staff) when treating patients who experience a miscarriage. The results may also influence hospital policies and systematic changes regarding scheduling dilation and curettage procedures, technicians' abilities to disclose miscarriages, waiting room policies and more.

We built upon previous literature regarding the use of PCC in miscarriage care and expanded our investigation beyond the disclosure appointment and the physicians who disclosed the news. In doing so, we uncovered several vital considerations that have not been discussed in previous studies: (a) the value of following up with miscarriage patients and guiding them through their reproductive journeys after loss; (b) the impact of simple procedural aspects of care (i.e., scheduling follow-up care in the waiting room full of pregnant people); and (c) the frustrations associated with having to advocate for fertility testing and/or additional scans in subsequent pregnancies.

Limitations and strengths

Our study’s sample should be considered when assessing the results and translating this research into practice. We had a largely homogenous sample of women (i.e., primarily non-Hispanic white, highly educated, married at the time of miscarriage, and trying to conceive). However, our sample did vary somewhat by age (range: 25-38), the number of losses (range: 1-6), location of diagnosis (OB/GYN vs. hospital/emergency department), and parity (range: 0-2). We spoke with two participants who did not intend to get pregnant when they experienced their miscarriage. The analysis did not highlight discernible differences between these women and those actively trying to conceive regarding our three thematic findings. Contextual factors, such as the intentionality behind pregnancy, may impact the relationship between miscarriage management and RSE and should be further explored. Additionally, the analysis and coding of the data were conducted by one researcher, but themes and subthemes were confirmed among all authors.

We acknowledge the qualitative limitations regarding generalization. Nevertheless, there are several benefits to conducting semi-structured interviews (Adams, 2015). The ability to produce in-depth and illustrative data helps us to understand more complex and socially integrated issues, such as pregnancy loss (Quirós et al., 2017). Since we conducted interviews over Zoom (video-conferencing software), the ability to establish rapport with participants was partially limited. Still, 11 of the 12 participants did utilize their cameras, which helped to feel more like an in-person interview. Consistency was also established by using one interviewer for all 12 interviews. Finally, the use of electronic storage and analysis made for a more efficient and systematic research process while enabling a clear audit trail (Mattimoe et al., 2021).

Future Directions

In addition to examining the potential effect of pregnancy intentionality on healthcare communication and RSE, the findings also reveal several other future research directions. Our study was focused on patient-provider communication during a miscarriage; however, we recognize that while a miscarriage *physically* occurs to a woman, her partner and their sense of RSE may also be impacted by the communication received by the healthcare team. Participants in our study pointed to the shared experience of miscarriage, noting that the perceptions and feelings following the miscarriage may have differed but that it was both partners' loss. A similar notion has been evidenced in the literature (Bute & Brann, 2015; Walker & Walker, 2015). Thus, future studies may wish to examine the experiences of healthcare communication during a miscarriage by their partners and partner perceptions of RSE following the loss.

Participants in the study also emphasized the importance of following up with their healthcare team after miscarriage. Therefore, future research should investigate the potential impacts of having a follow-up appointment after a miscarriage on a patient's sense of RSE. Similarly, researchers should consider the possible effect of having living children on the relationships explored within this study.

Conclusions

This study reveals the value of healthcare communication in the miscarriage setting, emphasizing the importance of patient-centered care on reproductive outcomes, such as RSE. It also acts as an important step in introducing the concept of RSE, opening up various directions for future research regarding miscarriage management and fertility outcomes. Our study echoes previous research on PCC and miscarriage care while offering new insights into post-miscarriage management and the process of trying to conceive. Women in our study desired care that is reassuring of long-term reproductive goals, provides guidance through the next steps of their reproductive journeys and is centered on the patient’s contextual and emotional needs. We believe that when all three of these aspects are met, healthcare providers can optimize RSE outcomes for their patients.

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Appendix 3-A. *Digital flyer used for recruitment on social media support group pages*

Miscarriage Research Study

PURPOSE: To understand how communication from your healthcare team influenced your experience of miscarriage & to understand perceptions, beliefs, and knowledge of pregnancy loss from pre-conception to post-miscarriage.

REQUIREMENTS: one 45-60 minute virtual interview (via Zoom/phone)

Recieve a $25 AMAZON GIFT CARD upon completion of the interview.

Are you eligible?

If you have had a miscarriage(s) in the last five years and...

- are a cisgender woman between the ages of 18-45
- live in the US and speak English, and
- were told by a healthcare professional that you miscarried

Click here for eligibility survey

IRB-22-1046

UNIVERSITY OF NORTH CAROLINA CHARLOTTE

Interested or have questions? DM me or
Contact me: Klacci@uncc.edu

Appendix 3-B. *Interview guide used for chapters 2 and 3 data collection*

Hello, I'm Kandice and I would first like to thank you for taking the time to talk with me today. We're here to discuss your experiences with pregnancy and miscarriage, and I'm looking to understand your perspective of trying to have a baby. I understand that this topic may be difficult to talk about and I appreciate anything you are willing to share with me. As a reminder, if at any point, there is a question you feel uncomfortable answering, you may ask me to skip to the next question or to come back to it at a later point – either possibility are completely okay. You may also let me know if you wish to stop the interview or withdraw from the study. The conversation will be recorded and transcribed – my dissertation committee members and I will be the only ones to have direct access to your interview. The things we discuss today will be written about in two manuscripts for my dissertation. Your information will be de-identified using a pseudonym.

If you are ready to begin, I am going to start with a few demographic and background questions.

1. How old are you now?
2. How old were you when you had your most recent miscarriage?
3. How many previous pregnancy losses had you experienced before this past miscarriage?
4. Where were you treated for your miscarriage(s)?
5. Were you married when you had your miscarriage(s)? [If not, did you have a partner?]
6. Was the pregnancy that ended in miscarriage a result of assisted reproductive technology?
7. What are your race and ethnicity?
8. What is the highest degree or level of education you have completed?
9. What city do you live in?

Now, I will be going into some more broad questions about your miscarriage experiences. Some of the questions or prompts may seem repetitive, but that is just to make sure that I am really understanding your story and will be able to comprehensively capture your experiences of pregnancy loss. If there is any question that you need clarification on, please do not hesitate to ask. Are there any questions you have for me before we begin?

10. Let's just start by telling me about your experiences trying to have a baby.
11. How do you refer to your loss? Is there a specific term you would like me to use instead of miscarriage or loss?
12. What was your experience of 'miscarriage' [term she uses] like?

The next few questions will focus specifically on your interactions with the healthcare team during your [miscarriage].

13. Can you tell me about the time when you received the news of your loss?
    a. Who was it that disclosed this news to you? Was it a doctor, nurse, or lab tech, for instance?
    b. [If they had a partner] Was your partner with you when you heard this news?
    c. What were some of the thoughts running through your head when you heard this news?
14. How well did you feel that the provider [doctor, nurse, tech…] communicated about what had happened to you at that time?

    a. Did the [provider] use any words that were unclear or unsettling to you?
    b. Did the [provider] ask you any questions to try to clear things up? Or did they ask you to repeat back any information?
    c. What type of information did the [doctor] provide about going forward with your [miscarriage] or the course of treatment? Did they discuss any potential risks?
    d. Were you aware of the various treatment methods for [miscarriage]?
    e. Did the [doctor] discuss each of the three treatment options? Did they ask you which you preferred?
    f. Did the treatment method that was chosen align with your desired option?
    g. When you left the office that day, were you left with any unanswered questions?
15. How supported by your [doctor] did you feel when they were telling you about your [miscarriage]?
    a. How would you describe any steps that the [doctor] took to demonstrate empathy or compassion for you at this time? For instance, was there a specific action that the [doctor] took or words they said that made you feel comforted?
    b. [If the partner was present] Did you feel that the [doctor] made an effort to include your partner in this discussion?
    c. Were you comfortable with the amount of time your [doctor] spent discussing this news with you?
16. Was there anything you wish the [doctor] had said or done to make you feel better in that moment?
17. Was there anything that the other healthcare team members could have done to better support you in that moment? For instance, the other nurses, the lab tech, or the reception staff.
18. Overall, how satisfied were you with the care you received during your [miscarriage]?
19. After this experience, how did you move forward with your reproductive journey?
    a. Were there any new barriers that came up in this journey because of your experiences with your earlier miscarriage(s)?
    b. How confident were you in your ability to get pregnant again, if this was something that you wanted?
    c. How confident were you that you could carry a pregnancy to full term and deliver a healthy baby?
    d. How long did it take before you wanted to try again?

The final few questions I have for you today will reflect your overall pregnancy experiences and perceptions of pregnancy loss. Are there any questions before we begin this final section?

20. Before getting pregnant, what were your expectations for pregnancy?
    a. What did you know about miscarriage?
    b. Had anyone you had known personally experienced a [miscarriage] before you?
    c. How else had you heard about miscarriage? [the media, pop culture, a doctor, etc.]
    d. When you had heard about miscarriage before, what was discussed? What did you learn about miscarriage from that [source]?
21. When you became pregnant, did you feel prepared for the possibility of facing a pregnancy loss?
    a. What were some of your concerns for your own pregnancy?

    b. What physical or emotional steps did you take to prepare for that pregnancy?

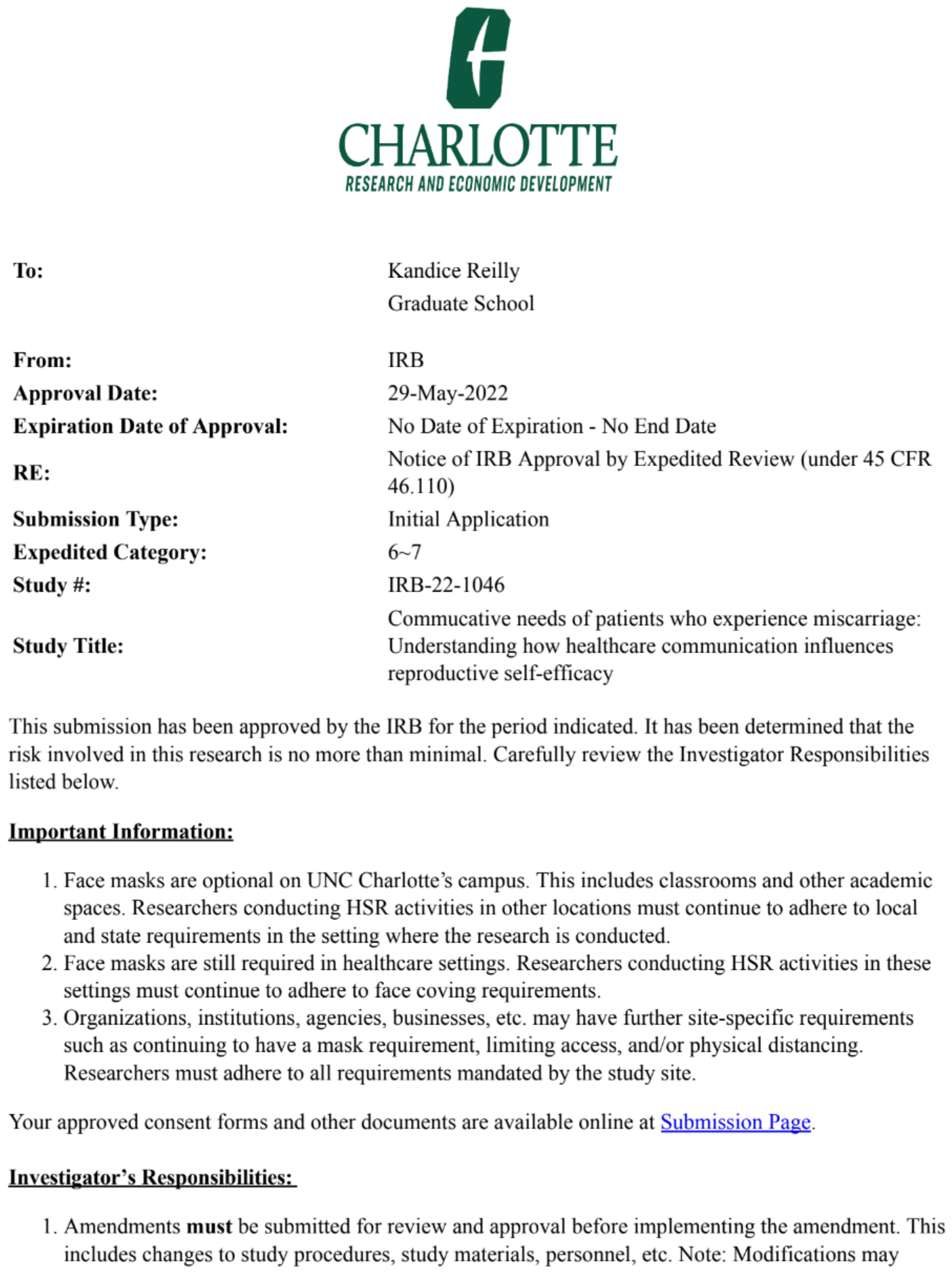
22. When you found out about your [miscarriage], was there any new information that you became aware of?
    a. Did your [doctor] tell you anything about miscarriage that you had not previously heard?
    b. How did your perceptions of [miscarriage] change when you experienced your first loss?
23. Following that loss, how would you say your thoughts about pregnancy have changed?
    a. Is there something that you wish you knew before getting pregnant that may have lessened the impact of your [miscarriage]?
    b. How did your [miscarriage] impact your plans to try again?
24. [If she had a pregnancy or child after a miscarriage] Can you describe any changes either mentally or physically that may have occurred in any subsequent pregnancies after your initial miscarriage?

That's all the questions I have for you. Are there any questions you have for me at this point?

Is there anything further that you would like to tell me that you feel is important for me to know?

Again, I would like to thank you for talking with me today. It is a very important subject to me and I appreciate you sharing your story. I will be in contact with you in the next few weeks to confirm some of the things we discussed today.

Appendix 3-C. *IRB approval letter*



CHARLOTTE
RESEARCH AND ECONOMIC DEVELOPMENT

To: Kandice Reilly
Graduate School

From: IRB
Approval Date: 29-May-2022
Expiration Date of Approval: No Date of Expiration - No End Date
RE: Notice of IRB Approval by Expedited Review (under 45 CFR 46.110)
Submission Type: Initial Application
Expedited Category: 6~7
Study #: IRB-22-1046
Study Title: Commucative needs of patients who experience miscarriage: Understanding how healthcare communication influences reproductive self-efficacy

This submission has been approved by the IRB for the period indicated. It has been determined that the risk involved in this research is no more than minimal. Carefully review the Investigator Responsibilities listed below.

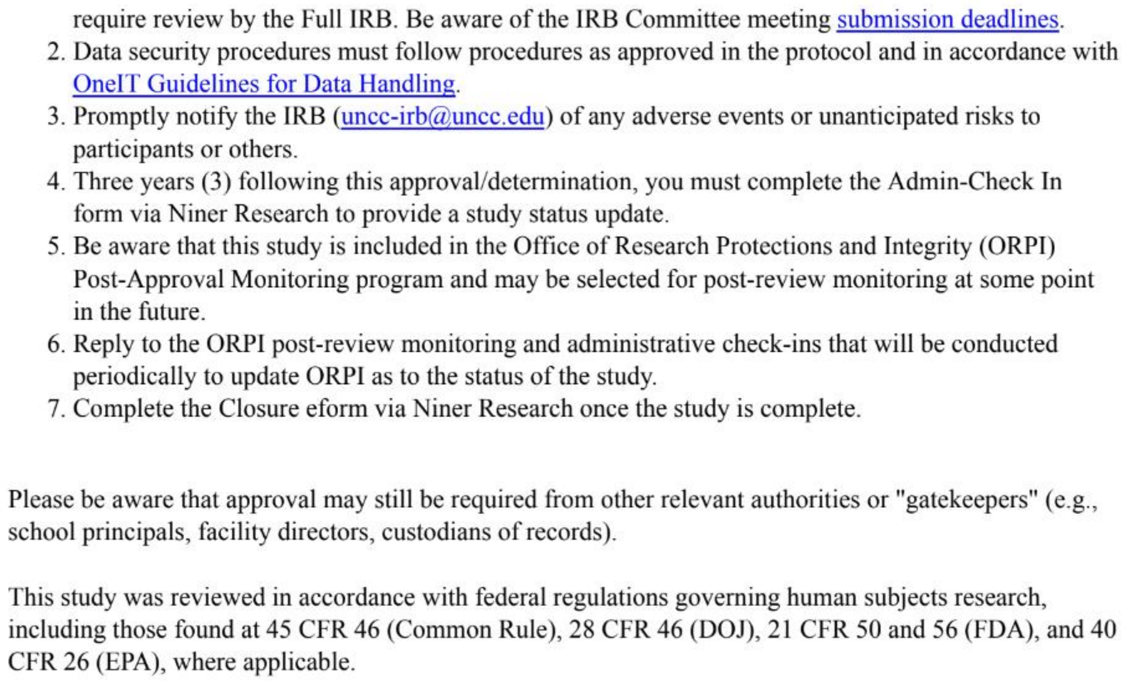
Important Information:

1. Face masks are optional on UNC Charlotte's campus. This includes classrooms and other academic spaces. Researchers conducting HSR activities in other locations must continue to adhere to local and state requirements in the setting where the research is conducted.
2. Face masks are still required in healthcare settings. Researchers conducting HSR activities in these settings must continue to adhere to face coving requirements.
3. Organizations, institutions, agencies, businesses, etc. may have further site-specific requirements such as continuing to have a mask requirement, limiting access, and/or physical distancing. Researchers must adhere to all requirements mandated by the study site.

Your approved consent forms and other documents are available online at Submission Page.

Investigator's Responsibilities:

1. Amendments **must** be submitted for review and approval before implementing the amendment. This includes changes to study procedures, study materials, personnel, etc. Note: Modifications may



require review by the Full IRB. Be aware of the IRB Committee meeting submission deadlines.

2. Data security procedures must follow procedures as approved in the protocol and in accordance with OneIT Guidelines for Data Handling.
3. Promptly notify the IRB (uncc-irb@uncc.edu) of any adverse events or unanticipated risks to participants or others.
4. Three years (3) following this approval/determination, you must complete the Admin-Check In form via Niner Research to provide a study status update.
5. Be aware that this study is included in the Office of Research Protections and Integrity (ORPI) Post-Approval Monitoring program and may be selected for post-review monitoring at some point in the future.
6. Reply to the ORPI post-review monitoring and administrative check-ins that will be conducted periodically to update ORPI as to the status of the study.
7. Complete the Closure eform via Niner Research once the study is complete.

Please be aware that approval may still be required from other relevant authorities or "gatekeepers" (e.g., school principals, facility directors, custodians of records).

This study was reviewed in accordance with federal regulations governing human subjects research, including those found at 45 CFR 46 (Common Rule), 28 CFR 46 (DOJ), 21 CFR 50 and 56 (FDA), and 40 CFR 26 (EPA), where applicable.

Appendix 3-D. *Informed consent documents*

UNIVERSITY OF NORTH CAROLINA CHARLOTTE
Department of Public Health Sciences
9201 University City Boulevard, Charlotte, NC 28223-0001

Consent to be Part of a Research Study (on Qualtrics)

Title of the Project: Communicative needs of patients who experience a miscarriage
Principal Investigator: Kandice R. Lacci, MPH, UNC Charlotte Department of Public Health Sciences
Faculty Advisor: Margaret M. Quinlan, Ph.D., UNC Charlotte Department of Communication Studies

You are invited to participate in a research study. Participation in this research study is voluntary. The information provided is to help you decide whether or not to participate. If you have any questions, please ask.

Important Information You Need to Know

- The **purpose of this study** is: (a) to understand the perceptions and experiences of healthcare communication by cisgender women who have had a miscarriage; and (b) to explore how knowledge, beliefs, and perceptions of miscarriage change over time as impacted by the healthcare team.
- You will be asked to complete a **virtual interview (approximately 45-60 minutes) via Zoom**. The interview will include questions about your miscarriage, your healthcare experience, perceptions of your healthcare team's communication style, as well as some questions related to your overall knowledge and beliefs regarding miscarriage.
- If you choose to participate, it is expected that the interview will last between 45-60 minutes.
- Risks or discomforts from this research include emotional distress when discussing previous experiences of pregnancy loss.
- You may not benefit directly by participating in this study; however, talking about these experiences can be helpful in the healing process and what we learn from you may be beneficial for others in your situation going forward.
- If you choose not to participate, there will not be any negative consequences. Please be aware that if you decide to participate, you may stop participating at any time and you may choose not to answer any specific questions during the interview.

Please read this form and ask any questions you may have before you decide whether to participate in the study.

Why are we doing this study?

The purpose of this study is: (a) to understand the perceptions and experiences of healthcare communication by cisgender women who have had a miscarriage; and (b) to explore how knowledge, beliefs, and perceptions of miscarriage change over time as impacted by the healthcare team. Early pregnancy loss, or miscarriage, is widespread in the US, with between 10-25% of known pregnancies ending in miscarriage. Many women are impacted by psychological or emotional health issues following a miscarriage, such as depression or anxiety. Yet, evidence shows that healthcare experiences during a miscarriage are often lacking in emotional and social support from one's healthcare team.

Communication surrounding miscarriage, particularly between healthcare teams and patients, is understudied. For a number of reasons, talking about one's pregnancy losses has been seen as taboo. We would like to explore how communication from one's healthcare team during a miscarriage may relate to their perceptions of reproductive self-efficacy and decision-making going forward.

Why are you being asked to be in this research study?

You are being asked to be in this study because: (a) you have experienced a diagnosed miscarriage(s) [pregnancy loss before 20 weeks of gestation] within the last five years, (b) you are a cisgender woman between the ages of 18 and 45, and (c) you live in the US and speak English.

What will happen if I take part in this study?

If you choose to participate in this study, you will be asked to complete a virtual interview asking a series of questions about your experiences of miscarriage. The interview will include questions about your experiences of trying to have a baby, your interactions with your healthcare team, perceptions of your healthcare team's communication style, and questions related to your knowledge and beliefs related to miscarriage over time. **This is a one-time interview that is expected to take 45-60 minutes to complete**. You will be asked to complete an electronic demographic survey upon signing the consent form below. The demographic survey will allow us to achieve a diverse sample to capture a more holistic view of healthcare communication around miscarriage. Due to the in-depth nature of the interviews, not everyone will be selected to complete an interview. If you are not selected for an interview, your demographic data and all other information you have provided will be deleted.

Once you have completed an interview, you may be contacted to ensure that the transcription of your interview is accurate. If you choose to participate in the process of validating your interview transcript, you will be emailed a copy of the transcript. Please note that there may be confidentiality limitations associated with email; however, all identifiers will be removed from the transcripts prior to this validation process.

The interview will include potentially sensitive questions, including details about how you felt emotionally following your miscarriage. For example, you will be asked to recall the emotions you felt when a healthcare provider disclosed the news of your miscarriage and to recount interactions with your healthcare team leading up to and during your miscarriage.

What are the benefits of this study?

You may not benefit directly from being in this study. However, organizations, such as the World Health Organization, suggest that talking about pregnancy loss can be beneficial in the healing/coping process, and we hope to honor each of the participant's stories through this process.

The study is designed to benefit society by gaining new knowledge about patient perceptions of healthcare communication related to miscarriage. We hope to learn more about patient experiences so that they may influence clinical practice going forward. The study results may be used to improve patient-provider communication for women experiencing a miscarriage, including more comprehensive training on patient-centered communication for healthcare teams.

What risks might I experience?

There are risks involved in all research studies. You may experience emotional distress when recalling details about your pregnancy loss. To minimize the impacts of this risk, emotional support resources will be provided at the end of the interview to offer tools and techniques for handling emotional distress related to pregnancy loss. Additionally, there will be multiple stopping points within the interview, where we can assess how you are feeling.

How will my information be protected?

We plan to publish the results of this study and may present study findings at future research conferences. To protect your privacy, we will not include any information that could identify you. The data we collect from our participants will be de-identified using pseudonyms for the analysis and reporting of study results in order to protect your confidentiality. In other words, your name will not appear anywhere in the dissemination of this research. If you choose to participate in the process of validating your interview transcript, you will be emailed a copy of the de-identified transcript. Please note that we cannot ensure confidentiality while communicating via email.

Once your interview has been transcribed and checked for accuracy, the audio recording files will be deleted, and the transcripts will be anonymized. These anonymized copies of the transcripts will be stored in a restricted-access UNC Charlotte Dropbox folder. Finally, a master list containing your contact information and accompanying pseudonym will used throughout data collection but will promptly be deleted once all data has been collected and all participants have received their incentives. If you have completed the demographic survey and were *not* selected to interview, your data will be deleted once the data collection has ended.

How will my information be used after the study is over?

After this study is complete, identifiers will be removed from the data and the data could be used for future research studies or distributed to another investigator for future research studies without additional informed consent. The data we share will **NOT** include information that could identify you.

Will I receive any incentive for taking part in this study?

If you are selected to interview, upon completion of your interview, you will receive a **$25**

electronic Amazon gift card via email to thank you for your time and contribution to the study. If you choose to withdraw from the study before completing the interview, you will not be eligible for the gift card.

What are my rights if I take part in this study?

It is up to you to decide to be in this research study. Participating in this study is voluntary. Even if you decide to be part of the study now, you may change your mind and stop at any time. You do not have to answer any questions that you do not want to answer.

Who can answer questions about this study and my rights as a participant?

For questions about this research, you may contact **Kandice Lacci** [klacci@uncc.edu; faculty advisor: Margaret M. Quinlan].

If you have questions about your rights as a research participant or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the Office of Research Protections and Integrity at uncc-irb@uncc.edu.

Consent to Participate:

By selecting **'I have read and understand this information and agree to participate'** below, you are agreeing to be in this study. Be sure that you understand what the study is about *before you sign.* If you have any questions about the study after you agree below, you can contact the principal investigator using the contact information provided above.

- ☐ I have read and understand this information and agree to participate
- ☐ I decline participation and would like to withdraw my name from the prospective participant list

To receive a copy of this document for your records, please enter your email address below:

____

Chapter 4: “Nobody teaches you about miscarriages”: Journey mapping miscarriage experiences through qualitative research

Abstract

Miscarriage is a common occurrence that often comes as a shock to those who experience it. The US encounters high rates of misunderstanding around miscarriage, with more than half of US adults believing miscarriage to be a rare event. Further, perinatal grief frameworks suggest that when expectations are not congruent with reality, grief may be more intense and longer lasting. Therefore, our study used phenomenology and narrative inquiry to explore how knowledge, expectations, and perceptions of miscarriage change from preconception through subsequent pregnancies focusing on communication received from one’s healthcare team. Individual, semi-structured interviews were conducted with 12 women who had experienced miscarriage. We mapped our findings onto a journey map, emphasizing four opportunities for healthcare teams to improve miscarriage management and enhance congruence between pregnancy expectations and realities: (a) engage in conversations about miscarriage and missed miscarriage with patients before they get pregnant and in early pregnancy; (b) avoid potentially triggering contexts such as waiting rooms full of pregnant people or exam rooms where miscarriages were diagnosed; (c) acknowledge the emotional impacts of miscarriage in subsequent care; and (d) be aware of pregnancy-related anxiety and allow for additional screening and/or appointments in subsequent pregnancies. Ultimately, more research is needed to evaluate these practices and to assess the use of these healthcare recommendations in miscarriage management.

Introduction

Between 10-25% of known pregnancies in the US will end in miscarriage (Farren et al., 2016; Prager et al., 2015). Miscarriage refers to the spontaneous pregnancy loss from conception through 20 weeks of gestation (World Health Organization, 2021). The pervasiveness of miscarriage and the associated health risks represent a pressing public health focus for individuals of child-bearing age.

In addition to high unexpected healthcare costs, which include prescriptions, surgical procedures, and follow-up visits, adverse physical and psychological comorbidities are also associated with pregnancy loss. Moreover, these patients are more likely to endure multiple and consecutive losses and are at greater risk for infection and other medical complications (Eunice Kennedy Shriver NICHHD, 2017; Larsen et al., 2013). Perinatal loss is also associated with an increased risk for depression, anxiety, and symptoms that mimic moderate to severe post-traumatic stress disorder immediately following the event and up to several years after loss (Farren et al., 2016; Leis-Newman, 2012; Lok et al., 2010).

Despite an increased risk for prolonged grief reactions, a majority of women become pregnant within one year of a pregnancy loss (Lamb, 2002). Unresolved grief resulting from a previous pregnancy loss may have lasting impacts on the parents as well as the subsequent children (Grauerholz et al., 2021; Lamb, 2002). A foundational study conducted in 1989 (Davis et al.) found that mothers who previously experienced a perinatal loss displayed replacement feelings towards their living child. The fear of loss, which can stem from improper perinatal bereavement, may also result in vulnerable child syndrome, unhealthy expectations for the living child and distortions of maternal perceptions (Grauerholz et al., 2021; Lamb, 2002).

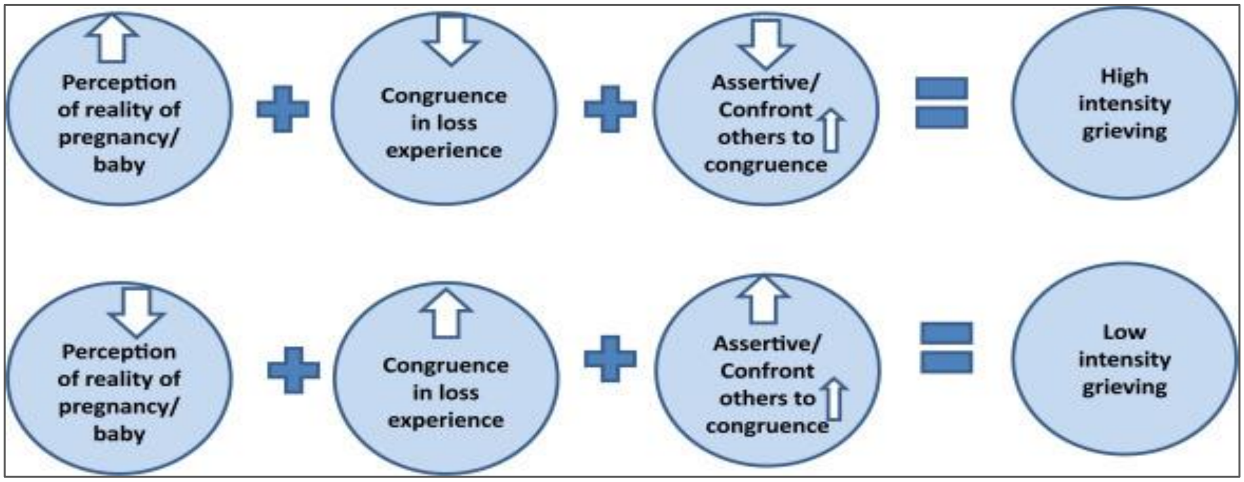
Technological advances in obstetric care since the late 1990s have also drastically changed the attachment process during pregnancy. More refined ultrasounds and 3D, 4D, and high-definition representations of the fetus modify how women perceive their baby at a much earlier stage of pregnancy (Kersting & Wagner, 2012). These advances have strengthened the bond-formation process, and thus, grief reactions may be inherently greater (Kersting & Wagner, 2012).

Theoretical Considerations

Hutti's Perinatal Grief Intensity Theoretical Framework (PGITF) focuses on the balance of reality and expectations, emphasizing congruence between the two (Hutti, 1992; Hutti, et al., 2013). The theory's central constructs, which were evidenced by Hutti's studies are: (a) the perceived reality of the pregnancy or the baby, (b) the congruence between the actual loss experience and the parents' perception regarding the loss, and (c) the parents' ability to make decisions or act in ways that increase this congruence (Hutti, 1992). Figure 1 outlines the relationship between these constructs.

Figure 1.

Effects of the perinatal grief intensity theoretical framework on grieving levels, 2013



Note. Lower intensity grieving results from a decrease in the perception of the pregnancy as a baby, the increase in congruence of loss experience and expectations, and the increase of actions needed to increase congruence.

While Hutti's sample was small (N=12), results indicated that the process or presence of grief may depend on tailoring expectations of pregnancy to align with realities of miscarriage.

The PGITF has subsequently been applied to perinatal grief research and evaluated. In 2013, Hutti, Armstrong and Myers (2013) further validated the framework and ensuing grief intensity scale developed in a study with a larger sample (N= 227). Cronbach's alpha was used to establish reliability (range for constructs: 0.75 – 0.82), and factor analysis was used to confirm the validity and accounted for 66.9% of the total variance (Hutti et al., 2013). Hutti and Limbo (2019) also used the PGITF to inform a study on perinatal bereavement care; the framework helped identify parents who are likely to experience highly intense grief and may require professional follow-up after loss.

Significance

Miscarriage is a common event; in most cases, it is unavoidable and out of the pregnant woman's control. Given the high prevalence of pregnancy loss, the occurrence, as well as its commonality, should be discussed with patients well-before it occurs to prepare them for the event emotionally and physically if it should occur. The US in particular experiences high rates of misunderstanding around perinatal loss. A 2015 national survey found that 55% (n= 596) of participants, both men and women, inaccurately believe miscarriage is rare (Bardos et al., 2015). Anxiety related to a lack of preparation can exacerbate the negative health outcomes associated with miscarriage (MacWilliams et al., 2016). In short, more comprehensive pregnancy risk education is needed.

While it may seem unpleasant to discuss the possibility of pregnancy loss with pregnant or soon-to-be pregnant patients, women who experience miscarriage report a feeling of unpreparedness and shock when the event occurs (Sanchez, 2001). Therefore, proper emotional preparation for patients regarding the possibility of pregnancy loss and providing resources and tools needed in the case of loss can help increase congruence between expectations and reality, thus lowering grief levels.

As such, our study sought to answer the following research question: how do knowledge, expectations, and perceptions of miscarriage change from preconception through post-miscarriage and beyond, as impacted by the healthcare team? Using a journey map, we highlighted four opportunities for healthcare providers to improve miscarriage care. These opportunities are presented as themes in the findings.

Methods

Design

Phenomenology and narrative inquiry were used to explore how knowledge, expectations, and perceptions of miscarriage change from preconception through post-miscarriage and beyond, focusing on communication received from one’s healthcare team. Narrative inquiry assumes that individuals tell stories to help make sense of their lives and give a voice to populations whose perspective is not often sought (Wells, 2011). It relies on the researcher to piece together information in a narrative fashion in order to communicate experiences in a way that is easily understood and relatable (Wells, 2011).

Participants were recruited through social media miscarriage support groups and informed consent was collected during recruitment. Individual, semi-structured interviews were conducted virtually (via Zoom) and an interview guide was used to structure the conversations (see appendix 3-B). Interviews were audio-recorded and transcribed for content analysis. Demographic information on all participants was also collected. The data retrieved in the semi-structured interviews were used to produce a journey map of the experiences of miscarriage through the following stages: preconception, conception, pregnancy loss, post-loss, and subsequent pregnancies (where applicable). The study protocols were reviewed and approved by the UNC Charlotte Institutional Review Board (Protocol #: IRB-22-1046).

Study Sample and Recruitment

Our study included women who had experienced a miscarriage(s) in the last five years, lived in the US, spoke English, and were between 18 and 45. A miscarriage was defined as unintentional pregnancy loss before 20 weeks of gestation (Centers for Disease Control and Prevention [CDC], 2020). Participants must also have been told by a medical professional that they had experienced pregnancy loss (i.e., they did not naturally miscarry at home before being seen by a medical professional). Purposive sampling was used to identify participants who met the criteria and sampling proceeded with maximum variation regarding all demographic variables. Saturation was achieved, resulting in a sample size of 12 participants. Participants were between the ages of 25 and 38 (average = 31.4), with just over half of the sample reporting one miscarriage (n=7, 58.3%) and the remaining participants reporting multiple miscarriages (range = 3-6). Most participants were non-Hispanic White (n= 10, 83.3%), had at least a 4-year college degree (n= 11, 91.7%), and were married (n=11, 91.7%). Further participant demographics are described in a previous report by Lacci-Reilly and colleagues (2022).

Social media sites, Facebook and Reddit, were used to recruit study participants. Nine miscarriage bereavement groups from these sites, such as “Pregnancy and Infant Loss Support Page” and “R/Miscarriage” were selected. Facebook and Reddit are considered fairly representative of the general US population, particularly when controlling for age (Kosinski, Matz, Gosling, et al., 2016; Shatz, 2017). Further, Reddit's subforum formatting allowed us to target specific populations (Shatz, 2017). A digital flyer (see appendix 3-A) was posted along with a description of the study, and a link to a Qualtrics eligibility survey. Eligible participants were asked to complete an electronic demographic survey and were then scheduled for an interview. All participants who completed an interview received a $25 electronic gift card to Amazon to thank them for participating.

Data Collection and Analysis

Individual, in-depth, semi-structured interviews were conducted via Zoom. Interviews lasted between 26-74 minutes (mean length = 48 minutes), were audio-recorded, and all conducted by Lacci-Reilly to ensure consistency. Lacci-Reilly complied with the Health Insurance Portability and Accountability Act to protect participants' sensitive and medical data. An interview guide was used to structure the conversations, and questions on the interview guide reflected each stage of the journey map. For instance, the guide includes questions about preconception and post-loss, as well as future conceptions, in order to create the entire narrative of miscarriage and to exhibit how perceptions and knowledge related to miscarriage may change over time with interactions from one's healthcare team. Participation was voluntary, informed consent was provided and participant confidentiality was upheld. Audio-files of the interviews were then transcribed using Rev.com.

Analyses were conducted digitally using Microsoft Excel and the RADaR (rigorous and accelerated data reduction) technique, which uses tables and spreadsheets to perform iterative data reduction and arrive at a synthesized narrative (Watkins, 2017). The narrative was then translated onto a journey map to display participants' experiences and perceptions of miscarriage during each phase of their reproductive journey. Direct quotes and recurring themes were presented on the journey map in their corresponding stage.

Rigor

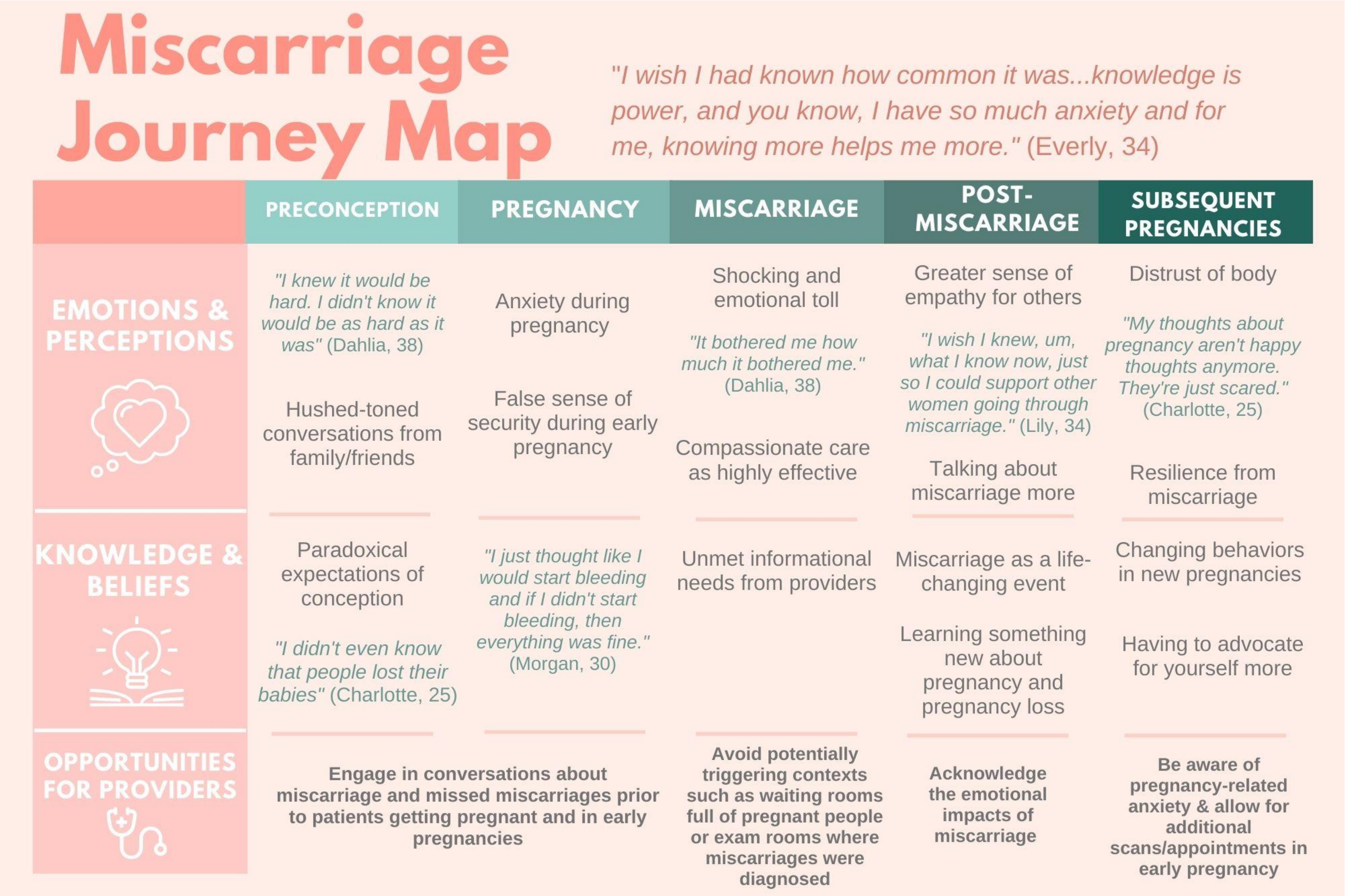
Member checks were performed with several participants to boost the accuracy and credibility of the findings. Participants were asked to confirm or correct information from the transcription and/or analysis. Diligent notetaking and reflexive journaling were also used to limit biases from the researcher's perspective and to support transferability. All documents, including the transcripts, analyses, journals, and communications with participants were maintained in a restricted-access university Dropbox folder for potential inquiry audits.

Findings

The participants' journey before, during and after miscarriage is mapped in Figure 2. This journey map illustrates the commonly shared experiences in and out of the healthcare setting, from preconception through post-miscarriage. Our analysis revealed several key findings related to each stage of the reproductive journey, highlighting four critical opportunities for improving the healthcare experience, presented as the following themes: (1) preconception and early pregnancy care should include conversations surrounding pregnancy outcomes such as miscarriage and missed miscarriage; (2) perinatal care should avoid potentially triggering contexts such as waiting rooms full of pregnant people or exam rooms where miscarriages were diagnosed; (3) perinatal care providers should acknowledge the emotional impacts of miscarriage in subsequent care; and (4) providers should be aware of pregnancy-related anxiety and allow for additional screening and/or appointments in subsequent pregnancies. The following subsections describe our findings related to the five stages of the miscarriage timeline.

Figure 2.

Journey map of participants' experiences of miscarriage



Miscarriage Journey Map

"I wish I had known how common it was...knowledge is power, and you know, I have so much anxiety and for me, knowing more helps me more." (Everly, 34)

	PRECONCEPTION	PREGNANCY	MISCARRIAGE	POST-MISCARRIAGE	SUBSEQUENT PREGNANCIES
EMOTIONS & PERCEPTIONS	*"I knew it would be hard. I didn't know it would be as hard as it was"* (Dahlia, 38) Hushed-toned conversations from family/friends	Anxiety during pregnancy False sense of security during early pregnancy	Shocking and emotional toll *"It bothered me how much it bothered me."* (Dahlia, 38) Compassionate care as highly effective	Greater sense of empathy for others *"I wish I knew, um, what I know now, just so I could support other women going through miscarriage."* (Lily, 34) Talking about miscarriage more	Distrust of body *"My thoughts about pregnancy aren't happy thoughts anymore. They're just scared."* (Charlotte, 25) Resilience from miscarriage
KNOWLEDGE & BELIEFS	Paradoxical expectations of conception *"I didn't even know that people lost their babies"* (Charlotte, 25)	*"I just thought like I would start bleeding and if I didn't start bleeding, then everything was fine."* (Morgan, 30)	Unmet informational needs from providers	Miscarriage as a life-changing event Learning something new about pregnancy and pregnancy loss	Changing behaviors in new pregnancies Having to advocate for yourself more
OPPORTUNITIES FOR PROVIDERS	**Engage in conversations about miscarriage and missed miscarriages prior to patients getting pregnant and in early pregnancies**		**Avoid potentially triggering contexts such as waiting rooms full of pregnant people or exam rooms where miscarriages were diagnosed**	**Acknowledge the emotional impacts of miscarriage**	**Be aware of pregnancy-related anxiety & allow for additional scans/appointments in early pregnancy**

Preconception

In alignment with Hutti's perinatal grief theoretical framework, we began our investigation into the miscarriage experience at the start, prior to ever being pregnant, to explore expectations of pregnancy and miscarriage. Findings from this stage revealed a lack of congruence between expectations and reality. One participant expressed, "I knew it would be hard. I didn't know it would be as hard as it was" (Dahlia, 38) when asked about her experiences of miscarriage. Eleven out of the twelve participants reported that their healthcare provider (i.e., an OB/GYN or primary care provider) had never discussed miscarriage with them. Further, participants indicated that knowing more about miscarriage and the likelihood of pregnancy loss would have helped better prepare them for the possibility and potentially lessen the grief or loneliness they experienced after their miscarriage. Several subthemes appeared related to hush-toned conversations, the paradoxical expectations of conception, and miscarriage awareness and expectations.

Hush-toned conversations

"It was always sort of one of those like hush tones conversations," thirty-five-year-old Kyra said as she described the ways she had heard about miscarriage before experiencing her own. Other participants noted similar incidents or referenced the often 'taboo' nature of pregnancy loss. Charlotte (25) who was at one end of this spectrum, stated, "I didn't know anything [about miscarriage]. Nobody…teaches you about miscarriages, like in sex ed or anything…I didn't even know. I didn't even know that people lost their babies." She was not the only participant to express the desire to have learned about miscarriage in reproductive education classes during grade school. Another participant described how couples often choose to wait a certain amount of time to announce a pregnancy to avoid having to disclose their miscarriage to others. She said, “I didn’t realize how common it was, um, until we kind of got started looking into it. I know that most people didn’t disclose they were pregnant until 12 weeks, but I didn’t know why” (Kamryn, 33).

Even among those aware of the commonality, many still felt little susceptibility or likelihood of it happening to them. One participant stated, “You don’t ever think it’s gonna happen to you and then you probably still don’t even believe it when it’s happening until it actually happens” (Kate, 28). Others, like June (31), expressed that they knew it could happen but that they were unaware of how emotionally challenging it would be to navigate. Maggie (32) described her witness to the prevalence of miscarriage through her experiences with her friends. She observed, “I was always aware that miscarriage was a thing that happens to women. And as I got older and most of my friends are a little bit older and they’ve had kids or have been trying to have kids, the stories almost multiplied. It was just really fascinating how common it really is.”

Paradoxical expectations of conception

Expectations of how long and challenging it would be to conceive significantly varied, with participants typically alluding to the unmet expectations. For Dahlia (38), her hopes for pregnancy were embedded in her from a young age. She explained,

> I am guilty of fully glamorizing trying to get pregnant, being pregnant and having a baby … And I’ve now realized a lot of that was instilled in me from my mom glamorizing pregnancy, um, and think, telling me it will be beautiful and perfect… The gap between what I thought would happen and what I thought I would feel and what actually happened could not have been bigger. (Dahlia, 38)

In congruence with our theoretical foundations, we found that when expectations are unmet in women like Dahlia, instances of grief and mental health challenges were often described in greater detail/more frequently. Similarly, Maggie (32), who experienced a missed miscarriage and was currently pregnant again during our interview, summarized, “I thought pregnancy was going to be so easy… There’s a naivety when you first get pregnant that everything’s perfect.”

Overall, beliefs about the process of getting pregnant were highly polarized. While some “expected it to be harder to get pregnant” (Kyra, 35), others felt “blindsided by [the process] to get pregnant” (Kate, 28). Kate expanded on this, recalling, “[…] they teach you in high school, you know if you have sex, unprotected sex, you’re gonna get pregnant and that’s not necessarily the case.” Kyra followed up her expectations on getting pregnant by explaining that she thought it would be far easier to stay pregnant, demonstrating common misconceptions about miscarriage.

Pregnancy

As we discussed pregnancy experiences and expectations, it became clear that anxiety during pregnancy is pervasive, even without having experienced a miscarriage first. The following subthemes emerged: pregnancy-related anxiety and false sense of security.

Pregnancy-related anxiety

Anxiety during pregnancy was not solely associated with miscarriage but encompassed many aspects of pregnancy. “I was just anxious about the whole thing; you know what I mean? Because it’s just a lot…your body gets taken over and um, how it changes your life and actually raising a kid like it’s all huge,” Kyra (35) explained. Another participant, Kate (28) spoke of body image issues that occurred during her pregnancies and were not openly discussed during pregnancy conversations. Moreover, she detailed the unspoken adverse symptoms that happened to her during pregnancy that also acted as a source of stress.

Participants also described feelings of restricting excitement and happiness during pregnancy in preparation for a negative outcome. When asked if they felt prepared for the possibility of facing a pregnancy loss, one woman responded, “I told myself yes…I would say, ‘Dahlia, like this could happen.’ And I remember thinking and saying, I’m trying not to get excited. I know this can end…but I was kidding myself” (Dahlia, 38). Everly (34), who had experienced three different types of miscarriages, spoke about withholding news of her pregnancy with her friends and family. She initially did not want to share the excitement with everyone if they would feel let down once facing a miscarriage. However, her sentiments in this changed with each miscarriage when she realized what a source of support her family and friends gave her in her pregnancy losses.

False sense of security

Participants often described expectations of miscarriage as having bleeding or cramping in the early gestational period, resulting in the loss of the pregnancy. However, missed miscarriages, or miscarriages in which the body fails to signal the loss, were fairly unheard of for participants. This misconception made many women feel a false sense of security when they had not experienced any physical symptoms of miscarriage. Morgan (30) expressed, “Every day that went by that I didn’t bleed, I thought it was like a, you know, an achievement… I just thought like I would start bleeding and if I didn’t start bleeding, then everything was fine.” She later voiced that she felt like “the floor wen out from underneath [her]” when she was diagnosed with a missed miscarriage.

Others felt a false sense of security when facing a later-stage miscarriage, believing that they had cleared the early pregnancy loss risk once they were heading into their second trimester. June experienced a second-trimester miscarriage when her water broke at 18 weeks. She recalled, “I feel like I kind of like had guarded optimism, but then like once I got the genetic testing back and I was, um, into the second trimester, I think it, it just didn’t really occur to me anymore as a possibility” (June, 31).

Provider opportunity*: *Engage in miscarriage conversations early

The findings from our conversations about preconception and early pregnancy care indicated a need for healthcare providers to engage in discussions about miscarriage and missed miscarriages prior to patients getting pregnant and in early pregnancy (*theme 1*). Addressing the gap in expectations and realities of pregnancy and pregnancy loss during these crucial periods may help to better prepare patients for the possibility of experiencing a miscarriage. Patients emotionally and physically prepared with relevant statistics, coping strategies, and social and professional support may experience lower-intensity grieving and stress following adverse pregnancy events (Hutti et al., 2013). Providers can lessen the divide between expectations and reality by having these discussions with patients before getting pregnant. As such, the responsibility lies with the healthcare team to address these needs.

Miscarriage

Several subthemes developed from the participants’ experiences and perceptions of their miscarriage(s). Additionally, a second theme is presented as an opportunity for healthcare providers during the miscarriage stage and immediately after.

Shocking and emotional toll

Several participants spoke of the shocking nature of miscarriage and how surprised they were at the emotional toll of their loss. For instance, Dahlia (38) frustratingly explained, “I consider myself to be a pretty, a pretty rational person… I had to feel the emotions and that was really tough for me…because I couldn’t make myself feel better and that, that sucked. Like it, it bothered me how much it bothered me.” Another participant recalled feelings of disbelief during her missed miscarriage, “I immediately just started crying…I was frantic and just so upset because even though like I said, I kind of felt like something was off the whole pregnancy, I didn’t really believe it till it happened. And then I still couldn’t believe it” (Kate, 28).

Another problematic aspect for participants was the waiting period between finding out about the miscarriage and technically miscarrying (either naturally, medically, or surgically). Among others, one participant, Kamryn (33), depicted the “weird feeling of ‘I’m carrying around a dead baby’” stating that she very much wanted to be done with this pregnancy so that she could move forward and have some semblance of closure.

Unmet informational needs

Many participants reported the desire to have been better informed about miscarriage, its prevalence, and the treatment options. Kyra (35) summarized this sentiment, stating, “It was [during my miscarriage] that they said just how common it is […] I like having information. I like preparing myself with information and it felt to me like if I had had any idea at the beginning how common it was, it maybe wouldn’t have been such a hard hit.” Likewise, Everly (34) wished she had known how common miscarriage is, stating, “knowledge is power, and you know, I have so much anxiety and for me, knowing more help me more.” Further, participants indicated that they were unaware of the different types of miscarriage and only learned about them after their own experiences.

Provider opportunity: Avoid triggering contexts

Efforts by healthcare providers to empathize with patients and to provide holistic, compassionate care during a miscarriage were very well received. Maggie (32) voiced the impact of her healthcare experience: "As much as I, this has been a horrible experience, I also like feel because of the care I received, the speed of the care I received, and the, like just ease of the miscarriage, I feel very lucky that it could have been a lot worse."

Several participant stories also demonstrated the impact of potentially triggering contexts within the healthcare setting. These stories pointed us to our second opportunity for healthcare providers to improve miscarriage care: avoiding placing patients in potentially triggering contexts, such as waiting rooms full of pregnant people or exam rooms where miscarriages were diagnosed in previous pregnancies. Lily (34) recommended that healthcare teams schedule follow-up care privately in the patient's room or virtually at a later point to subvert the extended waiting period among other pregnant women after finding out about a miscarriage. Other participants conveyed the retraumatizing nature of being seen in the same exam room where they had previously been told they had miscarried. They suggested that healthcare teams be aware of these contextual impacts and accomodate patients' desires to be seen in a different exam room (*theme 2*).

Post-Miscarriage

"There is a line in my life and it's before and after miscarriage. It changed who I am as a person" (Dahlia, 38). Dahlia's views of miscarriage as a life-altering event were shared with many. Despite the devastating nature of pregnancy loss, many participants also expressed positive facets that arose from their experience of miscarriage, including a greater sense of empathy for others, being able to talk about pregnancy loss more openly, and learning something new about miscarriage that has made them feel less alone.

Greater sense of empathy

Perhaps the most discussed aspect of post-miscarriage life was the overall enhanced ability to empathize with others who have experienced pregnancy loss. Lily (34) stated, "I wish I knew…what I know now, just so I could support other women going through miscarriages. I think this [experience] gave me a lot better empathy." One participant communicated her knowledge of miscarriage now after having experienced it and how it influenced her empathy for others:

> [We're told] if you get pregnant, you're gonna have a baby. And like that's not true for everybody…And the rate at which those things are not true is a lot higher than you would ever suspect. And so, for me, the miscarriage was sort of recognizing just how hard the reproductive journey is and I think is for most people. (Kyra, 35)

Dahlia (38) revealed that now having experienced pregnancy loss herself, she acknowledges that she did not always say the correct thing in the past to her friends or colleagues who disclosed their miscarriages. Throughout her six miscarriages, she explained:

> I sort of became an expert in how you should and shouldn't respond to someone who's experienced loss…I think that's probably one of the main things I've taken away that I'm grateful for is that it's made me more compassionate in general to people experiencing hard stuff. (Dahlia, 38)

Participants also voiced that this enhanced sense of empathy goes hand-in-hand with the lasting psychological and emotional impact of miscarriages.

Talking about it more

Multiple participants signified their gratitude for miscarriage becoming a more openly discussed topic. Some explained that because it has become more socially acceptable to talk about pregnancy loss, they have felt less alone in their own experience. Others expressed the need to destigmatize miscarriage further. Morgan (30), who had experienced recurrent miscarriage, communicated:

> People should be more aware of how hard it is because it's like, people just suffer in silence a lot of the time and it's like people are ashamed for some reason when they shouldn't be. So, I think just getting more attention on it and normalizing it more would allow people to get the support they need.

Everly (34) shared a similar call for people to recognize and speak about miscarriage, saying, "I've been talking about it more openly just because I remember how just lonely and isolating it felt…that support is, you know, invaluable because this is something still, I don't feel like its necessarily taboo anymore, but I don't think its something that's openly talked about."

Learning something new

Participants were asked about what new information they had learned since having their miscarriage that has impacted their perception of pregnancy loss. To which one participant responded:

> I think one of the blazing [things I've learned], especially given the current political climate is that like, technically I took the abortion pill, and I was scheduled to have an abortion and like just, I've been trying to share and be open with so many people to be like, 'hey, like a lot of times abortion is needed for…women to regain their fertility.' Like, I needed that cause otherwise my body thought I was still pregnant cause of a piece of placenta. (Lily, 34)

Just weeks before Lily's interview, in June 2022, the supreme court ruled in favor of overturning the abortion access protection granted from the historic cases *Roe v. Wade* and *Planned Parenthood v. Casey* (Artiga, Hill, Raji, & Gomez, 2022). Lily's commentary on abortion access as life- and fertility-saving medicine highlights the critical implications of the supreme court's decision and how women who experience miscarriage may be impacted psychologically and physically.

Other participants responded about how they researched their specific circumstances to try to find others with similar situations. Scarlett (31) recalled using Reddit and Google to obsessively research accounts of miscarriage as part of her coping mechanism. She now explains that she is "so much more aware about all the things that can go wrong…but of course it's like all the most horrific versions of events" (Scarlett, 31), acknowledging how she has biased her perceptions of pregnancy.

Life-changing nature of miscarriage

"[Having a miscarriage] changed everything," Kyra (35) said, pointing to all of the aspects of her life that had changed after her experience with pregnancy loss. Participants described changes in their perceptions of pregnancy, work, mental health, etc. June (31) explained how the grief from her loss transformed her life.

Everly (34) stated that she, “thinks about it like way too much, ya know, like all the time” (Everly, 34). She also expressed changes in her relationship after their miscarriage: “it changed both of us a lot and it changed our relationship, you know, I don’t think either one of us was prepared for that” (Everly, 34). Morgan (30), on the other hand, explained that her relationship with her partner improved following their experience, recalling, “I do feel like our relationship is better than it ever was, like we’ve grown a lot, like through it and [my partner] was, he’s just been like so, so great.”

Finally, participants shared a loss of innocence that accompanied their pregnancy loss. Maggie (32) revealed, “I don’t think anyone can recapture that innocence of early trying to conceive… I think it’s forever changed my perception on just how strong women are and how hard pregnancy is.” Another woman, Kate (28), felt like her experience with miscarriage took something important away from her regarding perceptions of pregnancy going forward. She said, “I’m very jaded. I don’t have the luxury I feel like that my friends that are pregnant have” (Kate, 28).

The life-changing nature of pregnancy loss brings us to our third opportunity for healthcare providers: acknowledging the emotional impacts of pregnancy loss (*theme 3)*. Healthcare teams must act and speak in empathetically to address the changed nature of those who experience a miscarriage. Doing so will promote improved healthcare for those women in the future as they plan how to proceed from their miscarriage.

Subsequent Pregnancies

Lastly, for the participants who had experienced a pregnancy after miscarriage, we asked them about how their experiences and perceptions of pregnancy loss impacted their subsequent pregnancies. Maggie's (32) summation of her emotional change signified the experiences of many of the participants: "[my second pregnancy] was just a lot darker, a lot more emotional. You know, I still felt very much in the thick of it." The following subthemes appeared: distrust of body, changing behaviors, resilience, and advocating for yourself.

Distrust of body

A majority of the participants discussed feelings of bodily distrust in the conversations about subsequent pregnancies. For instance, Lily (34) was pregnant at the time of our interview after her first miscarriage and voiced, "I think [pregnancy] is much more outta my control…it's much more fragile, especially in the early stages…Even though I've known I've been pregnant for three weeks, I just still feel like I'm not pregnant yet." Likewise, Dahlia (38) recalled being afraid that her pregnancies would end at any time since having had her first experiences with miscarriage. Kate (28) felt like she was "just walking on eggshells this pregnancy." Moreover, participants could not feel truly secure in their pregnancies until the baby was born. For June (31), making it to the point of viability was not enough; she needed him to be out of her and alive in order to reduce her anxiety.

Changing behaviors

Participants were asked to describe what behaviors may have changed in their pregnancies after loss. Lily (34) responded, "not getting as excited…I'm not telling people; I guess that's a big change…we're waiting at least until we see a heartbeat – no point in dragging everyone through the excitement with us." Disclosing pregnancy news was not the only behavior to change for multiple participants. Some displayed actions embedded in emotional cushioning or protection during subsequent pregnancies. For instance, Kate (28) stated that she was “trying not to be too connected or too hopeful, just kind of like low expectations.” However, others communicated that this technique might not be effective:

> I feel like there’s almost this temptation to not get too attached in case something goes wrong again, but also, um, I mean if something went wrong, I think I would still be pretty devasted no matter what. So, also like not getting too attached feels like a bad strategy from that perspective. And also, maybe not too healthy emotionally. (June, 31)

Attempts at emotional cushioning were also described as “guarded optimism” (June, 31) and being “cautiously happy” (Sadie, 26).

Resilience

Participant stories revealed evidence of resilience that emerged throughout the process of trying again and in subsequent pregnancies. Maggie (32), who was pregnant again at the time of our interview, expressed, “I’m just so much more grateful for what’s happening to my body now and just accepting of it and I think obviously if it happened again, it would be a horrible thing, but I think almost I would’ve been more resilient had it happened again.” Another woman, Scarlett (31), discovered her miscarriage before she even knew she was pregnant. She reflected on her experiences, saying, “I’m happy I went to the doctor to find out like, so that I have this one under my belt, so I know that I’ve had one. And so, then if it happens again, I’m much more aware that it’s like, this could be the start of a pattern” (Scarlett, 31).

Morgan (30) described her heart as being “a little bit more protected now than it was” when facing future pregnancies, explaining that she will still feel the hurt of any future miscarriages but that she was stronger now having had experienced recurrent miscarriages.

Advocating for yourself

Finally, responses about subsequent pregnancies revealed a strong need for women to advocate for themselves in their reproductive journeys. June (31) expressed, “I definitely will like be an advocate for myself and be like closely monitoring myself and probably taking like notes about things to refer back to if I need to.” Dahlia (38) also spoke about learning how to advocate for herself, saying, “I floundered a lot in the beginning […] I didn’t ask for what I needed to know, but then towards the end of my experience, I was like not afraid to speak up and ask questions.”

The final opportunity for healthcare providers developed from this perspective of being a patient advocate. To improve miscarriage care, particularly in pregnancies after loss, healthcare teams must be aware of pregnancy-related anxiety and allow for additional screening and/or appointments in subsequent pregnancies (*theme 4*). Patients should not have to battle procedural, financial, or social restrictions regarding their pregnancy care.

Discussion

The evident gap between expectations and knowledge of pregnancy and the realities of pregnancy loss may result in high-intensity and sustained grieving (Hutti et al., 2013). Healthy patterns of perinatal bereavement are critical, particularly for couples who intend to conceive again (Lamb, 2002). Grief that is improperly addressed can increase stress and adverse mental health outcomes in subsequent pregnancies (Lamb, 2002). Addressing this gap in the early stages of pregnancy can better prepare women for the possible outcome. Moreover, emotionally and physically prepared women with coping strategies and social and professional support may experience lower intensity grieving and stress. Healthcare providers also can impact psychological and emotional health outcomes related to the perinatal loss (Sanchez, 2001; Wool & Catlin, 2019).

Our journey map takes us through the stages of miscarriage while assessing emotions, perceptions, knowledge, and beliefs. Analysis from the preconception stage highlighted the hush-toned conversations that often accompany miscarriage, the paradoxical expectations people have regarding conception and pregnancy, and overall miscarriage awareness and expectations. The initial pregnancy stage shed light on topics such as pregnancy-related anxiety and the false sense of security that people may feel during early pregnancy when they do not experience symptoms of miscarriage. Data from the miscarriage stage revealed the shocking and emotional toll that often follows a miscarriage diagnosis, the unmet informational needs of miscarriage patients, and the value of compassion in the healthcare setting. Post-miscarriage conversations emphasized the greater sense of empathy that participants felt after their miscarriage, the importance of talking about miscarriage, the importance of learning something new about miscarriage and the life-changing nature of pregnancy loss. Finally, analysis from the subsequent pregnancy stage conveyed the sense of bodily distrust that individuals may feel in future pregnancies, altered behaviors, the value of resilience from miscarriage and learning how to advocate for yourself.

Limitations and strengths

Some limitations should be considered when interpreting this study. The sample was largely homogenous (i.e., primarily non-Hispanic White, highly educated, married, and trying to conceive), though did vary according to age (range: 25-38), number of losses (range: 1-6), location of diagnosis and treatment (i.e., OB/GYN vs. hospital/emergency department), and parity (range: 0-2). Interviews were conducted electronically (via Zoom); therefore, traditional benefits to in-person interviewing related to comfort level and ability to read body language were not applicable. However, 11 of the 12 participants kept their cameras on, which enhanced the quality of the interview. Analysis and coding of the data were conducted by one researcher, which may also be reflected in the findings.

However, the journey map, themes and subthemes were confirmed with all authors. We also established consistency in the data collection process, using one researcher to conduct all 12 interviews. Further, analyses were conducted digitally. Thus, storage and analysis of the data was streamlined and preserved to maintain an audit trail (Mattimoe et al., 2021). Lastly, by producing a journey map of the participants' experiences of miscarriage, the study's findings are presented concisely and valuably. The journey map includes recommendations for healthcare teams, which can be used to guide future miscarriage management training materials.

Future Research

The homogeneity of our study's sample and in previous perinatal loss research calls for future studies to explore miscarriage experiences of more diverse populations (i.e., racial and ethnic minorities, sexual and gender minorities, those with lower educational attainment, etc.). Further, given that miscarriage impacts both the person having the miscarriage as well as their partner, researchers should consider studying miscarriage communication and management within dyads (i.e., couples). Ultimately, more research is needed to evaluate these practices quantitatively and to assess these healthcare recommendations' use in miscarriage management.

Conclusions

The findings from our analysis tell the story of miscarriage from preconception through miscarrying and subsequent pregnancies. Our journey map points to four opportunities to improve care beginning in the preconception stage. To improve miscarriage management and communication and lessen the gap between expectations and reality, healthcare providers should seek to: (a) engage in conversations about miscarriage and missed miscarriage with patients before they get pregnant and in early pregnancy; (b) avoid potentially triggering contexts such as waiting rooms full of pregnant people or exam rooms where miscarriages were diagnosed; (c) acknowledge the emotional impacts of miscarriage in subsequent care; and (d) be aware of pregnancy-related anxiety and allow for additional screening and/or appointments in subsequent pregnancies.

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Chapter 5: Discussion

For many, miscarriage is a life-changing event with emotional and social effects that may never diminish. While the miscarriage itself does not often incur long-lasting physical or psychological consequences, the management of the miscarriage may impact how an individual grieves and reflects on their miscarriage (Brann & Bute, 2017; Sanchez, 2001; Wool & Catlin, 2019). The findings from this dissertation research support the notion that healthcare providers can mitigate these effects. Healthcare communication during a miscarriage remains a largely unresearched topic that has the potential to positively impact perinatal care in significant ways. There has been no attempt to review and synthesize this literature or to examine the socioemotional impacts of healthcare communication after a miscarriage. Moreover, no previous research has explored the context of reproductive self-efficacy following miscarriage management. The dissertation described above addresses these gaps and the findings demonstrate the need for more healthcare communication research in the US.

Review of Findings

In the first study, I conducted a scoping review of the literature related to miscarriage and healthcare communication in the US. I synthesized this research and identified the existing gaps in the literature, pointing to directions for future research. Eleven articles were included in the review. One significant finding was this scarcity of miscarriage healthcare communication literature set in the US. After charting the data, three primary themes emerged. First, patients overwhelmingly prefer patient-centered communication (PCC) (i.e., providers communicating empathetically in ways that acknowledge the gravity of the situation). Second, miscarriage tends to be overmedicalized in the healthcare setting, resulting in patient perceptions of poor communication. For instance, providers referring to the miscarried baby as ‘fetal tissue, contents or parts' was unanimously considered distressing. Lastly, practicing informed decision-making positively impacted miscarriage experiences. Several gaps were also identified. The research on miscarriage and healthcare communication in the US was lacking quantitative and longitudinal studies. Perhaps due to the sensitive nature of pregnancy loss, researchers often opt for qualitative approaches to exploring miscarriage experiences. Yet, more quantitative data may reveal important population-specific factors relating to miscarriage communication and longitudinal studies are needed to examine causality in these relationships. Further, the current literature failed to assess physician perspectives of miscarriage communication, evaluations and implementations of interventions/policies related to miscarriage, and patient perspectives from diverse populations.

The second study sought to explore the context around healthcare communication during a miscarriage and reproductive self-efficacy (RSE) and to identify aspects of care that impacted RSE. As described in the manuscript, RSE refers to a woman's confidence in her ability to get pregnant and to carry a pregnancy to full term, resulting in a live birth. The findings from the 12 individual in-depth interviews suggest that RSE can be optimized when patients receive care that: (a) reassures them of their long-term reproductive goals and discusses the implications of miscarriage; (b) guides their next steps with effective follow-through; and (c) is patient-centered and empathetic to their pregnancy history. This study is an important first step in introducing the concept of RSE as it relates to miscarriage experiences.

Finally, in the third study, I plotted findings from a narrative analysis onto a journey map, underscoring the opportunities for healthcare providers to improve miscarriage management and act in ways that enhance congruence between pregnancy expectations and realities. These opportunities were as follows: (a) engage in conversations about miscarriage and missed miscarriage with patients before they get pregnant and in early pregnancy; (b) avoid potentially triggering contexts such as waiting rooms full of pregnant people or exam rooms where miscarriages were previously diagnosed; (c) acknowledge the emotional impacts of miscarriage in subsequent care; and (d) be aware of pregnancy-related anxiety and allow for additional screening and/or appointments in subsequent pregnancies.

This work underscores the value of effective provider communication and the need to amplify patient voices in miscarriage care conduct. This project demonstrates that providers may play a much more significant role in improving healthcare delivery and a person's miscarriage experience. Learning from this impact, we hope to show the importance of proper miscarriage communication training and adherence for healthcare providers and staff. Existing research has already shown the lasting effects that miscarriage can have on an individual (Farren et al., 2016; Leis-Newman, 2012; Lok et al., 2010). Yet, the literature is devoid of studies examining the timeline around pregnancy loss. As such, birthing people who experience miscarriage are left wondering 'Why wasn't I prepared for this?' and 'What do I do now?'. As evidenced in all three manuscripts, the periods before and after a miscarriage appear to be as crucial in miscarriage perceptions and coping as the miscarriage itself. This finding indicates an opportunity for providers to improve perinatal care for those who experience miscarriage, resulting in healthier coping mechanisms and improved RSE. Collectively, the findings from these studies call for healthcare systems to amplify patient voices regarding miscarriage care and communication. Healthcare delivery would greatly benefit from a patient-centered approach to miscarriage communication training that is built upon patient preferences and experiences.

Collective Implications

Findings from this dissertation project have both collective and distinct implications for clinical practice and perinatal research. Primarily, all three studies indicate a need for further miscarriage communication research in the US healthcare setting. The scoping review supported this implication by revealing so few articles that fit the inclusion criteria. Even fewer of the identified articles directly set out to explore healthcare communication during a miscarriage. The second two studies uncovered critical information regarding miscarriage management and awareness in the US, revealing multiple avenues of subsequent related research. To our knowledge, study #1 is the first attempt to comprehensively review the literature on miscarriage and healthcare communication in the US. In doing so, the study identified several gaps in the extant knowledge further describing the research needs in the miscarriage field. The findings from this study also contribute to the holistic understanding of miscarriage management in the US.

The second two studies have more clinical implications for miscarriage care delivery and support research implications. Findings from study #2 echo previous research on patient-centeredness while offering new insights into post-miscarriage management and the process of trying to conceive. Unlike previous studies, this work also examines miscarriage communication from clinical and administrative employees, pointing out patient preferences for communication and procedural aspects of care. The findings directly indicate providers' steps to enhance a patient's experience, potentially bettering their sense of RSE. Clinicians and organizations such as the American Association of Medical Colleges can translate these findings into clinical and staff training and medical education materials. Additionally, this study introduces the concept of RSE and opens various research directions for validating and operationalizing RSE for future scale development. The final study produced a journey map with implications for clinical practitioners. Namely, the opportunities identified in this study should also be used to inform how providers are trained to handle miscarriage care and communication.

Jointly, these studies reveal the need for a patient-informed model of miscarriage communication. When we amplify patient voices and experiences of miscarriage communication, we avoid historically paternalistic models of care and establish care that works for all populations. This model could also extend beyond the diagnosis and treatment of miscarriage, opting for a more holistic approach to miscarriage care and communication, given the lasting effects of pregnancy loss.

Overall Limitations

This dissertation incurred several limitations that warrant discussion. The project focuses on miscarriage as defined by the ACOG (i.e., the spontaneous termination of an intrauterine pregnancy prior to 20 weeks gestation) (Prager et al., 2018). However, definitions of miscarriage vary; therefore, the findings may not be applicable to women who had a miscarriage falling outside of this definition. Further, I chose to focus the studies on miscarriage, which forgoes other types of pregnancy loss (i.e., ectopic pregnancy, abortion, stillbirth) that may experience and benefit from similar healthcare communication and health outcomes.

It is also important to note that the global COVID-19 pandemic may have impacted healthcare experiences, delivery, and interactions. This consideration may have reduced providers' abilities to provide comprehensive and personalized care. In March of 2020, ACOG disseminated a guide for alternate or reduced prenatal care schedules to minimize COVID-19 transmission risks, which were widely adopted in hospitals across the US (ACOG, 2020). The use of telemedicine and observed decline in antenatal care utilization during the pandemic may have limited the ways that healthcare teams communicated with their patients (Townsend et al., 2021).

Methodologically, all three studies were analyzed by a single investigator. Therefore, the findings depend on my ability to acknowledge my biases and synthesize data effectively. In addition, the lack of previous studies in the research area has left little indication of the need for the current studies. However, using my scoping review, I was able to identify the gaps in the literature successfully.

Lastly, the concept of RSE is yet to be operationalized and a measure of RSE has not been validated. As such, any findings related to RSE must acknowledge the emerging nature of this concept. Yet, Bandura's self-efficacy concept is an established and validated construct, which created a foundation for RSE to build upon with a novel approach.

Study Strengths

These studies will significantly contribute to the field of maternal health research, fulfilling the need to better understand the intricacies of miscarriage management. Healthcare in the US does not share the same qualities as many other healthcare delivery systems in developed countries (i.e., the absence of universal healthcare coverage and equitable healthcare access) (Davis et al., 2014). Thus, by focusing the three studies on US miscarriage experiences, I could incorporate the unique nature of US healthcare delivery without having healthcare delivery mode as a compounding factor.

Another strength of this dissertation lies in its qualitative approach to studying the topic. Qualitative research relies on human interaction and interpretation of human experiences (Mwita, 2022). Given the gravity of pregnancy loss, focusing on the humanness of the research (i.e., understanding and relating to the feelings and experiences of participants) is required to approach this subject. Further, qualitative research also minimizes the chances of missing data, is cost-effective, and collects in-depth and detailed information about these experiences (Mwita, 2022). Ultimately, qualitative methods can answer questions that quantitative approaches could only estimate (Mwita, 2022). The use of video-conferencing technology (i.e., Zoom) to conduct interviews also may have created a safer environment for participants who were discussing sensitive stories with someone they did not know. In this way, the mechanism may have acted as a personal barrier for participants. Moreover, Zoom is generally rated above other forms of qualitative data collection, such as face-to-face or telephone interviews. It is a cost-effective, easy-to-use, and secure option that provides great data management features (Archibald et al., 2019).

This work was also informed by several established frameworks and validated constructs, such as PCC framework, and Bandura's concept of self-efficacy, further supporting the rigor of the study designs and the validity of the findings. Additionally, I collaborated with several maternal health and communication researchers throughout the conception, design, analysis, and writing of these studies; thus, their expertise guided this project.

Conclusion

Miscarriage is an emotionally and socially complex pregnancy outcome. This project evidences the critical role that the healthcare team plays when experiencing a miscarriage and in post-miscarriage care. These studies emphasize the value of PCC and reveal the negative consequences that occur when PCC is lacking. When PCC is absent in healthcare interactions during and after a miscarriage, individuals may be prone to poor health and social outcomes, such as a lower sense of RSE when trying to conceive again. This phenomenon is particularly crucial in pregnancies after miscarriage, which may be enshrouded in grief and bodily distrust. The findings from all three studies may be used to inform a patient-centered model of miscarriage communication and care for clinicians and medical staff.

I would be remiss if I did not acknowledge the timing of this dissertation research with respect to the Dobbs decision (*Dobbs v. Jackson Women's Health Organization*). Weeks into data collection for studies #2 and 3, the US Supreme Court released a statement on their decision to overturn *Roe v. Wade,* effectively eliminating nearly 50 years of federal abortion protection (Kimport, 2022). This decision stripped Americans of their bodily autonomy and the ability to make decisions regarding family planning and reproductive health (UNC Charlotte statement, 2022). This legislation has critical repercussions such as restricting access to life-saving medical treatment for those seeking abortion and/or receiving miscarriage care, widening existing inequities in reproductive care for already marginalized populations (i.e., Black women, trans and other LGBTQ+ individuals) and undermining the patient-provider relationship. Further, those seeking care for pregnancies that do not end in a live birth (i.e., miscarriages, stillbirth, and abortions) are facing legal scrutiny, resulting in increased surveillance and criminalization that can affect all pregnant people (Kimport, 2022). The Dobbs decision has already begun changing the landscape of perinatal care in the US and will continue to have devastating consequences.

Many of the women in my dissertation studies experienced miscarriage during a time when reproductive rights were not under attack. This will not be the case for countless others who the court's decision will negatively impact. It will be crucial for miscarriage researchers to consider the effects of this legislation in future maternal health research.

Future Directions

The findings from these studies highlight other directions for future miscarriage research. Primarily, more quantitative studies are needed to explore this phenomenon across more extensive and diverse populations. Our scoping review revealed a minimal number of quantitative studies, and our qualitative findings should be confirmed using quantitative approaches (i.e., national surveys, database tracking of miscarriage, etc.). Longitudinal cohort studies are needed to explore the role of causality in miscarriage communication and health outcomes research.

Perhaps most immediately, study #2 points to the need to further examine RSE in couples trying to conceive. As noted earlier, the concept is in its early stages of development and requires operationalization and validation. Several scale development studies can emerge from these findings. A validated scale can ensure that we are indeed measuring the latent dimension of RSE as we intend to, which will support future investigations into the sources that improve RSE for families and the role of RSE in fertility practices.

Moreover, there is a need to investigate healthcare communication among minority and historically excluded individuals experiencing miscarriage (i.e., pertaining to race/ethnicity, sexuality and gender, educational attainment, etc.). There is limited research on miscarriage disparities for minority women despite evidence suggesting that adverse pregnancy outcomes differ by these characteristics (Everett et al., 2019; Mukherjee et al., 2013; Zheng et al., 2017). The extant literature and the studies described here are limited by their homogenous samples (non-Hispanic white, highly educated, cisgender women in heterosexual relationships). Therefore, the findings may not be applicable to those who do not identify with these samples due to cultural and historic contexts rooted in systemic discrimination. Future research may also explore healthcare communication during other forms of pregnancy loss (i.e., ectopic pregnancies, abortion, stillbirth) and the effect of this care on RSE.

As discussed previously, there is a need to establish a patient-informed model of miscarriage communication and care for healthcare teams. The future research directions discussed here can help to inform this care model with an emphasis on amplifying diverse patient voices and preferences for communication. Quantitative data can help to gain a broader perspective on miscarriage communication experiences in a healthcare setting, which is needed to create a model that will be effective in various healthcare settings and with different care providers.

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