

PERINATAL LOSS – BEREAVEMENT CARE EXPERIENCES OF INDIANA WOMEN  
AND HEALTH PROVIDER PERSPECTIVES

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To my life partner, Michael Hairston and to my mother Veronica Jackson, who have supported, encouraged and motivated me to never stop dreaming and to always reach for the stars.

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**Background:** Perinatal bereavement care after a miscarriage, stillbirth, or neonatal death is understudied in Indiana. The aims of this dissertation study were five-fold: (1) to understand perinatal bereavement care experiences of Marion County, IN women, (2) to examine how women’s participation in a peer support program impacts their journey with loss, (3) to collect bereaved women’s recommendations for improving existing bereavement care in Indiana, (4) to identify provider-reported challenges and gaps in perinatal bereavement care, and (5) to collect health provider’s recommendations to improve perinatal bereavement care in Indiana.

**Methods:** Adopting a critical theoretical framework, semi-structured interviews were conducted with 10 bereaved women and 8 perinatal bereavement nurses. Using a phenomenological approach, interview transcripts were coded, analyzed, and organized into categories and themes.

**Results:** Bereavement care experiences vary depending on the facility where the loss occurred, and the availability of a bereavement nurse. Widespread disparities in bereavement care for early term miscarriage persists, while attitudes of hospital staff continue to affect women’s emotional health. Support group participation impacts women positively through finding healing and purpose in their loss. Women recommend bereavement as a standard of care across Indiana birthing facilities, mandatory bereavement training for health professionals, robust follow-up care and mental health support for bereaved parents, and comprehensive lactation education for women who experience late to full term loss. Providers face challenges following up with patients, providing care to families as a result of financial barriers, and encounter language and

cultural difficulties when serving immigrant and refugee groups. Providers recommend creating more community-based and culturally inclusive bereavement resources, and increased financial support for loss families.

**Conclusion:** Future programs to improve perinatal bereavement care in Indiana must consider the experiences of bereaved parents and the recommendations made by women and health providers when designing interventions for this underserved group.

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## CHAPTER ONE: INTRODUCTION

### **Preamble**

This dissertation study investigates perinatal bereavement care among Marion County, Indiana women and health providers. In accordance with the wishes of bereaved parents in prior studies, this work uses the term ‘baby’ to refer to the infant or fetus that has died, regardless of gestational age (miscarriage, stillbirth or neonatal death).

### **Background**

The loss of a fetus or baby is an impactful event in a woman’s life. This type of loss not only affects the mother but profoundly impacts the entire family, community and society. For instance, treatment and hospitalizations associated with perinatal loss cost the U.S. health system about \$32.3 billion. Other effects of perinatal loss on society include loss of productivity due to maternal mental illness, complications, and potential unemployment. In the U.S., 15% to 25% of all pregnancies end in loss each year (Freeman et al., 2021). Perinatal loss is the term used to describe combined fetal deaths, including miscarriage, stillbirth, and neonatal deaths (Barfield et al., 2016).

Perinatal loss remains a public health issue owing to the associated adverse outcomes on maternal mental health. Residual grief from perinatal loss is associated with negative outcomes on maternal mental health, including increased risk for major depressive disorder, generalized anxiety disorder, PTSD, and increased risk of suicide (Cacciatore, 2007; Chin et al., 2022; Davoudian et al., 2021) . Bereavement services (grief counselling, support groups, mementos, memorial service, testing, information packets) help to improve maternal mental health by providing tools to help deal with unresolved grief and depression, manage trauma and anxiety

that could hinder a safe and healthy pregnancy, and prepares mothers for subsequent pregnancies (Helps et al., 2020).

Support after the loss of a baby ,which is primarily provided in the hospital setting, may not always be sufficient/ adequate. After leaving the healthcare facility, women may feel less supported as they are left to cope with the grief on their own. Research studies have discussed various coping strategies used by women and families to navigate their loss journey after leaving the healthcare setting, such as avoiding talking about the experience (Fernández-Basanta et al., 2021; Hawthorne et al., 2021), turning to family and friends (Jones et al., 2021), seeking support via social media (Andalibi & Garcia, 2021) and using the services of a spiritual counsellor/ looking to their faith to find meaning in the loss (Abdel Razeq & Al-Gamal, 2018). Another coping strategy which is commonly used by bereaved parents is peer support groups.

Peer support programs (hospital-based or otherwise) are effective strategies for promoting maternal mental health after perinatal loss. These support programs help to bridge the gaps in bereavement care for women and families after they have left the health facility (Boyle et al., 2015). Peer support programs keep women connected with other mothers who have had similar experiences of loss and grief (Boyle et al., 2015; Diamond & Roose, 2016). These programs are helpful in promoting the understanding that bereaved women are not alone and that by leaning on each other for support they can navigate the journey of grief, heartache and loss together (Brown, 2019). Peer support programs, most importantly, ensure that bereaved women and families are kept in the continuum of care so that their emotional and mental health needs are identified and addressed effectively (Boyle et al., 2015).

## **Problem Statement**

In the United States, Indiana has the 9th highest infant mortality rate (IMR) of 6.75 per 1000, with about 531 children under age 1 dying annually (Centers for Disease Control and Prevention [CDC], 2022). Indiana's IMR is significantly higher than the U.S. national average IMR of 6.6 per 1000 births (Indiana Department of Health [IDOH], 2022). Between 2016 and 2020, an estimated 2,833 Indiana infants died before their first birthday. In the year 2020, there were 522 infant deaths, and of this number, 313 were neonatal deaths. Additionally, 496 fetal deaths were recorded in the same year in Indiana (IDOH, 2022). Babies born in Marion County, Indiana, are particularly at risk of dying before their first birthday, with mortality rates reported at 7.4 per 1000 births. To illustrate, of the 522 infant deaths recorded in Indiana in 2020, 100 of those occurred in Marion County, the highest single contributor by county level (IDOH, 2022). These high mortality rates leave behind a lot of grieving families who need support to cope with their grief and their mental health.

## **Purpose and Research Questions**

Owing to the high infant mortality rates in Marion County IN, this study aims to explore bereavement care experiences of women living in Marion County IN and provider recommendations for improving bereavement support in the county. Using a critical theoretical framework, the study seeks to answer the following questions:

- (1a) What are the bereavement care experiences of Marion County, IN women who have experienced miscarriage, stillbirth, neonatal loss?
- (1b) How does being part of a peer support bereavement program impact women's journey with perinatal loss?

(2) What are bereaved women's recommendations to improve perinatal bereavement support in Indiana?

(3) What are provider identified challenges and gaps in perinatal bereavement care in Marion County, IN?

(4) What are provider recommendations to improve perinatal bereavement support in Indiana?

### **Theoretical Framework**

The current study is guided by critical theory and draws from the critical ethnographic approach to qualitative research developed by Phil Carspecken (1996). According to Carspecken (1996), critical research focuses on social inequities and advocates for positive social change through promoting equity and social justice for disadvantaged and underserved populations (Carspecken, 1996). In this study, bereaved mothers are affirmed as the underserved group, in need of robust bereavement support with the aim of promoting better health outcomes for this population. Critical theory, thus, serves as the most appropriate methodological framework for this study.

### **Relevance of the Study**

Bereavement support after perinatal loss is an understudied area in public health – especially in Indiana. While the state has one of the highest maternal and infant mortality rates in the country, bereavement support for mothers and families after loss has yet to be formally studied in local and state healthcare settings. Bereavement services within the state for women and families experiencing loss are opportunistic and depend on the health system/ facility where a woman seeks medical care. This study is particularly relevant because perinatal loss is a topic

that is rarely discussed and often, shrouded in secrecy and shame. The loss of a baby, while a difficult and sensitive issue, occurs more often than is culturally acknowledged and publicly discussed, and thus it is quite common for women to feel alone in their struggle and alone in the loss journey. Further, research reports widespread social stigmatization around the topic of perinatal infant loss (Andalibi & Forte, 2018; Silverman & Baglia, 2015). Often, women are blamed for the death of the baby and made to feel responsible based on something they may have done or did not do to prevent the death of the baby (Adebayo et al., 2019). Other bereaved mothers have reported feeling stigma from healthcare providers (Watson et al., 2019). This research, therefore, opens a dialogue around loss and places the voices and lived experiences of women above the present narrative. Moreover, it is important to assess the current scope of resources available to Marion County families, to identify existing gaps, and to provide recommendations for improving bereavement care within the county, and on a larger scale in the state of Indiana. The findings of the study will inform future programs that are tailored to the specific needs of grieving Marion County women and will advocate for effective programs within the state.

### **Delimitations**

Employing a critical qualitative approach, this study explored Indiana women's experiences with bereavement support after perinatal loss and provider perspectives. The delimitations for participants in the study were two-fold based on the two groups of study participants. For the first group consisting of bereaved women, individuals had to self-identify as a woman who is residing in Marion County IN at the time of the study, and who had experienced the loss of a child through a miscarriage, stillbirth or neonatal death in the last 20 years. The second group of participants, which comprised health professionals (FIMR Coordinators,

bereavement nurses, and support group administrators) had to be individuals whose work centers on providing direct support to bereaved mothers and families as well as those professionals who work to improve maternal, fetal, and infant mortality in Marion County, IN. Participants had to agree to participate in a semi-structured, 60-minute, one-on-one audio-recorded interview about their experiences with perinatal loss and recommendations on how to improve existing services. Interviews were conducted virtually in a private, secure Zoom web-based chat room or over the telephone, according to participant preference.

## **Limitations**

The current study has some limitations. First, although the researcher made the utmost efforts in framing research questions appropriately so as not to lead participant responses in one direction over another, there is the potential that research questions may be influenced by the researchers own personal biases and subjectivity. To minimize the possibility of this occurring, the researcher used semi-structured open-ended items to elicit in-depth responses from study participants.

Another limitation of the study stems from the researcher's outsider status which may influence the interpretation of the study findings. According to Clarke & Braun (2013), a researcher is considered an 'outsider' when they study a population or group to which they do not belong (Bukamal, 2022; Clarke & Braun, 2013). The researcher is of an outsider status relative to the study's eligibility criteria; specifically, although the researcher is 18 years or older, and self-identifies as a woman, the researcher did not reside in Marion County Indiana, and did not have experience with perinatal loss. Notwithstanding, the researcher received guidance from

a community partner who is an insider and who has experienced the loss of a child through stillbirth. This community partner acted as the first peer debriefer, providing insider perspectives on data analysis and interpretations of research findings. Additionally, the researcher's interpretations of study findings were supervised by an external individual, a peer debriefer who has expertise in critical qualitative research.

Last, the researcher used various forms of validity procedures to ensure the credibility and reliability of study finding; however, the researcher acknowledges the possibility that study findings could be interpreted differently. Study findings may not be generalizable to all Marion County IN women who have experienced perinatal loss.

### **Definitions**

**Baby** - In this study, baby refers to the infant or fetus that has died, regardless of gestational age (miscarriage, stillbirth or neonatal death) in accordance with the wishes of bereaved parents.

in accordance with the wishes of bereaved parents.

**Baby loss for medical reasons** - This occurs when expectant parents have to end a pregnancy due to serious anomalies that the baby may have which pose a threat to the baby's quality of life.

**Bad omen** - An event or happening which is perceived to be a warning that something negative or undesired is about to occur.

**Barren(ness) or infertility** - Not being able to become pregnant or conceive after 6 months to 1 year of unprotected sexual activity.

**Bereavement** - The state of sadness, grief and mourning after the loss of a loved one

**Bereavement care-** Involves a range of tangible, emotional and psychological support and resources to help the bereaved individual cope with the sadness and grief that characterize the mourning period.

**Burial (bury)** - A method of final disposition where the body of a deceased person is placed into the ground.

**Caring Companions** – Parents who have experienced a miscarriage, stillbirth, or neonatal death, who have worked through the grief, and who have the desire to guide and support newly bereaved families at the hospital bedside and throughout their grief journey.

**Cremation (cremate)** – A method of final disposition where the body of a deceased person is burned to ashes.

**Critical theory-** An approach to research that focuses on social inequities and advocates for positive social change by revealing, critiquing, and challenging power structures and the status quo. Critical theory is oriented toward promoting equity and social justice for disadvantaged and underserved populations.

**Ectopic pregnancies** - The baby develops outside the uterus and passes as a result of non-viability.

**Fetal death-** The spontaneous passing of an unborn baby at any time during pregnancy, typically measured beginning from the eighth week following conception.

**FIMR** – Fetal Infant Mortality Review. This is a community- owned, action-oriented process where stakeholders review fetal and infant deaths and make recommendations to spark system changes to prevent future or similar deaths.

**Mementos** - An object that is kept as reminder or souvenir of a person or an event.

**Miscarriage** – The spontaneous death of an unborn baby before 20 weeks of gestation.

**Neonatal loss** - The death of a newborn baby up to 28 days after birth.

**Perinatal loss** – The term used to describe combined fetal deaths including miscarriage, stillbirth, and neonatal deaths.

**Phenomenology** - This is a study design used in qualitative research. This type of study design describes the common meanings that individuals make of their lived experiences of a concept or phenomenon.

**PTSD** – Post traumatic stress disorder. This condition develops when a person has experienced or witnessed a scary, shocking, terrifying, or dangerous event. A person who experiences PTSD has difficulties such as re-living the traumatic event through unwanted and recurring memories, flashbacks, or vivid nightmares.

**Stigma (stigmatization)** - A set of negative and unfair beliefs that a society or group of people have about something or someone. Social stigmatization is the disapproval of, or discrimination against an individual or group based on perceived characteristics that serve to distinguish them from other members of a society.

**Stillbirth** - The spontaneous death of an unborn baby after 20 weeks' gestation until birth.

**Support group** – A gathering of people facing or experiencing similar issues. Through sharing experiences, members are able to offer and receive various types of help such as coping strategies, empowerment and building a sense of community.

**Taboo** - A social or religious custom prohibiting or forbidding discussion of a particular practice or forbidding association with a particular person, place or thing.

**Witchcraft** - The use of supernatural powers in the practice of magic or spells, especially for evil purposes.

## CHAPTER TWO: LITERATURE REVIEW

### **Defining Perinatal Loss**

*Perinatal loss* is the term used to describe combined fetal and neonatal deaths (Barfield et al., 2016). Although studies have reported inconsistent definitions of fetal death, generally, the term refers to the spontaneous passing of an unborn baby at any time during pregnancy and is typically measured beginning from the 8th week following conception (Barfield et al., 2016). In the United States, fetal deaths that occur earlier in the pregnancy before 20 weeks' gestation are called **miscarriage** (Barfield et al., 2016; O'Neill et al., 2013), and fetal deaths occurring after 20 weeks are termed **stillbirth** (Barfield et al., 2016; National Vital Statistics System, 2022). Fetal loss, in addition to miscarriages and stillbirths, may also include **Ectopic pregnancies**, where the fetus develops outside the uterus and passes as a result of non-viability (Stanford Medicine Children's Health, n.d.). While the above-mentioned types of fetal loss occur spontaneously, **baby loss for medical reasons**, where expectant parents have to end a pregnancy due to serious fetal anomalies, constitutes another type of fetal loss that is often overlooked (de Crespigny & Savulescu, 2008).

Globally, miscarriage remains the most common type of fetal loss, with about 10- 15% of all known pregnancies ending in miscarriage (World Health Organization, 2023a). Stillbirths also occur frequently, estimated at about 2 million stillbirths each year. Research shows that globally greater than 40% of all stillbirths happen during labor (World Health Organization, 2023b). In the U.S., 15% to 25% of all pregnancies end in fetal loss each year (Freeman et al., 2021). One in every four known pregnancies results in a miscarriage (Blackmore et al., 2011; Johnson & Langford, 2015). In terms of stillbirths, an estimated 24,000 babies are born still annually in the U.S. (CDC, 2020).

Neonatal death, the second component of perinatal loss, is the passing of a newborn baby up to 28 days after birth (Barfield et al., 2016). This type of loss is less common, occurring in 4 out of every 1000 live births in the U.S. (March of Dimes, 2017). Common causes of neonatal death include premature birth, low birth weight, birth defects, pregnancy complications such as preeclampsia, problems with the placenta, and newborn infections like sepsis and asphyxia (March of Dimes, 2017).

### *Scope of the current study*

Based on the definitions above, the current study focuses on the experiences of women who (a) lost a baby spontaneously before 20 weeks' gestation, (b) lost a baby spontaneously after 20 weeks' gestation up until the birth of the baby, and (c) lost a baby minutes after, up until 28 days following the birth. We seek to understand the experiences of women who have experienced any of the 3 above-mentioned types of loss occurring in the last 20 years.

### **The use of the terms Fetus, Newborn, Baby, and Infant**

A fetus is an unborn offspring developing in the mother's womb. The offspring is biologically considered a fetus from about 9 weeks after fertilization or 11 weeks of gestation (Biology Dictionary Online, 2023). According to the World Health Organization, a newborn is a live offspring under 28 days of age (World Health Organization, n.d.). While Merriam-Webster and the Oxford dictionaries both define baby as "a very/extremely young child" (Merriam-Webster Dictionary, 2023; Oxford Advanced American Dictionary, n.d.), the terms baby and infant are often used interchangeably.

In recent literature on experiences of miscarriage, stillbirth, and neonatal loss, parents have repeatedly referred to the dead offspring using the term 'baby'. Although others, including

medical practitioners, family and community members, may use technical terms such as embryo, fetus, newborn, and even “products of conception” to represent the deceased child, regardless of the duration of the pregnancy, bereaved parents recognize the passing of their child as just that: the death of their baby which has a lasting impact on their lives (Malacrida, 2016).

Based on this evidence, and to remain respectful of the wishes of study participants, the current study employs the use of the term ‘baby’ to describe all offspring that have passed as a result of a miscarriage, stillbirth or neonatal death.

### **Perinatal Loss as a Public Health Issue**

#### *Perinatal loss, the mother and family*

Perinatal loss is considered a public health issue owing to the associated adverse outcomes for the mother, family, and society as a whole. For the mother, this type of loss often causes complicated grief (CG) reactions that pose both psychological and physical harm to the well-being of grieving mothers (Kersting & Wagner, 2022). Research examining grief reactions after perinatal loss describe consistent feelings of guilt, self-blame, feeling like a failure, child envy and diminished maternal self-esteem, all which prolong the grieving process (Kersting & Wagner, 2022; Wonch Hill et al., 2017). Due to the associated grief that accompanies the loss of a baby, women often experience psychological effects on their mental health, which include increased risk for major depressive disorder (Herbert et al., 2022), generalized anxiety disorder (Davoudian et al., 2021), PTSD (Cacciatore, 2007) and an increased risk of suicide (Chin et al., 2022).

To illustrate, almost 20% of women who miscarry experience depression and anxiety (Nynas et al., 2015). Again, women with stillborn babies are two to four times more likely to

experience postpartum depression (MGH Center for Women's Mental Health, 2022; MGH Center for Women's Mental Health, 2018). Further studies indicate that depression and anxiety in women who have experienced a miscarriage or stillbirth persists even after having subsequent healthy children (Blackmore et al., 2011). A study investigating depression and post-traumatic stress (PTSD) in a sample of 377 women who experienced stillbirth or neonatal death found that bereaved women had 4 times higher odds of screening positive for depression and 7 times increased odds of experiencing PTSD (Gold, Leon et al., 2016). Moreover, researchers have found increased risk of suicide among women experiencing stillbirth or a miscarriage (Chin et al., 2022; Weng et al., 2018). Results from a nested case-control study of over one million cases showed that compared to women with live births, women who experienced a stillbirth had 5 times higher odds of committing suicide. Similarly, for women experiencing a miscarriage, the risk of completed suicide was 3-fold greater compared to women with live births (Weng et al., 2018). Again, women who experienced a miscarriage had a 2-fold greater risk of attempted suicide (Weng et al., 2018).

For the family, one adverse impact of perinatal loss can be seen in the potential for family separation. Indeed, research finds evidence of an increased risk of divorce among couples following a stillbirth or a miscarriage (Gold et al., 2010; Shreffler et al., 2012). In a nationally representative sample of 3,461 women, the odds of divorce among women who experienced a miscarriage or a stillbirth was 1.23 and 1.84 respectively, compared to their counterparts who experienced no loss (Shreffler et al., 2012). The breakdown of the family unit is of significant public health concern because divorce is reported to be one of the 10 identified adverse childhood experiences (Felitti et al., 1998) that may impact the long-term health outcomes of the surviving child(ren) of loss parents. Additionally, perinatal loss can have a significant effect on

the siblings of the baby who died. Particularly, if children are excluded from burial rituals and farewell ceremonies, they can feel isolated and neglected during the difficult time (Avelin et al., 2014; Murphy & Cacciatore, 2017). Findings of existing studies show that as families grapple with the loss, siblings are sometimes overlooked, and parents may be unavailable as a consequence of grief (Avelin et al., 2014). These experiences may affect the emotional and psychological wellbeing of the surviving sibling, leaving them feeling unloved and uncared for.

### *Perinatal Loss and Adverse Effects on the Community and Society*

While perinatal loss may appear to be an individual issue that affects specific women and their respective families, these losses have a profound impact on the community and the entire society. Previous miscarriage is found to be associated with a higher risk of preterm birth, fetal growth restriction, and other obstetric complications in subsequent pregnancies (Coomarasamy et al., 2021; Lancet, 2021; Quenby et al., 2021). Again, previous incidence of miscarriage increases a woman's risk of long-term health problems including cardiovascular disease, venous thromboembolism, and mental health complications (Coomarasamy et al., 2021; Lancet, 2021; Quenby et al., 2021). Hospitalizations and treatments for the above-mentioned health issues incur great medical and healthcare costs for the nation. Indeed, perinatal loss bears a direct relationship with infant mortality and maternal morbidity and mortality, which come with associated costs. To illustrate, in 2019, maternal and infant morbidity and mortality cost the US health system about \$32.3 billion, which included medical costs for treatment and hospitalizations as well as the loss of economic productivity and increased use of social services (O'Neil et al., 2021). Maternal mental health disorders represented the highest medical driver of both medical and nonmedical costs (\$18.1 billion). In comparison healthcare costs associated with child morbidity and mortality was estimated at \$23.3 billion (O'Neil et al., 2021).

Moreover, reviews of over 200 studies on stillbirth reveal its immense socioeconomic impact on society, including the toll of stigma and grief on long-term outcomes such as depression and anxiety, chronic pain, substance use, unemployment, and reduced social capital (Heazell et al., 2016). Existing studies have extensively documented the effect of stillbirth on parental psychological health, such as higher incidence of depression, anxiety, and PTSD (Blackmore et al., 2011; Cacciatore et al., 2009; Roberts et al., 2021; Sarkar et al., 2022; Westby et al., 2021). Other studies show associations between the loss of a child through stillbirth and chronic pain, sleep difficulties, and fatigue (Burden et al., 2016). Research also reports some negative coping strategies of bereaved parents, including increased alcohol and drug use (Henry et al., 2023; O’Leary & Warland, 2013; Stanhope et al., 2024 ).

Further, research has also revealed an association between stillbirth and reduced earnings from employment for bereaved parents or even the inability to return to work (Heazell et al., 2016). To illustrate, a systematic review of 209 studies on stillbirth globally found that 10% of families reported not going back to work within 6 months of the loss, while 38% of mothers and 21% of partners reported reducing work hours (Heazell et al., 2016). These studies highlight the immense adverse effects of stillbirths on not only the family’s finances, but on a country’s economic productivity. In the same vein, existing research reports that the associated costs related to stillbirth, such as investigations into the cause of death and healthcare cost are mostly borne by the government and insurance providers, although some of the indirect costs are passed on to the parents (Heazell et al., 2016). This implies long-term financial burden on all parties involved (Heazell et al., 2016). Further, the death of each subsequent baby not only robs the family of a kinsman or kinswoman, but additionally robs the society of his/her potential impactful contributions to society (Fox et al., 2014).

From the above, it is evident that perinatal loss is a public health issue that not only affects individual women and families but also bears implications for the health system and the US economy.

## **Historical, Societal and Cultural meanings of Perinatal Loss**

### *Cultural & Religious meanings of Perinatal loss*

Pregnancy and infant loss may be perceived and understood differently based on varying cultural and religious contexts. It is worth noting here that Marion county, IN is a community of people from various backgrounds. As such, it is crucial that providers understand and develop cultural competency to effectively attend to the needs of this diverse population. For instance, in some West and East African cultures, perinatal loss is conceptualized through several religious and cultural beliefs and practices. Specifically, in Nigeria and Ghana, women who experience a stillbirth or neonatal loss are discouraged from seeing or talking about the baby (Adebayo et al., 2019; Attachie et al., 2016). Most often, the baby is buried quickly in an unmarked grave where it cannot be located by the parents (Adebayo et al., 2019). Mourning, crying, or thinking about the dead baby is also frowned upon, as it is believed to bring bad luck to the family and may cause the woman to become barren or have recurrent losses (Adebayo et al., 2019; Attachie et al., 2016). This practice promotes secrecy, fear, and silence around perinatal loss. In Nigerian culture, there is the belief that “one’s child does not die” implying that perinatal loss is evidence that the baby did not belong to the family lineage in the first place (Adebayo et al., 2019).

Consequently, women are encouraged to forget and move on. In the Ghanaian culture, similar to Nigerian beliefs, women who experience perinatal loss are often told the popular proverb of the calabash or pot full of water. In this case, the calabash represents the womb of the

woman, and although “the water is spilled or poured out”, referring to the deceased baby, “the pot is still capable of holding water again” (Adebayo et al., 2019; Meyer et al., 2018). With this understanding, women are encouraged to try for another child. Another cultural belief in West African contexts is the belief in lingering spirits, where the spirit of the dead baby is believed to possess powers that can cause harm (Adebayo et al., 2019; Attachie et al., 2016). For this reason, grieving by the mother is seen as taboo because it could instigate the spirit of the dead baby to cause recurring losses (Adebayo et al., 2019; Attachie et al., 2016). For people of these cultures, the concept of womanhood and motherhood are strongly tied to a successful pregnancy and birth seeing as “there is no such thing as a mother to a dead child” (Adebayo et al., 2019, p.102). Consequently, the woman is stripped of her identity as a mother in the event of perinatal loss. Further, family and social dynamics also come into play as husbands may be pressured by the mother-in-law to raise another family outside of marriage (Adebayo et al., 2019). The bereaved mother is stigmatized, sometimes ridiculed, and blamed for perinatal loss, especially when losses are recurrent. This loss is presumed to be a punishment for a wayward lifestyle before marriage. In religious contexts, the loss of a child is believed to be the “will of God or Allah” (Adebayo et al., 2019; Attachie et al., 2016; Galanti, 2014).

In East African cultures, specifically in Uganda and Kenya, perinatal loss and the rituals surrounding it are also explained through cultural and religious beliefs. In both cultures, stillborn babies are not counted as individuals unless they have at least cried after being born (Ayebare et al., 2021). Taboos surrounding stillbirth make it necessary for the baby to be buried quickly and secretly, for fear that the corpse would be stolen and used for witchcraft (Ayebare et al., 2021). It is also common for the parents to be excluded from any burial rituals to prevent infertility or future recurrent losses (Ayebare et al., 2021). Perinatal loss is often associated with witchcraft

and may be a result of a curse imposed by witches or being possessed by an evil spirit (Ayebare et al., 2021). Moreover, social constructions of perinatal loss resides in the suspicion of infidelity and/ or extra marital affairs (Ayebare et al., 2021). In Ethiopia, perinatal loss is sometimes thought to be a consequence of previous abortions (Sisay et al., 2014).

Among the Hmong people of Laos, cultural meanings of stillbirth and neonatal death are interpreted through the beliefs around the cause of death. Hmong people believe that strenuous physical activity, such as carrying a heavy load or engaging in physically demanding tasks can cause distress to the baby which will make it stop growing and eventually result in a miscarriage, stillbirth or neonatal death (Rice, 2000). Another cause of perinatal loss lies in the imbalance of life auras between mother and child (Rice, 2000). Other cultural understandings of perinatal loss among the Hmong people resides in their belief in the 3 souls for each living being. Hmong people believe that when a person dies, one of the 3 souls goes to the spirit world, and waits to be reassigned to the womb of a woman by the King Deity. If a soul escapes from the spirit world and is reborn without permission from the King Deity, then at the time of birth, that soul must return since it was not given permission in the first place. This means that the baby will soon die after birth (Rice, 2000). Closely related to the belief in souls, is the belief in spirits. The Hmong of Laos conceive perinatal loss as a consequence of the mother being struck by spirits or an event resulting from the capturing of the baby's soul by spirits (Rice, 2000). Ultimately, miscarriages, stillbirths, and neonatal death are treated as non-significant events in the Hmong culture; as such there are no mourning rituals nor burial ceremonies as these are only reserved for babies that are older than 20 days and who have received a name (Rice, 2000).

In Taiwan, meanings ascribed to perinatal loss are deeply rooted in cultural taboos. For instance, Taiwanese culture considers death as a bad omen, and for this reason, cultural taboos

prohibit discussions pertaining to death and its related issues (Tseng et al., 2018). Consequently, in the event of perinatal loss, there are no funeral rites nor public mourning ceremonies (Tseng et al., 2018). Again, cultural taboos prevent mothers from holding and seeing the baby as it is believed to have adverse effects on subsequent pregnancies (Tseng et al., 2018). In order to cut ties and avoid misfortune, parents pray for a successful subsequent pregnancy in hopes of reversing any bad luck (Tseng et al., 2018).

From the above, it is evident that cross-cultural meanings of perinatal loss are closely associated with the cultural and religious beliefs of communities. Cultural meanings of perinatal loss are deeply rooted in underlying assumptions of loss as a symbol of failure – failure as a woman to perform her biological role to bear children (Reinharz, 1988). Perinatal loss is also seen as a reflection of a woman’s character or past behavior (Adebayo et al., 2019). In many contexts, women are held responsible for experiencing a miscarriage, stillbirth or neonatal death, deeming it a consequence of their own failings, either through doing too much or too little or because they invested too much or too little emotions in their pregnancy (Reinharz, 1988). Finally, cross-cultural perspectives of perinatal loss interpret death through a cultural and religious lens, which often promotes a culture of silence, isolation, and secrecy around loss.

### *Anthropological Constructions of Perinatal Loss*

Anthropological approaches to investigating the meaning of perinatal loss recognize pregnancy as a rite of passage, and as such, this rite becomes incomplete when a loss occurs (Layne, 1990). Perinatal loss, thus, leaves parents without a status as mothers or fathers and consequently presents a dilemma when trying to self-identify and define the deceased baby

(Layne, 1990). The struggle to define the baby as a real child is connected to the difficulty in accepting the status of the parent and in recognizing their loss as death (Layne, 1990). Because there are often no funeral or burial proceedings for miscarried and stillborn babies, bereaved parents often battle with a lack of social recognition of their loss (Layne, 1990).

### *Historical vs Modern understandings of Perinatal Loss*

Comparisons between historical versus modern understanding of perinatal loss underscore the concept of loss as more difficult in modern culture. It is argued that before the age of medical advancement, fetal and infant mortality was relatively high, and as such, the death of a baby through miscarriage, stillbirth, or neonatal death was quite expected. However, in more recent years, owing to decreasing infant mortality rates and with the advancement of medical science, perinatal loss became less of a concern for families (Letherby, 1993). Hence, women became more open to forming emotional bonds with their babies, regardless of gestational age, which has led to more intense feelings of grief and loss following death (Letherby, 1993). Again, in modern culture, miscarriage, and stillbirth are increasingly viewed as medical events, which tends to have an effect on the amount and type of support parents receive (Letherby, 1993). Further, there is an assumption that pregnancy is now typically safe and successful; this perception, coupled with the isolating modern hospital experience where mothers are not easily in contact with others who have had similar experiences, leaves parents with the erroneous belief that their experience is a personal failing and a private misfortune (Layne, 1992).

## **Perinatal loss and associated stigma**

Closely related to diminished support and feelings of isolation is the treatment of perinatal loss as a taboo subject, often linked to stigma and shame (World Health Organization, 2023a). Globally, women experiencing perinatal loss are made to feel that they cannot share and talk about their losses, and consequently that they should stay silent about their grief because loss is so common and an unavoidable occurrence ( Bellhouse et al., 2018; World Health Organization, 2023a) . Existing research has found this to be one of the most common recurring themes in the pregnancy loss literature (Gilbert et al., 2023; Pollock et al., 2020). Indeed, studies examining care experiences of bereaved parents after stillbirth, miscarriage, or neonatal death in high, middle, and low-income countries consistently report stigmatization, shame, and blame, regardless of the geographic location (Ellis et al., 2016; Fairchild & Arrington, 2022; Shakespeare et al., 2019; Watson et al., 2019). Negative reactions from health workers, family, and friends contribute to the intense grief and marginalization of bereaved parents (Shakespeare et al., 2019; Watson et al., 2019). While this holds true for bereaved parents across the globe, studies conducted in lower-income countries reported more intense stigmatization due to specific cultural practices and beliefs (Omar et al., 2019; Shakespeare et al., 2019). The negative social perceptions of miscarriage, stillbirth, or neonatal loss as a consequence of witchcraft and evil spirits, a curse from god, and a deficiency in a woman’s reproductive abilities contribute to the further stigmatization of bereaved parents, particularly the mothers (Adebayo et al., 2019; Attachie et al., 2016; Ayebare et al., 2021; Shakespeare et al., 2019).

## **Global Literature on Perinatal Bereavement Care**

Bereavement is the state of sadness, grief, and mourning after the loss of a loved one (National Cancer Institute, 2011). Bereavement care following perinatal loss involves a range of

tangible, emotional, and psychological support and resources to help the bereaved individual cope with the sadness and grief that characterize the mourning period (Zhuang et al., 2022). The literature on bereavement care following perinatal loss typically falls into two categories: medical approaches and mental health treatments (Malacrida, 2016).

Medical approaches provide recommendations to health workers on best practices in managing the loss experience within the hospital setting, including providing infant artifacts, encouraging contact with the baby, providing extra hospital support for parents and encouraging the study of long term parental needs (Bond et al., 2018; Malacrida, 2016; Wool & Catlin, 2019).

With respect to mental health treatments, studies have assessed health worker sympathy toward bereaved families (Geller et al., 2010), the effects of attending support groups on specific psychosocial measures (Gold et al., 2022; Sutan & Miskam, 2012), the role of religiosity on parental coping (Kim & Esmiol Wilson, 2018), among others. Recommendations from mental health research are similar to those of medical approaches, such as allowing parental contact with the infant and provision of infant artifacts (Malacrida, 2016). Guidelines that have emerged from the mental health literature on perinatal loss revolve around making recommendations to parents, providing advice on autopsy decisions, and recommending follow-up counseling to bereaved parents (Malacrida, 2016).

## **Perinatal Bereavement Care – Global and U.S.**

*What comprises bereavement care globally and in the U.S.?*

Bereavement care for perinatal loss varies around the world. Although international guidelines exist that present recommendations for providing bereavement care to women and

families experiencing miscarriage, stillbirth, or neonatal loss, adherence to these protocols is inconsistent and varies based on country, region, and from hospital to hospital (Roberts et al., 2022). Recommendations set forth by the international guidelines include using simple language and compassionate, caring expressions, such as referring to the baby rather than the fetus, making sure that parents spend time with their baby, providing information about the autopsy, respecting culture and religion, and arranging postnatal follow-up care (Roberts et al., 2022). In many Western cultures, the grieving family may be attended to by an interdisciplinary team of grief experts such as a social worker, chaplain, and nursing staff. Additionally, parents are given the option to see, hold, and name their baby, build attachments, and make meaning by keeping mementos (Roberts et al., 2022). While these commonly used strategies are embraced and often appreciated by parents in Western regions, these interventions may not always be welcome by parents from other global regions. Particularly, picture taking, seeing, and holding the baby and giving the baby a name are deemed culturally inappropriate and undesirable in some middle and lower income countries (Shakespeare et al., 2019). However, making sense of the loss and deriving positivity by helping others in similar situations appears to be a universal sentiment shared by bereaved parents (Shakespeare et al., 2019).

In the US, bereavement care may be provided by a social worker or a bereavement coordinator. These individuals offer meaningful gifts to the bereaved family in the form of mementos that consist of mold of the hands and feet of the baby, handprints, and photos (Blood & Cacciatore, 2014; Domogalla et al., 2022). Parents are also presented with the opportunity to attend support group and receive aftercare bereavement services (Domogalla et al., 2022). When possible, parents may be encouraged to bathe and clothe the baby, engage in religious rituals like naming ceremonies, introduce the baby to extended family and may keep special clothing and

blankets that have come in contact with the baby (Flenady et al., 2014). Memory-making remains a central piece in the bereavement care experiences of US women and parents, which reportedly has a significant positive impact on parental grief and coping outcomes (Thornton et al., 2019). An organization worthy of note in the US literature on memory-making after perinatal loss is a nonprofit named *Now I lay me down to sleep* (NILMDTS) (Limbo & Kobler, 2010; Willer et al., 2020). This organization operates in all 50 US states and is available in 40 different countries worldwide (Now I Lay Me Down to Sleep, n.d.). NILMDTS volunteers provides bereaved families with free professional portraits of baby, which serves as a channel for healing and a way to honor the life of the baby (Now I Lay Me Down to Sleep, n.d.; Ramirez et al., 2019).

### **Identified Gaps in Global Perinatal Bereavement Care**

While these studies are useful for understanding general recommendations to improve the bereavement care experiences for both bereaved parents and health workers, other studies have shed light on significant gaps in providing comprehensive bereavement care after miscarriage, stillbirth, and infant loss (Geller et al., 2010; Obst et al., 2021; Shakespeare et al., 2019; Smith et al., 2020). Accessibility challenges in receiving bereavement care following perinatal loss remain a critical issue. Research shows that there is no standard of care within health systems to attend to the emotional needs of women following perinatal loss (Geller et al., 2010). In the US, the services and resources provided by bereavement care programs are inconsistent, depending on a variety of factors such as type of loss, personnel training, mechanisms for follow-up care, website presence and so on (Wool et al., 2016). For instance, care for miscarriage is primarily limited to the woman's immediate physical needs, such as blood loss, infection prevention, and hemodynamic support, without much regard to emotional and psychosocial needs (Johnson &

Langford, 2015). Some studies have found that women experiencing early miscarriage may not receive any form of emotional care or support resources as health workers may underestimate the event as a significant loss that warrants empathic care compared to, say, a stillbirth or a neonatal death (Freeman et al., 2021; Geller et al., 2010).

Again, because treatment for miscarriage is typically offered in hospital emergency departments (ED), health workers may feel inadequate to provide specialized emotional care to bereaved parents as they may lack the training to do so (Emond et al., 2023). Consequently, parents experiencing miscarriage have reported more intense dissatisfaction with their bereavement care, or lack thereof, compared with bereaved parents experiencing other types of losses (Emond et al., 2023). Further, participants in various studies have commented on the inadequate follow-up care received after miscarriage, stillbirth or neonatal loss (Boyle et al., 2015; Siassakos et al., 2018) as well as the difficulty in locating bereavement support services (Radford & Hughes, 2015). Moreover, families who receive medical treatment in rural facilities report a general lack of bereavement support, and in cases where it is offered, bereavement care may not be tailored to women's specific needs (Domogalla et al., 2022).

## **Perinatal Bereavement Care – Parent's Experiences**

### *Miscarriage – Bereavement Experiences*

The loss of a pregnancy through miscarriage occurs often, and it is estimated that 1 in 10 women will have a miscarriage over her lifetime (Kuehn, 2021; Quenby et al., 2021). Global estimates of the occurrence of miscarriage are reported around 23 million per year (Lancet, 2021). Although miscarriage occurs often, it is managed in isolation, which promotes parent's private grief and

misconceptions about the cause of loss (Lancet, 2021). For instance, in some cultures, miscarriage is believed to be a result of lifting heavy objects during pregnancy; this understanding can lead to women feeling at fault and promotes self-blame (Lancet, 2021). Another widely held misconception is that there are no effective treatments when one is experiencing a threatened miscarriage. Consequently, women and their partners manage the loss by themselves (Lancet, 2021). Again, the rhetoric in the healthcare system that miscarriage is unavoidable, as well as some national guidelines that withhold medical investigation until a woman has experienced recurrent miscarriages, promotes acceptance of miscarriage as no big deal and urges women to ‘just try again’ (Lancet, 2021). This mindset underestimates and dismisses the psychological and emotional toll of miscarriage on women and has resulted in little to no care for women following a miscarriage (Lancet, 2021).

Parent’s experiences of bereavement care following a miscarriage reflect a gross lack of empathy and understanding of the emotional and psychological needs of parents. A systematic review of 9 papers from 6 countries (UK, USA, Australia, Canada, Israel and Sweden) investigating women’s experiences of early miscarriage (first 16 weeks’ gestation) showed that women overwhelmingly reported that their feelings and emotions were not recognized by healthcare providers (Radford & Hughes, 2015). While women interpreted their loss as the death of a baby and a major family tragedy, health workers viewed their loss as a clinical problem (Freeman et al., 2021). This was often expressed in their descriptions of the baby as “tissue,” “clots,” “failed conception,” “products of conception,” “missed abortion,” “reproductive wastage,” or “dead fetus” (Lee et al., 2023, p. 56). The importance of respectful care cannot be overstated, as many women across studies reported neglect, insensitivity, poor attitudes, and poor communication from health workers (Freeman et al., 2021; Radford & Hughes, 2015).

A systematic review by Lee et al. (2023) on women and partner's experiences with care following miscarriage affirms the need for more information about the causes, symptoms, and the management of a miscarriage. Specifically, studies showed that women experiencing a miscarriage reported not receiving enough information about possible causes of their miscarriage, what to expect as the miscarriage progressed, when it was safe to try again, and any possible complications that may arise as a result of the loss (Lee et al., 2023). This information, if provided, would help reduce feelings of self-blame and assuage their fears and concerns about future pregnancies (Lee et al., 2023). Another issue that was reported in several studies was the lack of written/ typed information for bereaved parents experiencing miscarriage. As women reported processing and retaining very little verbal information from healthcare personnel after receiving the news of their miscarriage, bereaved parents have expressed the need for written or typed information about the support resources available to them and where they can have their questions answered (Lee et al., 2023). Other challenges that have made the bereavement care experience difficult for women and parents experiencing a miscarriage is the subpar care received in emergency departments (ED). Often, treatment for a miscarriage is provided in the emergency department of hospitals. Women who have received care at the ER report that health providers are more concerned with their physical health needs and disregard their mental and emotional state (Emond et al., 2023). For parents experiencing a miscarriage, bereavement care experiences that were helpful involved situations when health providers used affirming terms that validated their experience of losing a baby (Smith et al., 2020).

### *Stillbirth– bereavement experiences*

The World Health Organization (WHO) estimates that globally about 2 million stillbirths occur annually; this translates as 1 stillborn baby every 16 seconds occur (World Health

Organization, 2023b). Stillbirths were an overlooked public health issue until 2011 when the Lancet series called for improved parent-caregiver interactions and increased investment in stillbirth research (Ellis et al., 2016). Consequently, researchers began to take more interest in identifying factors impacting stillbirth rates toward achieving the aims of the 2016 Lancet series on “ending preventable stillbirths” (Ellis et al., 2016). Research on stillbirth has thus examined care experiences of bereaved parents after stillbirth as well as health worker challenges and recommendations in high, middle and low income countries. Some systematic reviews of literature have examined parent’s bereavement care experiences after stillbirth from 26 countries across 7 regions, i.e., 9 from high income Western countries (Australia, Canada, Norway, South Africa, Sweden, Ireland, USA, UK, Italy) and 17 from middle to low income countries (South Africa, Brazil, Iran, Malaysia, China, Russia, India, Nigeria, Ghana, Bangladesh, Indonesia, Uganda, Benin, Ethiopia, Malawi, Somalia, and Tanzania) ( Ellis et al., 2016; Shakespeare et al., 2019). Interestingly, findings reveal much similarities in the experiences of bereaved parents after stillbirth, regardless of the geographic location. Specifically, stigmatization, shame, and blame were a recurring theme as parents, particularly women, reported negative reactions from health workers, family, and friends, which further contributed to their intense grief and marginalization (Shakespeare et al., 2019). While this was true for bereaved parents in high, middle and low income countries, participants from lower income countries reported more intense stigmatization as a result of some cultural practices and beliefs (Shakespeare et al., 2019). Negative social perceptions of stillbirth as a consequence of witchcraft and evil spirits, a curse from god, and a deficiency in a woman’s reproductive abilities contributed to the stigmatization of bereaved mothers(Shakespeare et al., 2019). These beliefs were associated with guilt, shame, and domestic violence, and ultimately, stigma for women (Shakespeare et al.,

2019). Further exacerbating the issue was the tendency to suppress mourning of the stillborn child, the absence of burial traditions / rituals and societies failure to acknowledge motherhood after stillbirth (Shakespeare et al., 2019). Other issues revolved around parents' exclusion from decision-making processes such as mode of birth (vaginal delivery or C-section) and aftercare procedures, including consent for post-mortem examinations and how fetal remains were treated / disposed of (Siassakos et al., 2018). This was found to be a topic of major concern, and the World Health Organization (2023a), through its research, found that depending on the hospital policy, the remains of the baby would be treated as clinical waste and incinerated; this prevented the parents from seeing, holding and making memories with the baby (World Health Organization, 2023a). Furthermore, the lack of a separate private space / room for bereaved parents was discussed. In some instances, women were required to deliver their dead baby in the same maternity and delivery wards, surrounded by women with live and healthy babies, which further exacerbated parental grief (Siassakos et al., 2018; World Health Organization, 2023a).

Bereavement care experiences that appeared to be beneficial for parents were those that provided appropriate psychological support, considered religious diversity, integrated family support, peer groups, self-medication, and traditional remedies (Shakespeare et al., 2019). Additionally, parents appreciated emotional support from health workers who took the time to talk with the family, used humor appropriately, allowed parents to cry, and those who spent sufficient time with the grieving family (Gold, 2007). Tangible care in the form of health workers bending rules to accommodate parents, expanding visiting hours and allowing children to be in the ward was also perceived to be helpful (Gold, 2007). Last, health workers who provided information and kept parents informed about their treatment plan, explanations as to

why the loss occurred and provided information about what to expect throughout their treatment plan and afterward was also appreciated by bereaved parents (Gold, 2007).

### *Neonatal Loss – Bereavement Experiences*

Parent's experiences of bereavement care after neonatal death have been examined, particularly in Neonatal Intensive Care Units (NICU) settings. Similar to the experiences reported by parents who experienced stillbirth, bereaved mothers expressed a need for more provider care and support, particularly in communicating the cause of the baby's death and answering parent's questions when breaking the news (Embaireeg et al., 2020). Others touched on provider sensitivity and using simple language devoid of medical jargon (Embaireeg et al., 2020). In a Kuwait study of 10 neonatally bereaved mothers, women appreciated when health providers were honest, professional, empathetic, and compassionate while discussing issues of loss and the passing of their baby (Embaireeg et al., 2020). Again, a UK study examining 249 women's experiences of care after the death of their newborn showed that mothers' concerns about bereavement care primarily centered around the quality of care received (Redshaw et al., 2021). While most women reported receiving very good care, the aspects of the bereavement care received which they felt could have been improved revolved around health provider's sensitivity and empathy, as well as women's need for their wishes and desires to be heard by providers (Redshaw et al., 2021). Again, women valued health providers who created a welcoming space to freely and openly ask questions about their loss and providers who treated women as individuals (Redshaw et al., 2021).

## **Healthcare Worker Experiences with Perinatal Bereavement Care**

Health worker experiences with bereavement care report an extensive emotional toll brought on by dealing with perinatal loss (Shorey et al., 2017). Health workers have commented on feeling ill-prepared, guilty, and having an internal conflict all of which affect their psychological wellbeing (Shorey et al., 2017). Owing to the intensity of providing emotional support to bereaved women and families, health workers often feel exhausted, burned out, demotivated, overwhelmed, and frustrated, feelings that often cause them to leave the profession (Shorey et al., 2017). Studies show that professional experience (years of clinical experience, position, knowledge, training experiences, professional encounters with death) as well as personal factors (age, communication skills, support from others) influence health worker experiences with providing bereavement care (Shorey et al., 2017). Perhaps the most notable factor is the amount of training possessed by health workers in dealing with perinatal loss (Ellis et al., 2016; Shorey et al., 2017). Generally, little or no experience in dealing with death, junior ranking in any of the healthcare fields directly serving pregnant women, insufficient communication skills, a lack of training in providing bereavement care and a lack of support from colleagues leave health workers feeling inadequate to provide bereavement care to grieving families (Kelley & Trinidad, 2012; Shorey et al., 2017; Steen, 2015). While the existing literature on health worker experiences with bereavement care following perinatal loss captures negative feelings and sentiments, some health workers have reported feeling rewarded for being a source of comfort to grieving families (Ellis et al., 2016; Shorey et al., 2017). Some studies have also identified cultural factors impacting health worker experiences providing bereavement care. In certain cultures, such as in China, Hong Kong, Singapore, and Japan, the topic of death and dying is generally accepted as a taboo or forbidden topic and hence viewed as a private

family matter (Chan et al., 2005; Gardner, 1999). Consequently, health workers are hesitant to discuss and express emotion with bereaved families; this hinders their ability to accurately assess health needs and provide appropriate care (Gardner, 1999).

### **Bereavement Care – Strategies and Interventions, Coping Mechanisms**

*What are the predominant coping strategies/mechanisms used by parents experiencing perinatal loss?*

Bereavement care following perinatal loss is primarily provided in health facilities, and parents often report feeling abandoned by the healthcare system especially, after the initial shock has subsided and they return home without a live baby (Boyle et al., 2015; Geller et al., 2010; Kelley & Trinidad, 2012;). Some studies shed light on various types of coping strategies that bereaved parents perceive to be helpful after they have left the hospital.

The most widely used strategies by parents experiencing perinatal loss are social coping mechanisms. While some parents turn to family and friends, others connect on social media with other parents who have experienced similar losses themselves (Abdel Razeq & Al-Gamal, 2018; Andalibi & Garcia, 2021; Fernández-Basanta et al., 2020; Hawthorne et al., 2021; Jones et al., 2021). Existing evidence reports extensive benefits of social support on health outcomes (Reblin & Uchino, 2008) which is especially helpful in reducing grief symptoms and aiding with adapting psychologically following the loss of a loved one (Aoun et al., 2018). Individuals who receive little or no support are at risk for depression, psychosocial maladjustment, compromised well-being, and reduced quality of life (Cacciatore et al., 2021). Prior studies examining social support in the context of perinatal loss find that informal types of support (family, friends,

support groups) are the most helpful. In contrast professional sources of support are the least used and least helpful (Aoun et al., 2018).

Some parents also report avoiding the issue of loss altogether by either distracting themselves with other activities, going to work and in the case of some fathers, turning to alcohol as a way to cope with the grief (Abdel Razeq & Al-Gamal, 2018; Hawthorne et al., 2021). While avoidance-related coping strategies may be used as a protective mechanism to shield from unsupportive comments and to avoid the discomfort of retelling the story of loss (Fernández-Basanta et al., 2021), these types of strategies are found to exacerbate complicated grief which could result in isolation from others, difficulty finding purpose in one's life and engaging in unhealthy behaviors (Lipp & O'Brien, 2022). Moreover, suppressing and avoiding reminders of the loved one may interfere with adapting to the loss and could put parents at risk of depression and other psychological distress (Iglewicz et al., 2020). Individuals experiencing loss are instead encouraged to learn to live with reminders, slowly but intentionally sitting with the discomfort and subsequently journaling feelings and thoughts, a process referred to as situational visiting (Iglewicz et al., 2020).

Other types of coping strategies used by bereaved parents are meaning-focused strategies connected to spirituality, milk donation, and memory-making. These types of strategies are found to be instrumental in a parent's journey with grief after the loss of a baby. Published literature on parent's grief following perinatal loss highlights the importance of spiritual counseling, prayer, and reading biblical scriptures for bereaved parents (Alvarenga et al., 2021). By finding meaning in their loss, parents are able to accept and move forward with the view that their circumstance was a test of faith and patience (Abdel Razeq & Al-Gamal, 2018; Eniola et al., 2020; Hawthorne et al., 2021). Again, mementos in the form of molds, hair samples,

blankets, handprints, and memorial services are a reminder of the existence of their beloved baby (Fernández-Basanta et al., 2020; Thornton et al., 2019). For some mothers, donating their breastmilk is a way to stay connected with the memory of their baby and also to gain recognition and affirm their status as a mother (Fernández-Medina et al., 2022; Oreg, 2019).

## **Support Group Programs as Effective Interventions in Perinatal Bereavement Care**

### *Overview and Evidence – Support Group Programs for Perinatal Bereavement*

Research shows that having adequate support significantly impacts the grieving process for parents experiencing perinatal loss (Carlson et al., 2012; Cacciatore, 2007; Umphrey & Cacciatore, 2011; Van & Meleis, 2002). Indeed, it is reported that parents who attend support groups after losing a child are four times more likely to find meaning in their loss (Murphy et al., 2003). While society typically expects parents to grieve for a short period of time and then move on to normal day to day activities, existing studies uncover that bereaved parents still have residual grief from their loss up to 20 years following the death of a baby (Gold et al., 2012). As such, the need for peer support through group interaction appears to be important for bereaved parents ( Carlson et al., 2012; Diamond & Roose, 2016). Historically, before the 1970s, owing to societal failure to recognize perinatal loss as an impactful event, parents were not allowed to make memories of the baby and were rather encouraged to forget, move on and have another baby (Carlson et al., 2012). At the time, no support groups existed to cater to the emotional needs of grieving parents (Lamb, 1992; McCurdy & Byrne, 1992). After 1972, the importance of bereavement care started to gain recognition and consequently, support groups began to be

accepted as fundamental in helping parents grieve, heal, find hope, and integrate their babies into their lives (Carlson et al., 2012).

Support groups are not aimed to fully resolving parental grief, but rather at helping bereaved parents develop new ways to live with the loss while simultaneously keeping the memories and connections with their baby alive (Carlson et al., 2012). Additionally, support groups create a safe space where parents can receive information, education, and resources as well as interact with other bereaved parents experiencing similar situations (Carlson et al., 2012; Gold, Normandin et al., 2016; Gordon et al., 2007). Support groups come in different formats and modes of organization. For instance, some groups have a closed format where the group meets for a specified number of sessions, while other groups are more open-ended where members can attend at will with no pre-determined number of sessions (Carlson et al., 2012).

Across the United States, there are various types of bereavement support programs for women and families experiencing perinatal loss; these programs are typically provided at regional or community hospitals, academic medical centers, and through a variety of community-based organizations, including faith-based programs, national and local level pregnancy loss organizations, as well as online support groups and networks that offer women and families an outlet to share their grief and to receive the support they need with the help of technological advancements (Gold et al., 2022; Wool et al., 2016). Still, some of the available bereavement support services are inaccessible to minority and hard to reach populations, women and families who do not have stable or constant access to internet as well as families who are not religious (Gold, Normandin, et al., 2016; Rice et al., 2022). Moreover, some support groups may not have culturally relevant programming that addresses the specific needs of diverse populations (Gold, Normandin, et al., 2016).

### *Face to Face Support Groups*

Face to face perinatal loss support groups are generally organized at a gathering place that feels comfortable and private enough to enable members to share real feelings in the hope of moving toward healing (Carlson et al., 2012). An important factor in establishing and maintaining a successful program begins with the facilitator; this individual should be nonjudgmental, a good listener, empathetic, able to educate and reflect parent's feelings as well as have the ability to intervene if a crisis occurs that threatens the sanctity of the safe haven for other members (Carlson et al., 2012). An essential characteristic of the facilitator is their expertise in perinatal death issues. This individual must be educated on the current research and interventions appropriate for dealing with perinatal loss; they must additionally possess effective skills to manage support groups (Carlson et al., 2012). Further, facilitators are not always leaders; instead, their responsibility is to address problems that arise, such as members comparing their grief stories, silence, people who dominate the conversation, and the formation of cliques that promote insider-outsider dynamics (Carlson et al., 2012). Moreover, the facilitator must provide additional support to any group member who may be engaging in unhealthy or suicidal patterns (Carlson et al., 2012). Face to face support groups are often governed by a set of 'ground rules' that are read at the beginning of each session. These include the understanding that all experiences are unique and valid, that sharing is entirely voluntary and not compulsory, the importance of confidentiality, and that members can leave at any point during the session (Carlson et al., 2012).

Some pros of face to face support groups include opportunities to demonstrate empathy through personal touch and non-verbal expressions of support and solidarity, forming strong connections, making new friends and the potential to receive support from older and more

experienced members (Diamond & Roose, 2016). Face to face support groups may not always be advantageous in situations where members have to travel long distances to the meeting site (Steiner, 2006). Again, because face-to-face support groups are limited in the frequency of meetings, which typically occur monthly or bi-weekly (Rachel's Gift Pregnancy & Infant Loss Programs, n.d.), this may leave parents without support for extended periods of time. Another drawback of face to face support groups is that they are centered around group dynamics with the potential to have certain members always dominating conversations, or in other cases no one sharing at all i.e. silence (Carlson et al., 2012; Dyregrov et al., 2014). Non-attendance and the formation of cliques are also potential challenges of face to face support groups (Carlson et al., 2012). Some parents have additionally reported an increase in anxiety after hearing about other complications leading to perinatal loss from group discussions (Mills et al., 2014).

### *Online Support Groups*

The expansion of pregnancy and infant loss support groups from strictly face-to-face modalities to a variety of online formats is made possible due to technological advancement in the last 2 decades (Carlson et al., 2012; Gold, Normandin et al., 2016). Bereaved parent support groups account for approximately 10% of all online support groups; groups for people who have experienced the death of a child are the third most common type of group on social media (van der Houwen et al., 2010). In addition to groups available via social media, blogs have also helped parents connect with and provide support to other bereaved parents (Carlson et al., 2012).

Although the benefits of online support groups on parental outcomes have not been researched extensively, studies show that parents may be more likely to form strong connections online due to the level of control that one has using this format (Carlson et al., 2012; Gold et al., 2012). Specifically, parents may find it easier to exit an online group that does not serve their

needs compared to a face-to-face meeting (Carlson et al., 2012). Again, online support groups have the potential to reach grieving fathers, who are less likely to attend face-to-face meetings (O’Leary & Thorwick, 2006). Some challenges of using online support groups revolve around issues arising from member anonymity such as trolls, who are people who join groups just to cause trouble, fakers who pretend they have experienced the death of a baby but actually have not, and members with self-harm issues which may be a trigger for other members of the group (Pector & Hsiung, 2011). Facilitators of online support groups may have a difficult time navigating these issues. Also, due to the absence of non-verbal cues such as tone, facial expressions and body language, online posts have the potential to be misinterpreted and cause misunderstanding and conflict due to the very sensitive nature of grieving a pregnancy or a baby’s death (Kang, 2007; Malik & Coulson, 2008). Moreover, owing to member anonymity in online support groups, it may be difficult for group administrators to provide follow-up support and resources to members who exhibit suicidal thoughts and intentions (Gilat & Shahar, 2009).

### *Peer Support*

A defining feature of perinatal loss support programs is the concept of peer support, where a trained ‘veteran’ parent who has experienced the same or similar loss provides one-on-one support to a recently bereaved parent (Boyle et al., 2015; Diamond & Roose, 2016). One principle of peer support is reciprocity, where both the provider and the recipient of support benefit through enhanced self-esteem, feelings of altruism, and gaining new perspectives on their own experiences (Boyle et al., 2015). Peer support may be delivered in a variety of modes including face-to-face group meetings or one-on-one settings, over the telephone or in online formats and may be delivered by a ‘lay person’ or by a trained professional (Boyle et al., 2015). An important element of note is that peer support is not intended to replace professional help;

instead it may be viewed as part of the continuum of care, serving as stand-alone support at times and a bridge to obtaining formal and specialized care in critical situations (Boyle et al., 2015). Owing to limitations with professional resources however, peer support facilitates sustained and intensive support for grieving parents which may be otherwise unavailable by depending on professional help alone (Boyle et al., 2015). One peer support program that is identified by the literature on perinatal loss support programs is the **Caring Companion** model of support (Diamond & Roose, 2016). This model was developed by Share Pregnancy & Infant Loss Support Inc., a US national organization for perinatal bereavement care, with the aim of educating and preparing parent volunteers to provide peer support to families experiencing pregnancy and infant loss (Share Pregnancy & Infant Loss Support, n.d.). Caring companions are parents who have experienced pregnancy loss or the death of an infant shortly after birth, worked through the grief, and have the desire to guide and support newly bereaved families at the hospital bedside and throughout their grief journey (Share Pregnancy & Infant Loss Support, n.d.).

*What are the documented impacts of perinatal support programs (peer or otherwise) on parent outcomes?*

There is scant documented evidence on the impact of perinatal loss support groups on parent outcomes. That notwithstanding, support programs, especially peer support groups, have been used widely in other areas of health with much success, including studies that have sought to address maternal postpartum depression (Cust, 2016; Dennis et al., 2009; Goodman & Santangelo, 2011), programs that aim to help people navigate the loss of a loved one (Bartone et al., 2019), programs seeking to link people living with HIV to treatment and retain them in care (Berg et al., 2021) and recovery programs for mental health, addiction and substance use

(Donovan et al., 2013; Tracy & Wallace, 2016). These studies provide strong evidence for support programs, particularly in situations where the psychological and emotional health of individuals are threatened.

The existing literature on support programs and perinatal loss does show some promising results in terms of the benefits of support group attendance on maternal mental health. For instance, one study examining the effects of support group attendance on post-traumatic stress in a sample of 47 mothers who had experienced stillbirth found that women who participated in local support groups had lower mean scores compared to women who did not attend support groups (Cacciatore, 2007). Time after the death of the child showed no significant bearing on PTSD levels; women who did not attend support groups still had high PTSD scores despite the length of time (death within 2 years vs greater than 2 years) after stillbirth (Cacciatore, 2007). This showed that extended time without adequate support did not, in fact, mitigate the effects of grief on bereaved parents after perinatal loss. However, while attending support groups appeared to have positive effects on women's post-traumatic stress, it did not indicate complete recovery from loss, but rather emphasized the idea that bereaved mothers who were well-connected to appropriate and adequate support systems developed better coping skills to manage the trauma of their loss (Cacciatore, 2007). Furthermore, of 47 women who participated in the study, 39 reported that support groups were the most helpful in dealing with the death of their baby (Cacciatore, 2007).

Other ways that support groups have helped bereaved parents through their loss include reduced feelings of isolation as a result of connections made with other grieving parents (Boyle et al., 2015; Carlson et al., 2012; Umphrey & Cacciatore, 2011) and having a space to openly grieve and share feelings without the fear of being judged by people who have little

understanding of their experience (Diamond & Roose, 2016; Leon, 2008; McCreight, 2007). Through sharing and listening to other parents stories, bereaved parents have reported learning new and more effective ways of coping with difficult times such as holidays and birthdays, managing emotions with friends and family members who have new babies and difficulties returning to work after the loss (Brown, 2019; Carlson et al., 2012). Again, parents reported being empowered to be more assertive with their healthcare provider, which helped them to advocate for themselves and their needs (Mills et al., 2014). Although there is more evidence that support groups help women than men (Flenady et al., 2014), couples who attended together reported increased understanding of gender differences in emotional expression and communication, thereby promoting dialogue and effective mutual support (Brown, 2019; Mills et al., 2014). Additional benefits of support groups on parental social outcomes include support toward concerns about current children, having feelings validated, and restoring hope for future pregnancies (Brown, 2019).

While there is some research showing the benefits of peer support on maternal outcomes after the death of a baby, these studies fail to provide rigorous evaluations of the impact of peer support programs on psychological outcomes (Boyle et al., 2015). Documented benefits are mostly self-reported, such as peer support as a unique outlet for sharing experiences and obtaining validation through each parent telling their story and making sense of the loss (Boyle et al., 2015). In addition to examining the impact of peer support on bereaved parent outcomes, studies have also investigated the experiences of parent peer supporters and how providing support to others has impacted their own loss journeys. Research shows that motivations to become peer parent supporters were rooted in personal experiences of peer support following pregnancy loss, a strong belief in the benefits of peer support, ensuring that parents had access to

good support, especially when their own support had been suboptimal, and a way of giving back (Boyle et al., 2015; Diamond & Roose, 2016). Reported benefits were of intrinsic value as parents supporters reported feeling satisfied about their ability to make a difference in the lives of other parents experiencing pregnancy loss, being able to honor their dead babies through helping others and finding meaning to their loss by volunteering (Diamond & Roose, 2016; Boyle et al., 2015). More tangible benefits included the recognition of their own personal growth and gaining continued support for their own experience of pregnancy loss (Boyle et al., 2015).

### **Justification for the Present research**

The loss of a child through miscarriage, stillbirth, and neonatal death is a significant loss event for women and bereaved families. This type of loss not only impacts individual families but has a toll on the entire community in terms of health system and financial burden. For instance, treatment and hospitalizations associated with perinatal loss cost the U.S. health system about \$32.3 billion. Other effects of perinatal loss on society include loss of productivity due to maternal mental illness, complications and potential unemployment. Perinatal loss is associated with negative mental health outcomes such as depression, anxiety, and even suicidal ideation among bereaved women (Chin et al., 2022; Davoudian et al., 2021; Herbert et al., 2022). Poor maternal health not only affects the individual but the entire community as it is associated with higher preterm birth (Coomarasamy et al., 2021; Lancet, 2021), cardiovascular disease, and obstetric complications (Quenby et al., 2021), all of which imply increased spending on medical costs for treatment and hospitalizations (O'Neil et al., 2021).

Additionally, perinatal loss is highly stigmatized worldwide resulting in silence and secrecy, which often leaves women with feelings of isolation, guilt and self-blame (Bellhouse et al., 2018; World Health Organization, 2023a). These conditions further aggravate women's mental health after the loss of a baby. Bereavement services in the form of sensitive, respectful, and patient-centered care have been found to improve women's grief and coping skills following perinatal loss (Zhuang et al., 2022). Recommendations such as allowing the parents to hold and name the deceased baby, providing infant artifacts like molds and blankets and encouraging parents to hold memorials for the baby appear to help parents cope well with their loss (Malacrida, 2016). Although these recommendations are generally accepted and followed in many healthcare settings, research has identified some gaps and challenges with bereavement care programs (Geller et al., 2010; Obst et al., 2021; Shakespeare et al., 2019; Smith et al., 2020). For instance, bereaved parents have repeatedly commented on the lack of adequate support they received from their health provider after the death of their baby (Ellis et al., 2016; Radford & Hughes, 2015). In response, pregnancy and infant loss programs have developed interventions to attend to the unique circumstances and needs of bereaved parents, such as professional and spiritual counseling as well as social support through support groups (Domogalla et al., 2022). Research shows that having adequate support significantly impacts the grieving process for parents experiencing loss (Carlson et al., 2012). It is reported that parents who attend support groups after losing a child are four times more likely to find meaning in their loss (Murphy et al., 2003). While support groups do not fully resolve parental grief, they create a space where parents can receive information, education, and resources (Gold, Normandin, et al., 2016). Additionally, participation in a support group helps to resolve feelings of isolation and has been found to decrease maternal post-traumatic stress (Cacciatore, 2007).

While the above-mentioned studies inform about the overarching features of perinatal loss and examine the role of bereavement care in protecting maternal mental health following the loss of a baby, a closer look reveals a number of gaps and shortcomings. Three major gaps are discussed below:

First, bereavement care after perinatal loss in the US remains an understudied topic. An exhaustive search of the current literature on bereavement support after miscarriage, stillbirth, or neonatal loss in the US in 3 of the most popular databases where such research is archived (PubMed, CINAHL, Scopus) revealed only a handful of relevant studies (n= 54) published in the last decade. Using Boolean phrases ‘stillbirth or miscarriage or neonatal death or perinatal loss’ AND ‘support groups or peer support or group support’ AND ‘bereavement care or bereavement support’ in CINAHL produced only 82 published content in the US between 1984 and 2023. After limiting the search to only academic literature that has been published in the last 10 years i.e. 2013 – 2023, the number further reduced to 44. A final sample of 15 relevant articles were identified after further excluding studies that did not focus on bereavement care for parents particularly after perinatal loss. The PubMed advanced search using the Boolean phrases ‘stillbirth or miscarriage or neonatal loss or perinatal loss’ AND ‘support groups or peer support or group support’ AND ‘bereavement care or bereavement support’ AND ‘United States [mesh] or United States [TIAB] or United States [OT] AND ‘mother or father or parent’ produced 245,172 published content in the US between 1945 and 2023. However, after limiting the search to academic literature published in the last decade, the search yielded 4,589 articles. Of these, only 13 relevant studies focused on bereavement care for bereaved parents (mothers and or fathers) following pregnancy and infant loss and were not duplicates of the CINAHL search. Last, the Scopus search using the same Boolean phrases employed in the CINAHL search

yielded a total of 364 published content in the United States between 1981 and 2023. After limiting the search to the last decade (2013- 2023), 100 studies were found, and only 26 studies focused on bereavement care after pregnancy and infant loss.

From the above, it is evident that the literature on perinatal loss, particularly focusing on bereavement care and social support after loss is fairly outdated. While there appears to be sufficient literature investigating grief responses and reactions of bereaved parents (Kersting & Wagner, 2022; Rosenbaum et al., 2015), some clinical guidelines in managing care after stillbirth, miscarriage, and neonatal death (American College of Obstetricians and Gynecologists, & Society for Maternal-Fetal Medicine, 2020; Rich, 2018) and studies examining parent satisfaction with services received and health worker experiences (Freeman et al., 2021; Gold, 2007; Radford & Hughes, 2015; Shakespeare et al., 2019; Siassakos et al., 2018; ), there remains a huge gap in research investigating the role of bereavement care as a protective factor in maternal mental health. This dissertation study will be one of the few research projects conducted in the United States that examines bereavement care in the form of peer support groups as a significant element in the maternal loss journey after perinatal loss.

Second, there are limited U.S. studies documenting the role of peer support programs in the maternal loss journey. From the literature search, and to my knowledge, only one study (Diamond & Roose, 2016) has toed this line of investigation. The study was conducted in a midwestern U.S. city, and adapted the Caring Companion model of support developed by Share Pregnancy & Infant Loss Support Inc (SHARE) to create a peer support program for bereaved parents (Diamond & Roose, 2016). Although the study provided critical insights into the pros and cons of participating in a peer support program, significant flaws in the study design, such as lack of face-to face interaction between some parent pairs, limited options for preferred contact

and limitations with continued communication, underscore the need for further exploration in this area. This dissertation, thus, will contribute to the scant literature on self-reported effects of participation in a peer support volunteer program by bereaved mothers.

Finally, bereavement care following perinatal loss has been studied on a national scale, without much focus on local level factors that may impact care. Bereavement care after miscarriage, stillbirth or neonatal loss in the U.S. has been studied in a limited number of U.S. states such as in Michigan (Gold, Normandin, et al., 2016), Washington State (Kelley & Trinidad, 2012), Iowa (Heiman et al., 1997) and Arizona (Umphrey & Cacciatore, 2011). Recruitment for such studies is predominantly conducted through national level organizations and social media platforms that are open to and patronized by the general public (Andalibi & Forte, 2018; Cacciatore & Bushfield, 2007; Gold et al., 2012; Kavanaugh & Hershberger, 2005). While these strategies provide a holistic picture of the successes and shortcomings of bereavement programs for women and families experiencing perinatal loss on a national scale, they fail to shed light on the unique set of challenges faced by bereaved parents and health workers at the local level. This is important in order to create interventions and policies that are tailored to the specific needs of bereaved women and families in the community setting.

### **The Current Study- Objectives and Research Questions**

This work explores bereavement care following perinatal loss in Marion County, Indiana. Specifically, the study explores the bereavement care experiences of Marion County IN women, and examines the role of peer support in the grief journey. The study additionally investigates provider-identified gaps in bereavement care for women experiencing perinatal loss in Marion

County IN and collects health provider's recommendations to improve the existing care offered to bereaved women and families.

The significance of the current study cannot be overstated as Indiana has the 9th highest infant mortality rate in the US, estimated at 6.75 per 1000; this translates to about 531 Indiana infants under age 1 dying annually (CDC, 2022). Between 2016 and 2020, an estimated 2,833 Indiana infants died before their first birthday. In the year 2020, there were 522 infant deaths, and of this number 313 were neonatal deaths. Additionally, 496 fetal deaths were recorded in the same year in Indiana (IDOH, 2022). Babies born in Marion County are particularly at risk of dying before their first birthday, with mortality rates reported at 7.4 per 1000 births compared with the national average of 6.6 per 1000 births and the Indiana State average of 6.7 per 1000 births (IDOH, 2022). Of the 522 infant deaths recorded in Indiana, 100 child deaths occurred in Marion County, the highest single contributor by county-level (IDOH, 2022). These high mortality rates leave behind a lot of grieving families who need support to cope with their grief and their mental health.

Furthermore, Indiana has the third highest maternal mortality rate of 44 deaths per 100,000 live births compared to the national average of 32.9 deaths per 100,000 live births (CDC, 2023; IU Public Policy Institute, 2022). Research shows that inadequate maternal mental health services before, during, and after pregnancy significantly contributes to the high maternal morbidity and mortality rates in the state (IU Public Policy Institute, 2022). This is especially true for women experiencing perinatal loss owing to the potential adverse effects on women's physiological and psychological wellbeing. To illustrate, women who have previously experienced a pregnancy loss are at increased risk of developing anxiety in subsequent pregnancies (Herbert et al., 2022). Excessive anxiety during pregnancy can prompt spikes in

blood pressure, which is a risk factor for developing preeclampsia (D'Arrigo, 2021). Specifically, pregnant women who have excessive anxiety have a 32% increased risk of gestational hypertension, a 52% increased risk of preeclampsia, and an 81% greater risk of eclampsia (D'Arrigo, 2021). Moreover, additional evidence suggests that recurring pregnancy loss and infant deaths could increase the risk for maternal substance use (Brecht & Herbeck, 2014).

Owing to the evidence that demonstrates the adverse effects of poor maternal health on maternal and infant mortality, it is important to identify gaps and create effective programs that protect women's psychological wellbeing, especially after the loss of a pregnancy or an infant. Bereavement support after perinatal loss in Indiana is severely understudied; in fact, this area has yet to be formally studied in local and state healthcare settings. The current study is novel, and to the best of our knowledge, it is the first research program to systematically examine bereavement care and support in Indiana and to provide recommendations for improving care following a miscarriage, stillbirth or neonatal loss.

### ***Research Questions***

The study seeks to answer the following questions:

- (1a) What are the bereavement care experiences of Marion County IN women who have experienced miscarriage, stillbirth, neonatal loss?
- (1b) How does being part of a peer support bereavement program impact women's journey with perinatal loss?
- (2) What are bereaved women's recommendations to improve perinatal bereavement support in Indiana?

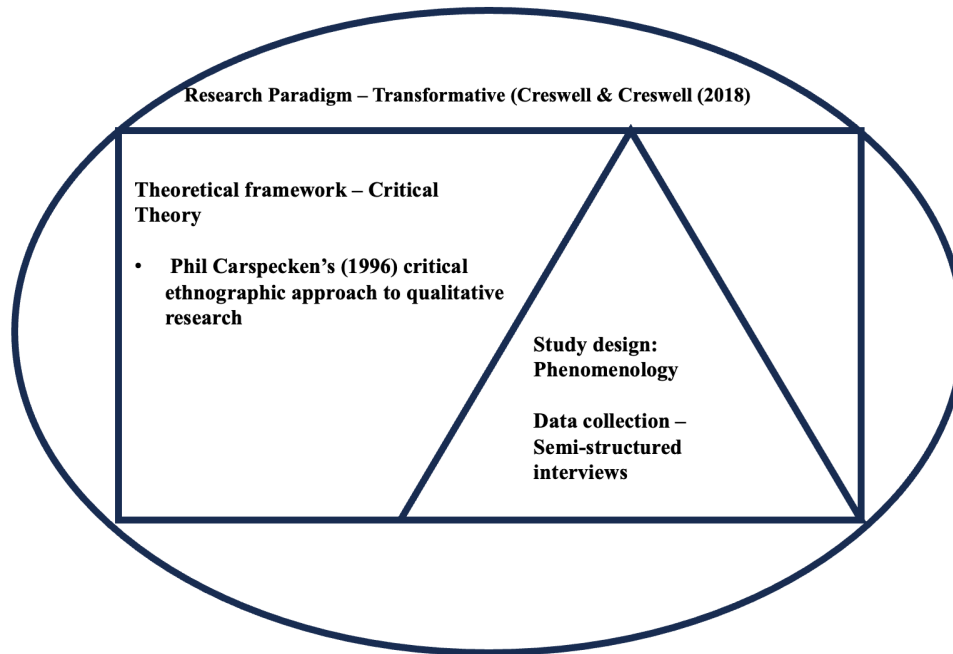
(3) What are provider identified challenges and gaps in perinatal bereavement care in Marion County, IN?

(4) What are provider recommendations to improve perinatal bereavement support in Indiana?

Findings of the study will inform the creation of effective programs that are tailored to the specific needs of grieving Marion County IN women.

## CHAPTER THREE: RESEARCH METHODS

Figure 1. Overview of Study Methodological Framework



### Research framework (worldview)

Creswell and Creswell (2018) use the term ‘worldview’ to describe the philosophical orientations that researchers bring to a study, which are shaped by the researcher’s discipline and research communities, advisors and mentors as well as past research experiences (Creswell & Creswell, 2018, p.5). The authors identify four research worldviews which include postpositivism, constructivism, transformatism and pragmatism (Creswell & Creswell, 2018). The current study is oriented toward the transformative worldview.

### The Transformative Worldview

The transformative worldview is concerned with social issues that affect marginalized or disenfranchised groups in society (Creswell & Creswell, 2018). This research paradigm has a

focal view on issues of power and social justice, discrimination, and oppression (Mertens, 2019). Researchers who embrace the transformative paradigm affirm that the role of research is to provoke actionable change in the lives of marginalized people, with this change usually brought on as a result of some political intervention (Mertens, 2009). In this vein, issues that are of concern to the transformative researcher include “empowerment, inequality, oppression, domination, suppression and alienation” (Creswell & Creswell, 2018, p.9). In order to prevent the further marginalization of participants, transformative research is conducted collaboratively. Because transformative research provides a platform to elevate unheard voices in advocating for change, participants are involved in several steps of the research process, from designing questions, collecting data, analyzing the information, and reaping the rewards of the research (Creswell & Creswell, 2018). Transformative researchers include but are not limited to “Critical Theorists, Participatory Action Researchers, Marxists, Feminists, researchers concerned with Racial and Ethnic Minorities, Persons with Disabilities, Indigenous and Postcolonial Peoples, and members of LGBTQ communities” (Creswell & Creswell, 2018, p. 9)

A variety of theoretical approaches may be used to guide transformative research, such as feminist perspectives, racialized discourse, **critical theory**, queer theory, and disability theory (Creswell & Creswell, 2018). Mertens (2009) describes four key features of the transformative worldview; first this type of research is characterized by an emphasis on the lives and experiences of traditionally marginalized groups with a keen interest in how individual lives have been inhibited by injustices and the strategies that they use to resist, challenge and create solutions to address these obstacles (Mertens, 2009). Second, another key feature of the transformative worldview resides in the focus on inequities based on gender, race, ethnicity, disability, sexual orientation, and socioeconomic class that promote differential power dynamics

and relationships (Mertens, 2009). A third feature of the transformative worldview “links political and social action” to the identified inequities, and the fourth feature states that “transformative research uses a theory of beliefs about how the world works and why social problems of oppression, domination and power relationships exist” (Creswell & Creswell, 2018, pp. 9 - 10; Mertens, 2009; Mertens, 2019).

### **Application of the Transformative Worldviews to the Current Study**

The current study examines women’s experiences with bereavement support and gathers provider perspectives toward making actionable change for this population, through recommendations for improving bereavement support for bereaved mothers. This is in line with a transformative worldview as the ultimate goal of this study is to gather information that will form the basis for designing effective bereavement support programs for grieving families. The main tenets of the current study are closely aligned with the key features of the transformative worldview in that this study places importance on the experiences of a group of people who have traditionally been marginalized, i.e., women who have lost a pregnancy through miscarriage, stillbirth or neonatal loss. Further, the current study highlights and advocates for social and political intervention in protecting maternal mental health after perinatal loss.

### ***Theoretical Framework***

In line with the transformative worldview, the study uses critical theory as a framework to guide the research. Specifically, the current study draws on the methodological insights from Carspecken’s critical ethnography to develop a critical interview study (Carspecken, 1996).

Carspecken’s critical ethnography is informed by Jurgen Habermas’ Theory of Communicative

Action (1985), which posits that meanings are constructed through dialogue and therefore these meanings are intersubjective (Habermas, 1985). As such, human interactions are oriented toward mutual understanding; meaning is reconstructed as we strive toward mutual understanding (Habermas, 1985). Habermas redirects our focus from solely the individual perspective toward social contexts within which individual actions are performed. In this way, critical researchers are oriented toward understanding the relationship between power, value, thought, and truth claims (Carspecken, 1996). By situating meaning making within the social context, researchers uncover implicitly embedded meanings (i.e., social norms and values) through explicit actions (e.g. dialogue with individuals). Through communication we uncover individual's intentions, feelings, desires and gain insights into how they make sense of the world around them (Habermas, 1985).

According to Carspecken (1996), critical research focuses on social inequities and advocates for positive social change (Carspecken, 1996). Critical theory is oriented toward promoting equity and social justice for disadvantaged and underserved populations; Thus, the value orientation of critical researchers is geared toward bettering the oppressed and downtrodden (Carspecken, 1996). Owing to the differential treatment for mothers with dead babies compared with those who have a live birth, critical theory serves as the most appropriate methodological framework for this study. To illustrate, motherhood is recognized based on physical observation, i.e., the presence of a living child. To that effect, women who have experienced perinatal loss and consequently have no living children are often not recognized as mothers, even if they consider themselves to be one. Additionally, women are only considered to be mothers of their living children; for this reason, bereaved mothers may have to decide whether to prioritize other people's comfort over their own truths. The internal dilemma and uneasiness

with expressing one's reality versus doing what is socially acceptable can put bereaved mothers in a peculiar situation.

The critical theoretical framework, therefore, brings to the fore inequities and gaps that exist in serving grieving mothers and advocates for social justice and health equity for these women and families. By exploring women's experiences with bereavement care and the associated influence that this care has on the loss journey through participation in a peer support program, women assume the position of power and control over their lived experiences and stories.

### **Assumptions**

Some underlying assumptions of this work based on Carspecken's (1996) concept of critical research include that research should support efforts for change and that because "certain groups in society are privileged than others", it is important to elevate the voices of the less privileged to improve systems and deconstruct the status-quo (Carspecken, 1996; p 7). In this regard, this research study aims to support ongoing efforts toward improving bereavement support for women and families that have experienced perinatal death. Another assumption is that "oppression has many faces", meaning that researchers should not only focus on the most popular forms of oppression and ignore other types of inequities that are not very well-known or researched (Carspecken, 1996; p 7). In this study, inadequate or lack of bereavement support for women experiencing perinatal loss is considered a form of 'oppression'. As such, the researcher strives to bring to the fore and expose the inequities inherent in this understudied area of investigation. A final assumption underlying this work is that research should be used to uncover subtle forms of oppression so that it becomes visible to not only those affected by it, but also

those who perpetuate these forms of oppression with the aim of challenging and removing oppression altogether (Carspecken, 1996). Because perinatal loss is shrouded in secrecy and characterized by social stigma, it becomes challenging to expose the injustices perpetuated against women and families who experience loss. This study hopes to uncover subtle forms of oppression that typically go unnoticed or unreported. In this vein, injustices will be exposed with the intention of proposing new and improved ways of providing support to women and families experiencing perinatal loss.

### **Study Design**

The design of the current study is phenomenology. According to Creswell (2012), phenomenology “describes the common meanings that individuals make of their lived experiences of a concept or phenomenon” (Creswell, 2012, p. 76). Data collected in phenomenological studies describe ‘what’ participants experienced and ‘how’ they experienced it (Moustakas, 1994). Researchers who use phenomenological study designs set aside their own preconceptions about reality and only accept truths that participants affirm based on their lived experiences (Moustakas, 1994). As phenomenology describes participants’ lived experiences and the essence and meanings attached to these experiences (Creswell & Poth, 2018), in this study, the researcher describes the bereavement care experiences of Marion County IN women who have lost pregnancies through miscarriage, stillbirth, or neonatal death. Thus, the shared/common phenomenon in this research is the experience of perinatal loss.

### **Data Collection Strategies**

Data collection for phenomenological studies often involves interviews with a heterogenous group of a minimum of 3 or 4 individuals and up to 25 participants who have

experienced the phenomenon being studied (Creswell, 2012; Polkinghorne, 1989).

Phenomenological studies may use additional data collection methods, including observations, journals, poetry, music, documents, and taped conversations (Van Manen, 1990). Interviews for phenomenological studies are quite in-depth and may occur multiple times (Creswell, 2012). To gain a deeper understanding of participants lived experiences, researchers ask broad open-ended questions that seek answers to (a) what participants have experienced in terms of the phenomenon studied and (b) specific contexts and situations that have affected or influenced their experiences of the phenomenon (Creswell, 2012). Responses to these two broad areas of inquiry help the researcher understand the commonalities in experiences of the phenomenon by producing textual and structural descriptions of participant experiences (Creswell, 2012).

In this study, the researcher used semi-structured interviews. Semi-structured interviews are commonly used in qualitative research and typically consist “of a dialogue between researchers and participants guided by a flexible interview protocol and supplemented by follow-up questions, probes and comments” (Creswell, 2012, p. 2). Interview questions may be modified to fit the context of each participant (DeJonckheere & Vaughn, 2019). Semi-structured interviews can be administered in various modes including, via face-to-face interactions, over the telephone, or through text messaging or emails. Again, semi-structured interviews can be conducted with a single individual, or a group of people and they may be brief or in-depth, depending on the objectives of the study (DeJonckheere & Vaughn, 2019). Because semi-structured interviews are especially effective when exploring participant thoughts, feelings, and beliefs and are extremely beneficial in delving deeper into sensitive topics (DeJonckheere & Vaughn, 2019), this data collection method is ideal for the current study.

## **Recruitment**

### *Eligibility*

The eligibility criteria to participate in the study as a bereaved woman/mother included self-identifying as a woman, being 18 years or older, living in Marion County, IN at the time of the study, and having experienced a miscarriage, stillbirth or infant death in the past 20 years. Eligibility of health professionals was based on individuals whose work centered on providing direct support to bereaved mothers and families as well as those professionals who worked to improve maternal, fetal, and infant mortality in Marion County, IN.

### *Recruitment*

Study participants were identified and recruited with the help of several community partners. First, the researcher established collaborations with personnel from the Fetal-Infant Mortality Review team (FIMR) at the Indiana Department of Health-Division of Fatality Review and Prevention. The primary point of contact was the program manager of the FIMR team. This individual oversees all programs related to Fetal and Infant deaths in the state of Indiana. The program manager's agenda is to find effective strategies to reduce fetal and infant deaths in the state of Indiana. As part of their duties, the program manager meets regularly with 17 FIMR coordinators who supervise and document all fetal and infant deaths within their assigned county/ jurisdiction. FIMR coordinators, FIMR nurses, and medical assistants/ abstractors work closely with bereavement nurses, with the aim of collaboratively identifying areas that are most in need of support. Last, bereavement nurses are situated in local hospitals and provide support and resources directly to women and families who experience the loss of a pregnancy or an infant.

Next, the researcher established collaborations with a key informant, who is a member of a bereaved mothers group known as Caring Companions. Caring Companions is a volunteer program established in the Franciscan St. Francis Indianapolis health system and is made up of women who have experienced loss through miscarriage, stillbirth, or neonatal death and who have the desire to help other grieving mothers and families navigate their loss journey. In addition to attending the Franciscan health support group known as Memories to Hold Pregnancy and Newborn loss program, volunteers of Caring Companions receive special training from Resolve Through Sharing (RTS) bereavement services and learn principles and practices of support to better serve grieving families (Resolve Through Sharing – Gundersen Health System, n.d.).

### **Recruiting providers**

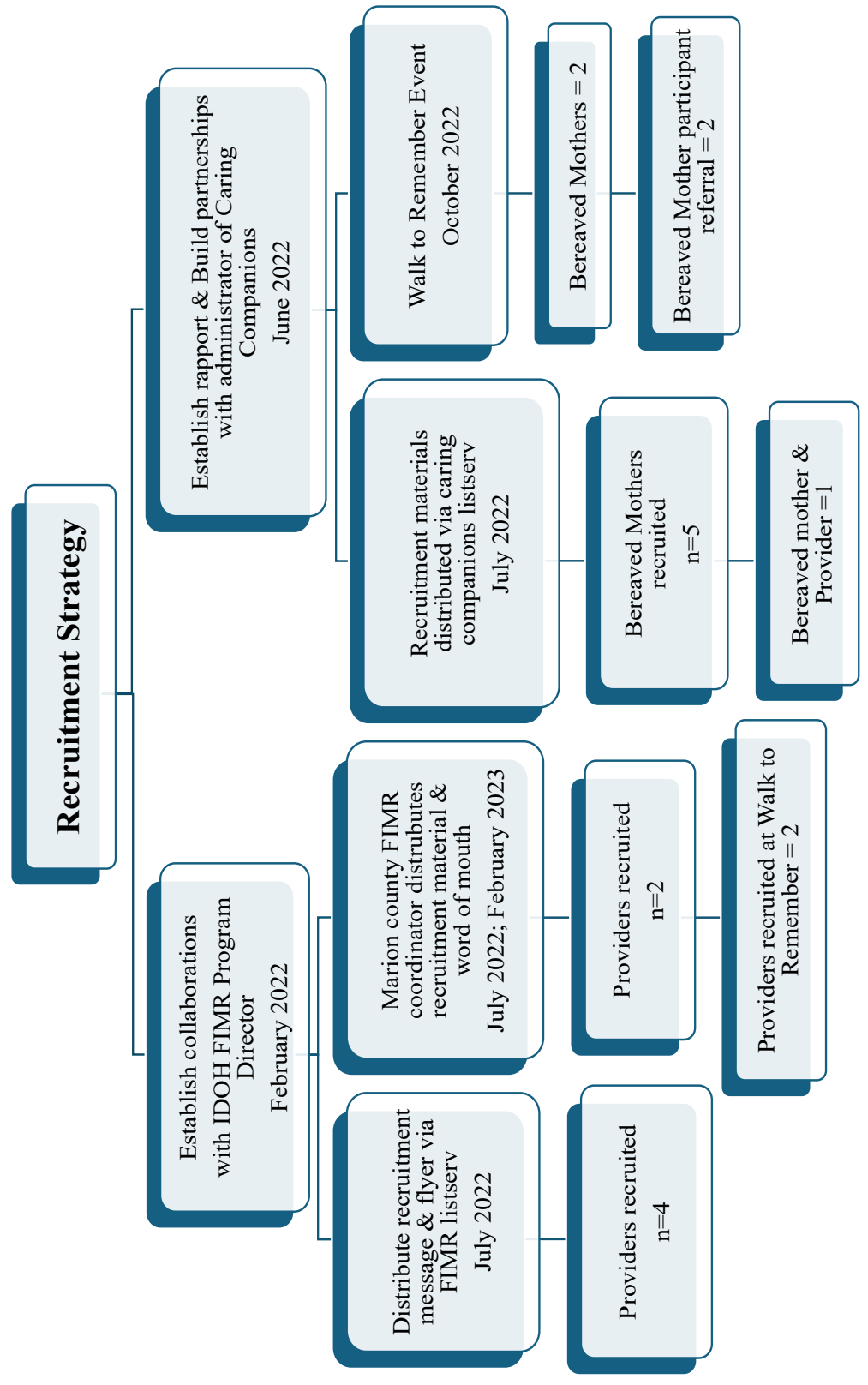
Prior to the start of the study, the researcher attended FIMR meetings to build rapport with FIMR coordinators and to gain a deeper understanding of the subject matter. As such, the researcher was added to the FIMR email listserv which comprises FIMR coordinators, FIMR nurses and FIMR medical assistants/ abstracters. After IRB (Institutional Review Board) approval for the study was received, the researcher distributed a recruitment email message (see Appendix A) with an attached recruitment flyer (see Appendix B) through the FIMR listserv with the permission of the FIMR program manager. The email message and recruitment flyer contained details about the research study, the purpose for which it was being conducted and how participants could contribute to the study. Four (4) initial study participants (providers working in Marion County) were recruited via the FIMR listserv and recruitment email. Two (2) additional participants were identified and recruited through the help of the Marion County FIMR Coordinator, who expressed interest in helping out with the study after receiving the

recruitment email and flyer. Consequently, the Marion County FIMR Coordinator provided the contact information for FIMR nurses and bereavement nurses working in the local hospitals in Marion County, IN. Last, two (2) additional bereavement nurses were subsequently recruited at a pregnancy and infant loss memorial event – A Walk to Remember in Indianapolis (See appendix C). A total of eight (8) providers participated in the study.

### **Recruiting Bereaved Mothers**

Bereaved mothers were recruited through purposive sampling and snowball techniques. Initial recruitment was conducted by distributing a recruitment email (Appendix D) and flyer (Appendix E) through the Caring Companion email listserv. Five (5) participants were recruited via the initial email recruitment strategy. To recruit additional participants, the researcher attended the Walk to Remember event organized by the Franciscan St. Francis Health in Indianapolis (See Appendix C). Two (2) additional participants were recruited at the event. An additional two (2) bereaved mothers were recruited through participant referrals. One (1) participant who was both a health provider and a bereaved mother also shared her lived experience with perinatal loss. A total of ten (10) bereaved mothers participated in the study.

Figure 2. Recruitment Strategy for Perinatal loss- Bereavement care experiences of Indiana women and Provider Perspectives



## **Collecting Study Data**

### *One-on-one interviews*

After the recruitment period, the researcher contacted respondents who volunteered to participate in the study and scheduled a time to conduct an interview. The informed consent form was sent via email to participants to review prior to the scheduled interview date. Participant consent was obtained verbally prior to the start of each interview; verbal consent was captured on the audio recording of each interview and can be verified from the interview transcript. All interviews were conducted via Zoom video conferencing (Zoom, n.d.) or over the telephone, based on participant preference.

There were 2 sets of interview questions used in this study (a) interview protocol for bereaved mothers, and (b) interview protocol for providers. Each protocol started with a background section where participant demographic information was captured. The protocol for bereaved mothers asked for women's age, occupation, length of time living in Indiana, town or city of residence, and number of living children and details about loss. The background information obtained from providers included age, current occupation/ position as it relates to bereavement and what provider motivations are in their field of work. Other sections of both interview protocols included bereavement prompts, bereavement nurse specific questions, Caring Companion specific questions and the intervention prompts. Details of both interview protocols showing how interview questions aligned with the overall research questions of the current study can be found below (Table 1 & 2). Interviews lasted anywhere between 39 minutes and 136 minutes. Interviews were audio recorded using the Zoom recording feature and transcribed verbatim with an online transcription tool – Descript (Descript, n.d.).

**Interview Protocol- Bereaved Mothers Caring Companions (Indiana Women)**

Table 1. Interview questions asked to bereaved mothers showing how they relate to the research study questions

A. Background
<ul style="list-style-type: none"> <li>• Could you please tell me your age, what you do/current occupation, how long you have lived in Indiana? What town or city do you reside?</li> <li>• Are you a parent? If yes, how many living children do you have?</li> <li>• Could you describe your loss journey to me?</li> </ul>
<b>Research Question 1a:</b> What are the bereavement care experiences of Marion County IN women who have experienced miscarriage, stillbirth, or neonatal loss?
B. Bereavement Prompts
<ul style="list-style-type: none"> <li>• Can you think back to the moment when you learned that your baby would not live. Describe to me how you were feeling and what was going on in your mind.</li> <li>• At what stage of pregnancy/ birth did loss occur? How long ago was this? Where did loss occur (state and city/town/county).</li> <li>• After your loss were you offered bereavement care at a healthcare institution? What was that like?</li> <li>• Can you describe to me what your interactions with health providers was like? Follow-up: What services did you receive? What was the level of information and detail provided about your loss?</li> <li>• Can you tell me what you know about your partner/ family and the support they received/ sought throughout this experience?</li> <li>• Tell me about some of the other support you received from family, friends, etc.</li> </ul>

- Looking back now are there resources or support you wished you had?
- What kinds of resources would you recommend for a friend who is having a loss?
- Tell me about your most challenging moments/ a moment that was particularly hard during your loss journey
- What made your bereavement care particularly difficult or better?

C. Caring Companion specific questions

**Research Question 1b:** How does being part of a peer support bereavement program impact women's journey with loss?

- Can you tell me about how you became involved with the volunteer program?
- What was the motivation behind your decision to join the group? How long have you been volunteering?
- Tell me about some recent experiences while volunteering in the program.
- What stories could you share with a mom who has had a loss that would help them decide to become a caring companion?
- Understanding that bereavement is a journey, how would you describe volunteering as part of your loss journey?

**Research Question 2:** What are bereaved mother's recommendations to improve bereavement support in Indiana?

D. Intervention Prompts

- Imagine that you have been invited to sit on a task force whose goal is to improve bereavement support in Indiana. What recommendations/ programs would you

implement? How do you believe that said programs would improve overall maternal, fetal and infant mortality rates in the state?

**Interview Protocol- Health professionals (FIMR Coordinators, bereavement nurses, support group administrators)**

Table 2. Interview questions asked to providers showing how they relate to the research study questions

A. Background
<ul style="list-style-type: none"> <li>• Could you tell me a bit about yourself? Your age, current position, where you work and affiliation with bereavement in Indiana?</li> <li>• What are your motivations to do this work?</li> </ul>
<b>Research Question 3:</b> What are the gaps in perinatal bereavement care in Marion County IN?
B. Bereavement Prompts
<ul style="list-style-type: none"> <li>• Tell me about your most recent contact with bereavement / the last time your position came into contact with bereavement. Follow up: Does this occur typically? What experiences stand out?</li> <li>• Could you describe to me what is done as part of bereavement support? What is done for miscarriage (usually happening in the ER) ?</li> <li>• Can you talk about any disparities you have seen in terms of who is more likely to experience loss? What do you think accounts for these differences?</li> </ul>

C. Bereavement nurse specific questions

- Could you talk about follow-up procedures after families leave the health center?
- What resources do you provide for partners and children of the bereaved family?  
How is this care different from that which is provided to bereaved mothers?
- In your opinion, why do you think some hospitals offer bereavement and others do not?
- In your opinion, is bereavement a standard of care? If no, can you think of reasons why bereavement is NOT a standard of care?

**Research Question 4:** What are provider recommendations to improve bereavement support in Indiana?

D. Intervention Prompts

- What are some challenges you experience in your work? How can said challenges be addressed?
- Given your experiences with Bereavement, what would you recommend for a hospital that is coming up?
- If new nurses were coming in, what would be some recommendations or advice?
- Imagine that you have been invited to chair a committee that is tasked to improve bereavement support in Indiana. What recommendations/ programs would you implement? How do you believe that said programs would improve overall maternal, fetal and infant mortality rates in the state?

## Data Saturation in Qualitative Research

Data saturation in qualitative studies is the point in the research process when the researcher determines that adequate data has been collected which will help him/her develop a robust and valid understanding of the studied phenomenon (Hennink & Kaiser, 2019). At this stage, any subsequent data collected will produce no new insights and may repeat that which has already been reported (Hennink & Kaiser, 2019). According to Creswell (2012) and Polkinghorne (1989), phenomenological studies typically include a minimum of 4 individuals and a maximum sample size of 25 (Creswell, 2012; Polkinghorne, 1989). Data saturation for the current study was achieved with the 17<sup>th</sup> participant.

## Data Analysis

Data analysis followed a 3 step approach described by Creswell (2012), which is widely used by many phenomenologists. The first step was a process known as **horizontalization**, where the researcher read the interview transcripts in order to become familiar with the data (Moustakas, 1994). Next, the researcher went through a process of open coding where they highlighted significant statements, quotes and sentences that spoke to how participants experienced the phenomenon. The researcher additionally highlighted significant quotes that responded to the research questions of the current study.

The second step in the data analysis process focused on answering the two foundational questions of a phenomenological study; that is, to understand **what** participants experienced (**textural description**) and **how** the phenomenon experienced by participants were either similar or different (**structured description**) based on the context and settings influencing the participant's lived experience (Moustakas, 1994). In order to explicate the 'what' and 'how' of

the studied phenomenon, the researcher applied two analytic techniques used by critical researchers – Meaning field Analysis and Reconstructive Horizon Analysis (Carspecken, 1996).

Meaning field analysis enumerates a range of possible meanings of a speech act (Carspecken, 1996). In other words, meaning fields express multiple and layered meanings of participant words or actions (Dennis, 2021b). This type of analysis articulates all possible interpretations of a significant quote and uses conjunctions to indicate how meanings are related to one another (Dennis, 2021b). It is important when doing meaning field analysis to articulate the range of possible meanings from the perspective of the first person ‘I’, in order to take the position of the participant and interpret the meaning as they would (Dennis, 2021b). In this phenomenological study, meaning field analysis is essential to bring out both implicit and explicit meanings embedded in participant statements and actions. Peer debriefing will be conducted consistently throughout the data analysis process to ascertain the validity of the researcher’s interpretations and constructions of meaning fields.

Reconstructive Horizon Analysis involves efforts to articulate components of meaning that are both explicitly depicted in participant acts and words and/or implicitly inferred (Carspecken, 1996). According to Carspecken (1996), when humans interact, meanings are recognized through an interplay of structural factors, i.e., the Horizon. A ‘horizon’ of meaning is made up of a continuum of foregrounded to backgrounded elements (Carspecken, 1996). Foregrounded meanings are what the actor emphasizes, while backgrounded meanings are a range of complex assumptions made by the actor about knowledge, beliefs, and values (Carspecken, 1996). In reconstructing meaning, the researcher must ask a variety of questions such as “what meaning seems to be the most salient or foregrounded?” and “If this meaning is true and makes sense, then what other claims can be inferred (backgrounded)?” (Dennis, 2021a).

In addition to analyzing foregrounded and backgrounded meanings, it is important that critical researchers analyze truth according to the type of validity claims entailed as a way to understand subtle and rich interpretations of meaningful actions (Dennis, 2021a). The range of possible validity claims can be organized into **objective** claims, **subjective** claims, **normative** claims, and **identity** claims. **Objective validity claims** refer to the existence of things and how they work; these types of validity claims work off of the principle that multiple people can verify the same claim by employing the same methods and definitions (Dennis, 2021a). **Subjective validity claims** comprise feelings, intentions, desires, and states of mind that are internal to the actor/ participant (Dennis, 2021a). **Normative (evaluative) claims** emerge out of mutually agreed upon and shared sets of norms and values (Dennis, 2021a). These types of claims indicate what is good/bad, right/wrong. Meaning reconstructions that are expressed in “should” or “ought to” fall within this category. Last, **identity validity claims** emerge out of the individual’s positionality and the autonomous ‘I’, a reflection of oneself that is a product of self-efficacy and self-awareness (Dennis, 2021a). A basic underlying assumption of identity validity claims is that every meaningful act communicates something about a person’s identity that can only be expressed and understood socially (Dennis, 2021a). In sum, reconstructive horizon analysis will comprise foreground-background relations and categories of validity claims (objective, subjective, normative, and identity claims).

In this study, the researcher used both meaning field analysis and reconstructive horizon analysis to help derive findings from the data. These analytic strategies are useful for finding patterns and divergencies of meaning, complexities in interpretations and what constitutes as truth for study participants through interpretative patterns (Dennis, 2021a). A combination of the two analytic strategies is essential as meaning fields provide more holistic meanings, i.e., broad

stroke interpretations and reconstructive horizon analysis maps out in a more refined way, meaning that is implicit to the analyzed acts (Dennis, 2021a).

The researcher subsequently developed ‘**clusters of meaning**’ from the codes and data analysis, developed themes and selected quotes to support each theme and sub-theme (Creswell, 2012).

In the third step, the researcher compiled a comprehensive report of the ‘**essence**’ of the phenomenon, detailing the deeper meanings, understandings and commonalities as well as divergences in participant experiences of the studied phenomenon. According to Polkinghorne (1989), the reader should leave with a better understanding of what it is like for an individual to experience the studied phenomenon after reviewing the essence of the phenomenological work (Polkinghorne, 1989).

### **Establishing Validity in Qualitative Research**

Qualitative researchers often have to provide evidence of credibility and validity of research findings. Creswell & Miller (2000) identified nine (9) different types of validity procedures that may be used by researchers (Creswell & Miller, 2000). These include triangulation, member checking, audit trail, disconfirming evidence, prolonged engagement in the field, thick, rich descriptions, researcher reflexivity, collaboration, and peer debriefing (Creswell & Miller, 2000).

In this study, the researcher employed three (3) validity procedures to ascertain the credibility and validity of research findings. Specifically, the researcher used **triangulation**, **peer debriefing**, and **researcher reflexivity**.

### *Triangulation*

Triangulation simply refers to the use of multiple methodologies in a single study of the same phenomenon (Denzin, 1978). Triangulation may be applied to a study by combining (a) multiple theories in a single study, (b) having multiple observers or interviewers rather than a sole researcher, (c) employing two or more methods in generating data for a study, i.e., interviews, observation, documents etc. and (d) consulting a variety of data sources, i.e., children, experts, policymakers etc. While triangulation was initially proposed as a tool for increasing the reliability and the validity of qualitative findings, Denzin (1989) builds upon this strategy by including its potential for generating a broader, deeper, and more comprehensive understanding of the studied phenomenon (Denzin, 2012; Denzin, 1989). Validity is established through triangulation as the researcher identifies common themes and categories that cut across multiple data sources and methods to corroborate study findings (Creswell & Miller, 2000). Divergent themes and differences are also identified and categorized to understand the whole picture of the studied phenomenon (Creswell & Miller, 2000). In this study, validity was established by employing triangulation of data sources i.e. bereaved mothers and providers.

### *Peer Debriefing*

Another way of establishing validity is through peer review or peer debriefing. This involves a review of data and research processes by an external individual who is familiar with the research or the studied phenomenon (Creswell & Miller, 2000). The peer reviewer/ debriefer provides support while also challenging the researcher's assumptions and asking hard questions about methods and interpretations (Creswell & Miller, 2000). Additionally, the peer reviewer/ debriefer provides valuable feedback and serves as a sounding board for ideas and interpretations (Creswell & Miller, 2000). Through close collaboration between the external reviewer and the

researcher, the credibility of research findings is established (Creswell & Miller, 2000). In this study, there were 2 peer debriefers – 1 individual with lived stillbirth experience who provided guidance to the researcher on interpretations of findings, and 1 external individual who is an expert in critical qualitative research. Both peer-debriefers checked researcher biases and substantiated research findings.

### *Researcher Reflexivity*

At the core of every research study is the researcher's own personal motivations and value systems. As such, it is important that researchers self-disclose the assumptions, beliefs, and biases that they bring to the study (Creswell & Miller, 2000). It is essential that researchers reflect and describe their entering beliefs and biases early in the research process so that readers understand their positionality as the study progresses (Creswell & Miller, 2000). Researcher reflexivity as a validity procedure includes a careful introspection about how the researcher's socio-cultural and historical backgrounds influence his/her interpretations of the study data and research findings (Creswell & Miller, 2000). To do this, researchers may select from several options to include reflexivity in their work, such as (a) including a separate section titled 'Role of the researcher', (b) providing a section at the end of the report, also known as the epilogue (c) using interpretative commentary throughout the discussion of findings (d) bracketing themselves out by describing personal experiences (Moustakas, 1994). In this study, researcher reflexivity as a validity procedure is included as a separate paragraph titled *Role of the researcher*.

### **Role of Researcher**

As the researcher of the current study, I come to this project as an outsider – a woman who has not experienced perinatal loss in her lifetime. Yet, my motivation to toe this line of investigation

stems from a culmination of three consecutive events and experiences of close personal friends, which led me to take an interest in perinatal loss and bereavement care.

Growing up, I always heard about maternal mortality and maternal health as a critical issue. As a Ghanaian, I knew the implications of maternal death on the community, but it did not hit home until I lost a dear friend to pregnancy-related complications in 2017, which led to her sudden demise. Adwoa was a course mate of mine at the university, and we attended small groups together. I learned that Adwoa had died shortly after her wedding in 2017; she had been about 4 months pregnant and had experienced late-term miscarriage. She went in for a routine D&E and died a few weeks later due to complications from the procedure. This was the first time I personally knew someone who had experienced pregnancy loss and unfortunately lost her life in the process. I started taking more interest in maternal health, particularly in situations that resulted in loss and ways to improve the current systems to ensure better health outcomes for women. The next impactful event was the death of another colleague, Paulina, from the same college cohort. She died after the birth of her twin girls. Our group made a donation to her husband. This got me thinking of the spouse and what types of support - be it emotional, financial, or tangible, that he had available to him. Finally, I learned of another good friend who had experienced 2 miscarriages in the first year of her marriage. Because of stigma, she did not disclose her losses to others and did not seek mental health services. Unfortunately, her husband blamed her for the losses and the only way to cope was to suffer in silence.

I decided to learn more about mental health support for women who lose pregnancies or babies shortly after they are born. I was curious about what was typical and if the standard of care could be improved in any way to better support grieving women and families. I hope that through this study, women from diverse backgrounds who experience perinatal loss may be

comforted, encouraged, and empowered to share their loss stories and be an advocate for other bereaved mothers who are unable to do the same.

My value system as a researcher who investigates social phenomenon qualitatively is informed by the transformative worldview described by Creswell & Creswell (2018). Thus, I believe that research should ultimately be used to inform ways to improve the lives and conditions of the socially disadvantaged. Additionally, I stand by the assumptions of critical inquiry, which posits that as researchers, we should not only focus on the most popular forms of oppression and ignore other types of inequities that are not very well-known (Carspecken, 1996). The objective of the current study, which is to investigate the perinatal bereavement care experiences of women, is an area within public health that is not very well-studied. Although existing research has shown the links between perinatal loss and adverse maternal mental health outcomes, this area continues to be overlooked. I am hopeful that with this research study we will begin to take definitive steps toward improving wellbeing holistically for bereaved mothers and families.

My socio-cultural and historical background shape how I interpret the data collected in this study. This is because, in my Ghanaian context, women's pain is often ignored. Women who experience the loss of a baby are discouraged from speaking about it, dwelling on it, and often told to just move on quickly and have another child. This cultural imposition bears a significant burden on women's mental health, which ultimately takes a toll in the long run. In light of these realities, I developed a desire to articulate the struggle of the bereaved mother through their own words. In this way, bereaved mothers collectively take a definite step toward breaking the silence around baby loss and make recommendations based on their personal experiences toward improving bereavement care for other bereaved mothers.

In sum, the combination of triangulation, peer debriefing and researcher reflexivity assists the researcher in satisfying three validity questions when using meaning field and reconstruction horizon analysis in critical research: (1) Are the interpretations plausible given an insider perspective? (2) To what extent are the interpretations free of the effects of power between researcher and researched? (3) To what extent do the interpretations put into discourse the fullest range of meaning plausible? (Dennis, 2021a).

### **Ethical Considerations**

To ensure the protection of participant rights, the researcher sought and obtained approval from the Indiana University Human Subjects Research Review Board (Appendix F). The Human Subjects Research submission included details about recruitment, eligibility criteria, informed consent, venue or sites where study processes would take place and the management of participants' personal and identifying data that is collected. After satisfying all the requirements, the submission was approved by the IU Human Subjects Research Review Board (protocol #14851, dated July 18, 2022).

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## CHAPTER 4: MANUSCRIPT 1

**Title: Perinatal Bereavement Care Experiences of Mothers in a Midwestern American State.**

### **ABSTRACT**

**Background:** Perinatal bereavement care following a miscarriage, stillbirth, or neonatal death is severely understudied in the state of Indiana. This study sought to understand bereavement care experiences of Marion County, IN women who have experienced perinatal loss. We additionally examined how participation in a peer support program influenced women's journey with loss and also collected bereaved mother's recommendations for improving existing bereavement care in Indiana.

**Methods:** Adopting a critical theoretical framework, we conducted semi-structured interviews with 10 Marion County IN women. Using a phenomenological approach, interview transcripts were coded, analyzed, and organized into categories and themes.

**Results:** Bereavement care experiences of Marion County, IN, women span both positive and negative experiences. The availability of perinatal bereavement care varies greatly and is inconsistent across birthing facilities in the county. Other themes include the effect of hospital staff attitudes on women's grief and disparities in bereavement care for early-term miscarriage. Two themes emerged on the impact of support group participation on women's loss journey: 1) The positive impact of shared experiences in bereavement support groups, and 2) Finding healing and purpose in bereavement volunteerism. Recommendations to improve bereavement care in Indiana include standardizing perinatal bereavement care across the state, mandatory bereavement education and training for health professionals, robust follow-up care and mental

health support for bereaved parents, and comprehensive lactation education for bereaved mothers who experience late to full-term loss.

**Conclusion:** Future programs to improve perinatal bereavement care in Indiana must consider the experiences and recommendations of bereaved parents when designing interventions for this underserved group.

**Keywords:** Perinatal loss, bereavement care, experiences, miscarriage, stillbirth, neonatal death, Indiana, woman, mother

## BACKGROUND

Perinatal loss, which refers to the death of a baby through a miscarriage, stillbirth, or a neonatal death (Barfield et al., 2016), continues to be a public health issue owing to the adverse outcomes on maternal mental health. This type of loss is associated with increased maternal risk for major depressive disorder (Herbert et al., 2022), generalized anxiety disorder (Davoudian et al., 2021), PTSD (Cacciatore, 2007), and increased risk of suicide (Chin et al., 2022; Weng et al., 2018). Additional evidence suggests that recurring pregnancy loss and infant deaths could increase the risk for maternal substance use (Brecht & Herbeck, 2014). Furthermore, studies have found that women who have recurrent pregnancy loss are at risk of developing increased anxiety. Excessive anxiety during pregnancy can prompt spikes in blood pressure, which is a risk factor for developing preeclampsia (D'Arrigo, 2021). Specifically, pregnant women who have excessive anxiety have a 32% increased risk of gestational hypertension, a 52% increased risk of preeclampsia and an 81% greater risk of eclampsia (D'Arrigo, 2021). Owing to the evidence that underscores the adverse effects of perinatal loss on maternal and infant well-being, bereavement care services have been created and designed to protect women's psychological and emotional health after the loss of a baby. The following paragraphs discuss bereavement care services provided after perinatal loss, parent's experiences with perinatal bereavement care, a justification for the research study, and the research questions that guide the study.

Bereavement care is a tool for prevention as it aims to help with unresolved maternal grief, and prepares mothers for subsequent pregnancies through managing anxiety that could hinder a safe and healthy pregnancy (Helps et al., 2020). Perinatal bereavement care involves a range of tangible, emotional, and psychological support and resources to help the bereaved individual cope with the grief that characterizes the mourning period (Zhuang et al., 2022).

These services are primarily provided in health facilities, and in the U.S., bereavement care is typically provided by a bereavement nurse/ coordinator or a social worker. Bereavement care often consists of mementos such as molds of the baby's hands and feet, hand and footprints and photos (Blood & Cacciatore, 2014; Domogalla et al., 2022). When possible, parents may be encouraged to bathe and clothe the baby, engage in religious rituals like naming ceremonies, introduce the baby to extended family, and may keep special clothing and blankets that have come in contact with the baby (Flenady et al., 2014).

Additionally, parents are presented with the opportunity to attend support groups and receive aftercare bereavement services (Domogalla et al., 2022). The peer support network is an essential component of perinatal bereavement care as it helps to bridge the gaps in bereavement care for women and families after they have left the health facility (Boyle et al., 2015). In this way, peer support programs keep women connected with other mothers who have had similar experiences of loss and grief (Boyle et al., 2015; Diamond & Roose, 2016). These programs are helpful in promoting the understanding that bereaved women are not alone and that by leaning on each other for support, they can navigate the journey of grief, heartache, and loss together (Brown, 2019). Peer support programs, most importantly, ensure that bereaved women and families are kept in the continuum of care so that their emotional and mental health needs are identified and addressed effectively (Boyle et al., 2015).

In reviewing the existing literature on parent's experiences of bereavement care following a miscarriage, stillbirth or neonatal loss, research overwhelmingly affirms the need for comprehensive care (Geller et al., 2010; Obst et al., 2021; Shakespeare et al., 2019; Smith et al., 2020), and identifies gaps in accessibility (Geller et al., 2010) as well as inconsistencies with bereavement as a standard of care (Wool et al., 2016). For instance, women who experienced a

miscarriage reported a lack of empathy and understanding from health providers. A recent systematic review investigating women's experiences of early miscarriage during the first 16 weeks' gestation showed that women overwhelmingly reported that their feelings and emotions were not recognized by healthcare providers (Radford & Hughes, 2015). While women interpreted their loss as the death of a baby and a major family tragedy, health workers viewed their loss as a clinical problem (Freeman et al., 2021). This was often expressed in their descriptions of the baby as "tissue," "clots," "failed conception," "products of conception," "missed abortion," "reproductive wastage," or "dead fetus" (Lee et al., 2023, p.56). The importance of respectful care cannot be overstated, as many women across studies reported neglect, insensitivity, poor attitudes, and poor communication from health workers (Freeman et al., 2021; Radford & Hughes, 2015).

Furthermore, parents who experienced the loss of a baby through stillbirth have reported negative reactions from health workers, family, and friends (Shakespeare et al., 2019; Ellis et al., 2016). The negative social perception of stillbirth as a consequence of a deficiency in a woman's reproductive abilities has contributed to the stigmatization of bereaved mothers (Shakespeare et al., 2019). Women have reported losing their social identities as mothers because society fails to acknowledge the motherhood of dead babies (Shakespeare et al., 2019). Moreover, because there are often no burial rituals or traditions for a stillborn baby, women are often encouraged to suppress mourning their babies or to forget quickly and to have another baby, which further exacerbates and prolongs women's grief (Adebayo et al., 2019; Meyer et al., 2018; Shakespeare et al., 2019 ). Other issues around bereavement care following stillbirth include parents' report of being excluded from decision-making processes such as mode of birth (vaginal delivery or C-section) and aftercare procedures, including consent for post-mortem examinations and how fetal

remains are treated / disposed of (Siassakos et al., 2018). This was found to be a topic of major concern, and the World Health Organization (WHO) through its research, found that depending on the hospital policy, the remains of the baby would be treated as clinical waste and incinerated; this prevented the parents from seeing, holding and making memories with the baby (World Health Organization, 2023). Furthermore, the lack of a separate private space / room for bereaved parents has been reported. In some instances, women are required to give birth to their babies in the same maternity and delivery wards, surrounded by women with live and healthy babies, which further exacerbates parental grief (Siassakos et al., 2018; World Health Organization, 2023).

Similar to the experiences reported by parents who experienced stillbirth, bereaved mothers who had a neonatal loss expressed a need for more provider care and support, particularly in communicating the cause of the baby's death and answering parent's questions when breaking the news (Embaireeg et al., 2020). Others touched on provider sensitivity and using simple language devoid of medical jargon (Embaireeg et al., 2020). A UK study examining 249 women's experiences of care after the death of their newborn showed that mothers' concerns about bereavement care primarily centered around the quality of care received (Redshaw et al., 2021). While most women reported receiving very good care, the aspects of the bereavement care received which they felt could have been improved revolved around health provider's sensitivity and empathy, as well as women's need for their wishes and desires to be heard by providers (Redshaw et al., 2021).

In the U.S., bereavement care following perinatal loss has been studied on a national scale, without much focus on local level factors that may impact care. Recruitment for such studies is predominantly conducted through national level organizations and social media

platforms that are open to and patronized by the general public (Andalibi & Forte, 2018; Cacciatore & Bushfield, 2007; Gold et al., 2012; Kavanaugh & Hershberger, 2005). While these strategies provide a holistic picture of the successes and shortcomings of bereavement programs for women and families experiencing perinatal loss on a national scale, they fail to shed light on the unique set of challenges faced by bereaved parents and health workers at the local level. This is important in order to create interventions and policies that are tailored to the specific needs of bereaved women and families in the community setting.

Bereavement care after perinatal loss in Indiana is severely understudied and has yet to be formally investigated at the local and state levels. Because Indiana has the 9th highest infant mortality rate in the U.S., which leaves behind a lot of grieving families who need support to cope with their grief and their mental health, we have identified this U.S. state as an ideal starting point of investigation. Additionally, we choose Marion County as the study site owing to the relatively higher infant deaths recorded. Marion County's population is 14.1% (968, 460) of the total state population (6,862,199), yet about 19% of the state's infant deaths occurred in the county (STATS Indiana, 2023). Specifically, of the 522 infant deaths recorded in Indiana in 2022, 100 child deaths occurred in Marion County, the highest single contributor by county-level (IDOH, 2022). Given the scant literature on perinatal bereavement care in Indiana, we seek to add to the existing literature within this field. To our knowledge, no previous studies have toed this line of investigation. To this end, the current study seeks to answer the following questions:

(1a) What are the bereavement care experiences of Marion County IN women who have experienced miscarriage, stillbirth, or neonatal loss?

(1b) How does being part of a peer support bereavement program impact women's journey with perinatal loss?

(2) What are bereaved women's recommendations to improve perinatal bereavement support in Indiana?

### **Theoretical Framework**

This study is guided by critical theory and draws on the methodological insights from Carspecken's critical ethnography to develop a critical interview study (Carspecken, 1996). Carspecken's critical ethnography is informed by Jurgen Habermas' Theory of Communicative Action (1985), which posits that meanings are constructed through dialogue and therefore these meanings are intersubjective (Habermas, 1985). Through communication we uncover individual's intentions, feelings, desires and gain insights into how they make sense of their experiences and the world around them (Habermas, 1985). With this in mind, Carspecken (1996) highlights the focus of critical research as one that identifies social inequities and advocates for positive social change (Carspecken, 1996). Critical theory is oriented toward promoting equity and social justice for disadvantaged and underserved populations (Carspecken, 1996). In this study, bereaved mothers are affirmed as the underserved group, in need of robust bereavement care with the aim of promoting better health outcomes for this population. The critical theoretical framework, therefore, brings to the fore inequities and gaps that exist in serving grieving mothers and advocates for social justice and health equity for these women and families. In this way, critical theory guides the entire research design of the current study and informs the study's research questions. Thus, critical theory serves as the most appropriate methodological framework for this study. By exploring women's experiences with bereavement care and its influence on the loss journey through participation in a peer support program, women assume the position of power and control over their lived experiences and stories.

## METHODS

We followed the Consolidated Criteria for Reporting Qualitative research (COREQ) guidelines in reporting methodological approaches, strategies, and study findings (Tong et al., 2007). The COREQ is a 32- item checklist that serves as a guide for reporting important aspects of qualitative research, including details about the research team, study methodology, the study's context, data analysis procedures, study findings, and interpretations of these findings(Tong et al., 2007). In this study, the aspects of the COREQ checklist that have been reported below include details about the study's design, the data collection instrument, participant eligibility and sampling strategies, participant recruitment, data collection procedures, information on data saturation, data analysis, and establishing the validity of study findings.

### *Study Design*

The design of the current study is phenomenology. According to Creswell (2012), phenomenology “describes the common meanings that individuals make of their lived experiences of a concept or phenomenon” (Creswell, 2012, p.76). Data collected in phenomenological studies describe ‘what’ participants experienced and ‘how’ they experienced it (Moustakas, 1994). As phenomenology describes participants’ lived experiences and the essence and meanings attached to these experiences (Creswell & Poth, 2018), in this study, the researcher describes the bereavement care experiences of Marion County IN women who have lost pregnancies through miscarriage, stillbirth, or neonatal death. Thus, the shared/ common phenomenon in this research is the experience of perinatal loss.

### *Instrument*

Interview questions were informed by the existing literature on parents' bereavement care experiences following a miscarriage, stillbirth, or neonatal loss ( Ellis et al., 2016; Radford & Hughes, 2015; Redshaw et al., 2021; Shakespeare et al., 2019 ). Interview questions were designed to elicit responses that spoke to the research questions of the study. As is typical of research using phenomenology as a study design, semi-structured interviews were used to explore women's bereavement care experiences following perinatal loss. The interview protocol consisted of 4 parts with the following structure:

- a. Background information: We asked about the participant's background including the number of living children, the type of loss experienced, the number of losses total in her lifetime as well as the city of residence and health facility where the loss(es) occurred. This was done to obtain a holistic picture of perinatal loss for each participant and to set the stage for follow-up questions.
- b. Bereavement prompts: We asked participants to describe their experience of loss and the care they received following the loss. Participants were also asked to describe resources or care that they felt were positive and those that they believed were lacking throughout their experience. This positioned women as experts in their own stories and allowed participants to share as much as they felt comfortable sharing.
- c. Bereavement support group questions: We asked about women's participation in a peer support program as well as descriptions of any benefits of being a part of such programs. This was done to understand participant's reported perceptions about how peer support programs have influenced their loss journey.

d. Intervention prompts: With their personal experiences in mind, we asked participants to provide recommendations on how to improve existing perinatal bereavement care in Marion County, and in the state of Indiana.

### *Eligibility and sampling*

To be able to take part in the study, participants had to self-identify as a woman, be 18 years or older, live in Marion County, IN at the time of the study, and report having experienced a miscarriage, stillbirth, or neonatal death in the past 20 years. Because the loss of a baby is an extremely sensitive issue and women may be at varying stages of grief and recovery, we extended the eligibility window to include women whose experiences occurred up to 20 years ago. Research shows that residual grief from perinatal loss can last several years (Cacciatore, 2010; Campbell-Jackson & Horsch, 2014; Kersting & Wagner, 2012); as such, some women may not be ready to share or talk about their experiences following the loss of their baby. For this reason, we believe that the 20-year window served as an ideal timeframe in order to be inclusive of potential participants who would be willing to share their bereavement care experiences.

### *Recruitment*

Following approval of the study by the Human Subjects Review Board of the author's institution, participants were recruited using a combination of purposive sampling and snowball sampling methods. The researcher established collaborations with a key informant, who is a member of a bereaved mothers group known as Caring Companions. Caring Companions is a volunteer program established in the Franciscan St. Francis Indianapolis health system, and is comprised of women who have experienced loss through miscarriage, stillbirth, or neonatal

death, and who have the desire to help other grieving mothers and families navigate their loss journey. In addition to attending the Franciscan health support group known as Memories to Hold Pregnancy and Newborn loss program, Caring Companions receive special training from Resolve Through Sharing (RTS) bereavement services and learn principles and practices of support to better serve grieving families (Resolve Through Sharing – Gundersen Health System, n.d.).

First, with the help of the key informant, initial recruitment was conducted by distributing the recruitment flyer and message via the Caring Companions email listserv. Additional participants were recruited at the local ‘Walk to Remember’, a community event for perinatal loss organized by the Franciscan St. Francis Health in Indianapolis. The researcher contacted potential participants directly via email. Participants were informed about the study purpose, objectives, and eligibility criteria and were asked to voluntarily participate in the study. Participants who decided to enroll in the study received an informed consent sheet prior to the interview. At the end of each interview, participants were asked if they knew of a friend or colleague who satisfied the eligibility criteria and one who might be interested in the study. Participants provided the contact information of friends and colleagues who expressed interest in participating in the study. This constituted the participant referral/ snowball sampling strategy of recruitment.

### *Data Collection*

After the recruitment period, the researchers contacted respondents who volunteered to participate in the study and scheduled a time to conduct an interview. The informed consent form was sent via email to participants to review prior to the scheduled interview date. Participant consent was obtained verbally prior to the start of each interview; verbal consent was captured

on the audio recording of each interview and can be verified from the interview transcript. All interviews were conducted via Zoom video conferencing (Zoom, n.d.) or over the telephone, based on participant preference. Interviews lasted between 39 – 136 minutes. Interviews were audio recorded using the Zoom recording feature and transcribed verbatim with an online transcription tool – Descript (Descript, n.d.).

### *Data Saturation*

Data saturation in qualitative studies is the point in the research process when the researcher determines that adequate data has been collected which will help him/her develop a robust and valid understanding of the studied phenomenon (Hennink & Kaiser, 2019). At this stage, any subsequent data collected will produce no new insights and may repeat that which has already been reported (Hennink & Kaiser, 2019). According to Creswell (2012) and Polkinghorne (1989), phenomenological studies typically include a minimum of 4 individuals and a maximum sample size of 25 (Creswell, 2012; Polkinghorne, 1989). In the current study, data saturation was realized with the 9<sup>th</sup> participant as each subsequent participant repeatedly spoke of similar experiences of bereavement care and motivations to serve others. We conducted one additional interview with the 10<sup>th</sup> participant to confirm data saturation. Thus, data saturation for the current study was achieved with the 10<sup>th</sup> participant.

### *Data Analysis*

Data analysis followed a 3-step approach described by Creswell (2012), which is widely used by many phenomenologists. The 3 steps include horizontalization, developing clusters of meaning, and providing the essence of the work (Creswell, 2012). In this study, data management, including coding and analysis were performed using the qualitative analysis

software MAXQDA 2024 (VERBI Software, 2024). Working with MAXQDA 2024 helped to organize codes and summarize the study data. Additionally, given the evidence that supports the use of multiple coders in qualitative research by improving reliability and trustworthiness of interpretations, as well as checking researcher biases (Church et al., 2019; Patton, 2014; Richards & Hemphill, 2018), in this study two researchers performed the data analysis processes. Specifically, the lead researcher and a second coder, collaboratively worked on data analysis, interpretations and generating themes for this study.

Thus, in the first step of the process known as **horizontalization**, the researcher read and re-read all the interview transcripts to become familiar with the data (Moustakas, 1994). Next, using a process of open coding, the researcher developed a codebook with 89 initial codes after reading the first 3 transcripts. The researcher then coded all 10 interview transcripts while simultaneously adding in emerging codes. Through this inductive method of coding, 34 new codes were added, bringing the total number of codes to 123. Next, a second coder randomly selected 5 out of the 10 transcripts (50% of the transcripts), read and re-read each transcript, and then coded the selected transcripts using the codebook of 123 codes created by the researcher. The second coder then conducted an audit of the codes in the codebook by confirming the representativeness of each code to the narratives provided by study participants. In this way, the second coder's audit served as a quality control measure of how closely codes aligned with the stories and experiences reported by interview participants. This process also served to increase the rigor and trustworthiness of the researcher's interpretations of participant narratives. Following this process, both researchers independently highlighted significant statements, quotes, and sentences that spoke to how participants experienced the phenomenon and responded to the research questions of the current study.

The second step in the data analysis process focused on answering the two foundational questions of a phenomenological study; that is, to understand **what** participants experienced (**textural description**) and **how** the phenomenon experienced by participants were either similar or different (**structured description**) based on the context and settings influencing the participant's lived experience (Moustakas, 1994). To explicate the 'what' and 'how' of the studied phenomenon, the researchers applied two analytic techniques used by critical researchers – Meaning field Analysis and Reconstructive Horizon Analysis (Carspecken, 1996). Disagreements in coding were resolved through discussions by both researchers until the researchers reached a consensus (Chinh et al., 2019). The lead researcher subsequently developed '**clusters of meaning**' from the codes and data analysis, developed themes and selected quotes to support each theme and sub-theme (Creswell, 2012).

In the third step, the researcher compiled a comprehensive report of the '**essence**' of the phenomenon, detailing the deeper meanings, understandings and commonalities as well as divergences in participant experiences of the studied phenomenon.

#### *Establishing validity of study findings*

Validity and credibility of study findings were established through peer debriefing (Creswell & Miller, 2000). With the help of two peer debriefers, one individual with lived stillbirth experience who provided guidance to the researcher on interpretations of findings, and one external individual who is an expert in critical qualitative research, interpretations of research findings were substantiated, and researcher biases were called into question.

## RESULTS

### *Participant Description*

We explored the perinatal bereavement care experiences of 10 Marion County IN women. Women’s ages ranged between 27 and 58 years. Women reported experiencing between 1 – 5 total losses in their lifetime. The average time that had passed since losses occurred was 8 years (range 2 – 20 years). Nine (9) of the ten (10) women who participated in the study reported being a part of a volunteer bereavement support group known as Caring Companions. Three (3) out of the ten (10) participants experienced their loss at the Franciscan St. Francis Indianapolis hospital, and an additional 4 women attended support groups at this institution. Thus, study participants’ experiences of the loss journey are significantly shaped by their participation in the bereavement services offered through the Franciscan St. Francis Indianapolis health system. In the current study, all participant names have been replaced by pseudonyms to preserve the confidentiality and anonymity of respondent’s identities. Details of participant characteristics are provided in Table 3.

Table 3. Participant characteristics showing participant age, total number and type of loss, time since loss occurred, and membership as a caring companion

Participant	Participant Age	Total number and type of loss (gestational age)	Time (in years) since loss(es) occurred	Member of Caring companions
Jane	58	3 miscarriages (17-18 wks)	20	Yes
Mary	27	3 miscarriages (15-17 wks)	5, 3	Yes
Anne	31	1 stillbirth (20 wks), 1 miscarriage (8 wks)	10, 7	Yes
Liz	33	1 stillbirth (33 wks)	3	Yes
Karen	42	2 miscarriages (4-6 wks), 1 stillbirth (38 wks)	14, 12	Yes
Eva	40	1 miscarriage (10- 12 wks), neonatal loss (6 hours after birth)	3, 2	No

Lisa	35	2 miscarriages (1 <sup>st</sup> trimester), 1 ectopic pregnancy, 1 miscarriage (18 wks), 1 miscarriage (1 <sup>st</sup> trimester)	6, 5, 4	Yes
Ruth	38	1 miscarriage (10 wks)	13	Yes
Donna	52	1 stillbirth (25 wks)	14	Yes
Abby	53	1 neonatal loss (8 hours after birth)	18	Yes

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All participant names in this study are pseudonyms to preserve confidentiality and anonymity of respondent's identities

### *Format for Reporting Study Findings*

In reporting the findings of the current study, the researcher will first discuss the perinatal loss experiences of the 10 bereaved women who participated in the study. This description will include women's accounts of their emotional and psychological experiences as they navigated the journey of losing their baby. While this does not speak directly to the study's research questions, these accounts provide an in-depth understanding of what it means to experience the loss of a baby. It also contributes to understanding the essence of the phenomenon experienced by study participants (Creswell, 2012).

Next, the researcher will discuss findings by themes organized according to each of the 3 research questions. Thus, in this section, the researcher discusses the salient themes from women's accounts of their bereavement care experiences following perinatal loss, the role of peer support bereavement programs in perinatal bereavement care, and recommendations to improve perinatal bereavement care in Indiana.

### *Perinatal Loss Experiences*

Prior to describing the bereavement care that they received, participants recounted the experience of losing their baby. Women provided detailed descriptions of their emotional and psychological state after finding out that their baby would not survive, or that they had just lost a

baby. Participants described their loss experience as “*traumatic*”, “*a horrific experience*”, “*overwhelming*” and, “*an awful unfinished feeling with not very much closure*”. Jane, a participant who conceived triplets with the help of fertility treatments but ultimately lost all 3 babies, describes her experience as “*definitely the worst day of her life*” and was in complete shock as she “*had spent all this money and knew she couldn't do that again*”. Mary, who had experienced 3 recurring losses describes that after each subsequent loss she felt more and more frustrated as she had hoped that the experience would not repeat itself, yet she continued to lose subsequent babies. In her words, she explains that her perinatal loss experience “*was frustrating cuz you know, we were like, it's not gonna happen again. It can't happen again. And it did*”.

Again, participants described their emotions throughout the loss experience. Karen, a participant who experienced a stillbirth at 38 weeks, recounted her intense feelings of anger after being informed about the passing of her baby. She describes how she desperately needed someone to blame for the loss, hence redirecting her frustrations to everyone around her- “*I was mad at everyone. I was mad at my doctor for not knowing; I was mad at the nurses, I was mad at my husband, because he didn't make me go to the hospital sooner. I mean, I was just mad- you name them, I was mad at them*”. Karen ultimately blamed herself for the passing of her baby -“*I was really mad at myself because I thought, like I'm her mother. How did I not know there was something wrong and do something*”. Self-blame was a recurring emotion for most of the bereaved mothers, as Mary also recounts how she blamed herself for the passing of her 3 babies through miscarriage -“*it felt like it was my fault that we didn't get to keep them*”.

Other participants shared that they experienced a range of emotions from sadness, to grief to disbelief after the passing of their baby. Donna, a participant whose baby died at 25 weeks shares that she felt like she was in a bad dream that she hoped she would wake up from-“*I was*

*sad, I was overwhelmed, I was confused, I was angry, but yet I just kept going in and out of like, this is really happening. No, this isn't really happening. This is a bad dream. And I'll wake up”.*

Losing a baby through perinatal death was described by some participants as a uniquely traumatic event. For instance, Lisa, a participant who had experienced 5 total losses, shared her story about the time when she had an ectopic pregnancy, knowing that her baby would not survive and feeling hopeless about the situation. What made the experience particularly challenging was the dilemma of wishing that her baby would pass due to the fear of rupturing a fallopian tube, but at the same time feeling an intense sense of grief and guilt as a mother- *“I kind of had to hope that my baby would die, and my numbers would go down because otherwise I could end up with an exploded fallopian tube or, you know, like a ruptured tube or bleed out, so that was very stressful and traumatic”*. Additionally, trauma from perinatal loss was experienced differently depending on the gestational age of the baby. Specifically, women who had experienced 2 or more losses reported that their later term losses had been more traumatic compared to earlier losses. Lisa shares how she experienced the death of her second-trimester baby differently from previous first trimester miscarriages – *“at that point, I already lost babies, but this was the first time that I'd lost in the second trimester. Um, and so this was the time it really just hit me in a different way, all the trauma that was associated with it”*.

For some women, returning home from the hospital was especially challenging particularly, if they had children at home waiting for their baby brother or sister. In Abby's case, she sympathized greatly with the older siblings and described that *“coming home empty handed was very hard to explain”* to her older children. This made the loss experience particularly hard for her as she had to navigate her own grief and that of her children.

Furthermore, participants used various metaphors and figurative expressions to describe the profound meaning that losing a baby had on them. For Mary, losing her babies implied emptiness, because “*her arms were ready for a baby and she was not given a baby*”. Lisa held on to the knowledge that her “*grief was the love for her baby that was left behind*”, and Karen would never forget her little one as she uses the symbols of a rock and a boulder to describe the void she continues to feel 12 years after the death of her baby –“ *Grief is like a rock in your pocket, so you always know that it's there. Other days it's like a boulder where it's just crushing you and you can't catch your breath to get the boulder off of you because it's crushing you. Most days my baby is a pebble in my pocket. Um, but 12 years out, there are days where it is absolutely crushing. I'm okay, but I'm never going to get over it*”.

### *Bereavement Care Experiences*

To better understand the bereavement care experiences of Marion County IN women who have experienced miscarriage, stillbirth, or neonatal loss we identified 4 salient themes from our interviews: (1) Bereavement care experiences of Marion County IN women are positive due to the quality of care received from bereavement support staff, (2) The availability of perinatal bereavement care is inconsistent across birthing hospitals, (3) Attitudes of hospital staff have an emotional impact on women’s bereavement care experiences, and (4) Disparity in bereavement care for early term miscarriage. We discuss these themes in detail below.

### **Theme 1: Bereavement care experiences of Marion County IN women are positive due to the quality of care received from bereavement support staff.**

In our study, women described the bereavement care they received in generally positive ways. Participants expressed contentment with the care they received following their loss, like Jane,

who expressed that “*she couldn't have asked for better care at the hospital*” and Liz, who reported that “*as far as things that she needed, she basically had access to a lot of care, more, than she ever dreamed*”.

Some specific bereavement items that women received included molds of hands and feet, hands and footprints, photos of baby, things that baby had touched including blankets, hats, socks, jewelry such as an angel pin, necklace, bracelet, birth notices in the form of poppy plates, newsletters, food vouchers or gift certificates, photo books and a cuddle teddy bear for siblings. Women also recounted that they were given the opportunity to hold and see the baby, attend support group/ group therapy, and attend memorial services. Further, women reported receiving information about burial and cremation, information about (genetic) testing or autopsy, and appreciated being kept in the continuum of care through email listservs.

In many instances, the bereavement nurse and hospital staff made the bereavement care experience particularly memorable. Women described bereavement support staff as “*an absolute angel*” – Jane, “*phenomenal*” – Abby and “*so sweet*” – Eva. The pivotal role played by the bereavement staff in providing both immediate and emotional support to grieving families was highlighted throughout as women shared their stories. To illustrate, Liz recounts how the bereavement nurse who attended to her facilitated the creation of the most precious mementos of her baby, a heartbeat recording, immediately after she received the fatal diagnosis. This coordinator also gave her a gift certificate for a company where parents could custom-make their own stuffed animals. In this way, Liz was able to put the recorded heartbeat of her baby inside the stuffed animal as well as her baby’s ashes. In her own words, Liz affirms that these items “*turned into the most meaningful things for her*”. Donna also describes the dedication with which her bereavement nurse attended to her throughout the day during her entire hospital stay.

Other ways that the bereavement staff supported women was by connecting them with external resources that weren't offered at their own hospital. For instance, Abby shared an anecdote of the two bereavement nurses who provided recommendations for ongoing support groups in another hospital due to the lack of support groups in their own institution – “ *At that time, the hospital I attended had two nurses on staff and they were amazing...as I went home, the two bereavement staff said, listen, we don't have any support groups here at our hospital, but we know that another hospital does, and we know that you live near there. Go check it out*”.

In some situations, bereavement staff stepped in and made critical decisions that positively impacted women's loss journey. Karen described how a decision taken by a floor nurse became the only memento she has from her stillbirth experience- “*...the nurse came in and asked if I wanted to have pictures taken. And I threw her out of my room, like get out what, what the hell is wrong with you get out of here! Of course, I don't want pictures of this. And luckily she said, forget you, I'm doing it anyway. And I have me some pictures. I'm very fortunate that she totally ignored me*”.

## **Theme 2: The availability of perinatal bereavement care is inconsistent across birthing hospitals**

Although most women (6) in our study reported receiving good bereavement care at the facility where the loss(es) occurred, this was not a universal experience. Participants commented that, to their knowledge and based on anecdotal reports from family and friends, perinatal bereavement care was not always provided to bereaved parents – “*So I've been told - I have a friend that works at X hospital in Indianapolis, that they have no bereavement care. And then I've heard it's not great at Y hospital either*” – Anne. Another participant, Jane also shares what she knows about the lack of perinatal bereavement care in some birthing facilities in the county -

*“For me, I was very blessed, but I know, unfortunately, that I'm probably maybe one of the exceptions. I know that not all hospitals offer bereavement care” – Jane.*

Four (4) out of the ten (10) participants recounted stories of their bereavement care experience as not so pleasant and felt that the care they received left something to be desired – *“So with my loss, we got footprints and we got a few pictures, and blankets that touched my son, things like that, they gave us. But it was kind of few and far between, and it felt like being cared for, it felt like they drew the short end of the stick that day... I don't have handprints of my sons, and I don't have molds. Looking and thinking back now, I think they could have definitely been done, but nobody took the time to do them” – Anne.*

When asked about factors that could possibly explain the reported inconsistencies with perinatal bereavement care in some birthing hospitals, participants felt that these could be attributed to staffing issues and a lack of training for bereavement staff – *“I don't know for sure but I think right now staffing is- staffing sucks. Um, but also taking the time, it's just- I feel like staff feeling inadequate, not feeling trained to provide bereavement care, the lack of knowledge of how to do it, the training of how to do it and the staffing of like having such a heavy patient load that people just don't have time” – Anne.*

Further, the priorities of hospital administration was identified as another possible factor impacting the availability of bereavement care in some Marion country IN birthing hospitals. According to some participants, hospital administrators did not recognize perinatal bereavement as a critical need for loss families. As such, their decisions determined whether a bereavement nurse would be on staff to care for loss patients, and the scope of resources provided to bereaved families. Consequently, the bereavement care in such institutions, if they existed, did not see much improvement, regardless of the time that had passed. For instance, Karen revealed that in

her experience, she barely received any bereavement care. Coincidentally, ten years after her stillbirth experience, she had the opportunity to speak with some hospital administrators about improving the state of perinatal bereavement care in their facility, however, the administration appeared to be unwilling to bear the financial responsibility for the service. Ultimately, the discussions ended and to her knowledge there has been no further action taken in that regard- *“I delivered at X hospital and they did not have a bereavement nurse then. And they only sort of do now if I'm being totally honest. Um, I myself had a meeting with the, um, vice president of women's services about their lack of care for these mothers and these families. And they were very open to, um doing more because I said in 10 years, you've done nothing to make this better. Um and then as soon as she said, well, are you gonna like do this? And like, as a volunteer and you're gonna plan all these things. And I was like, no, I mean, I will absolutely help, but if you want me to do that you're gonna be paying me, she stopped having conversations and it never got better”*.

### **Theme 3: Attitudes of hospital staff have an emotional impact on women’s bereavement care experiences**

Although less often cited, participants reported negative attitudes of physicians, hospital staff and floor nurses as events that made their loss journey difficult. For instance, Donna commented on her negative encounter with a doctor when she experienced a stillbirth due to preeclampsia. While being informed that she was losing her baby as a result of preeclampsia, the doctor on call asked the nurses to tie her hands up and restrain her for fear that she might try to hurt herself. Donna describes the moment when the nurses entered her hospital room with “mitts” and “ties” as completely “awful”. Even when she requested to speak with the doctor *“the*

*doctor wouldn't come in the room. She was told that doctor was busy and wouldn't come in the room and talk to her”.*

Liz also recounts how hurt she felt when her baby was ignored by a floor nurse. For Liz, in not recognizing that her baby was still there, the nurse failed to acknowledge that her baby mattered and that she was loved. This act was particularly hurtful as she realized that her baby would not have been ignored if she had been born alive - “One of the nurses that was taking care of me, um, I believe it was the first night.. She came in and I had my baby in the room with me. She was in the little basinet in the room with me. Um, and she came in and didn't acknowledge my baby....I just wanted her to acknowledge that she was there. You know, I just wanted her to see that my baby was still there. Cuz I know that, you know, they walk in the room with any other patient with a living baby and it's oh, look at her, She's doing so wonderful. She's doing great. She's beautiful. And she walked in and didn't acknowledge my baby and then I was hurt by that”.

#### **Theme 4: Disparity in bereavement care for early term miscarriage**

In the current study, women who experienced early miscarriages reported not receiving any bereavement care. This held true for women whose loss(es) occurred in the first trimester, between 1 – 12 weeks of gestation. Ruth commented that “*we're bad as a society about even recognizing early losses. But I was just handed up a book and told, well, if you get pregnant again, you can come back and see us and an obstetrician. I should have been about 10 weeks, technically 10-week miscarriage*”. In fact, women commented on their miscarriage being dismissed as no big deal. For instance, Lisa shared how her doctor never used the word

“miscarriage” to describe her unexplained bleeding but instead just stated that “*her numbers did not look good*” and then quickly added “but that's okay, you'll get your period and then you can try again”. Lisa added that her doctor never explained to her that she was pregnant before but now losing her baby. Her doctor’s reaction was “*very passive and very just, Oh, it just didn't work out kind of thing*”. Ultimately, she “*was told that she wasn't really allowed to be upset because it wasn't that big of a deal*”.

In contrast, women who experienced loss(es) in the second trimester reported receiving more bereavement care. For instance, Mary who experienced three miscarriages all between 15 and 17 weeks’ gestation reported receiving good bereavement services including having pictures taken, hand and feet molds, prints, and a birth notice for all 3 babies.

#### *Inadequate guidance and information in management of early miscarriages in the ER*

Another issue that emerged regarding miscarriage care was the lack of information given to women who were actively experiencing a miscarriage. Specifically, in many instances, women were not presented with all their options regarding the disposition of their baby’s remains. Ruth discusses how in her case the ER staff neglected to inform her about the option to cremate or bury her baby privately. She reports that ER staff did not provide her with any support materials neither did they inform her of the disposition options available to her.

Related to inadequate guidance for women experiencing early-term miscarriage, hospital staff would sometimes ask women who are actively miscarrying to catch the ‘products of conception’, and bring it in to the hospital for testing and for a proper disposition/cremation. However, women are often sent home with no further instructions or resources to actually

perform the required action. Ruth shares an anecdote of being told to catch her baby without any resources or further instructions- *“Um, so they sent me home the first week to see if I miscarried on my own. They sent me home the second time with a prescription for medication that they said just insert this medication vaginally, you're gonna start bleeding, you'll get a little crampy. Um, here's a prescription for pain medicine and goodbye. If you catch it, you can bring it in and we can do testing. So both times they sent me home with nothing to catch the baby in. But instructions to catch”*.

### *Peer Support Bereavement Programs*

Recognizing the critical role of peer support as part of perinatal bereavement care, we examined the impact of women’s participation in a peer support program on their loss journeys. Through interviews, we identified 2 salient themes: (1) The positive impact of shared experiences in bereavement support groups, and (2) Finding healing and purpose in bereavement volunteerism. These themes are discussed in detail below.

### **Theme 1: The Positive Impact of Shared Experiences in Bereavement Support Groups**

In this study, four out of ten women reported attending pregnancy and infant loss peer support groups organized through the hospital. Women shared the positive impact that attending support groups had on their loss experience. Reported benefits focused on finding a community, helping with feelings of isolation, having a place where they could discuss their loss experience, and recognizing and dealing with trauma from the loss.

In terms of finding community, participants reported that at a support group, they were able to find a community of people who understood their unique circumstances. Donna explains

that “*in the support group it was more the unity of it, the camaraderie. Um, you had like these built-in cheerleaders and encouragers and, um, comforters. Um, and so that was amazing to have*”. Again, Lisa who attended a community peer-led support group recounts the profound feeling of support she felt from other women as they each shared their stories of loss. The opportunity to share with other women who understood exactly how she was feeling “*made such a big difference for her*” and on her loss journey.

For others, attending support groups helped with the loneliness that comes with the grief of losing a child. Because not everyone experiences this, participants commented on how helpful it was to sit with others and not feel so lonely and isolated. This understanding is expressed in Donna’s words—“*It’s a very lonely journey ...support group was helpful because I got to hear other stories and know that I’m not alone, and just to have people that can rally with you, um, and that you can depend on and that get you*”.

In some cases, support group became a safe haven for women, where they could discuss details of their losses openly. Abby shares that “*support group gave her a safe place to talk about the loss because no one wanted to talk about it*”.

Finally, attending support groups also helped women recover from the trauma of losing a baby. Abby describes that sitting “with a group of other women, and fathers and hearing that they were going through the exact same thing” helped her resolve the trauma of losing her baby.

## **Theme 2: Finding Healing and Purpose in Bereavement Volunteerism**

At the time of the study, 9 out of 10 women were members of Caring companions, a peer support program that provides direct support to grieving parents both at the bedside and through community events. While these women provide support to bereaved parents, they also support

one another. In this way, Caring Companions is both a volunteer program and a peer support program for perinatally bereaved parents. Ways in which being a part of Caring Companions helped women in their loss journey included deriving positivity from a negative situation, finding meaning in the loss, and healing after loss.

Participants shared that volunteering as a caring companion, which allowed them the opportunity to provide support to newly bereaved parents, was their way of turning the negative experience into a positive one, like making lemonade out of lemons. Abby describes volunteering to help newly bereaved parents in this way- *“Uh, volunteering was my lifesaver. Um, I was drowning in sadness until I found support group, and then when I found the Caring Companions, I realized that I'm doing the world a lot better by honoring my baby and talking about him than just being sad. I'm actually doing something positive out of something negative. Um, and it's turned my life around”*.

For other participants, being a part of a volunteer bereavement support group like Caring Companions helped them to ascribe some meaning to their loss experience. Women described that perhaps they were meant to live through the difficult experience in order to help others through their hard and trying times. Jane felt this way when she shared that volunteering *“helped it all make sense, that maybe one of the reasons that this happened was because she was then hopefully going to be able to help somebody else through it”*. Similar to Jane, Mary revealed that her motivation for why she volunteers in the bereavement support program was to be able to find meaning in her loss. She expressed this thought in the following words - *“Um, so at least, you know, volunteering, I feel like I can make like my own why and be able to help, or at least give some sort of reason because the lack of reason is miserable. If I'm gonna go through it, I'd like to be able to at least help someone else who has to go through it”*.

Another way that membership in the volunteer bereavement support group helped women is through healing from the loss. Bereaved mothers in this study recounted how volunteering helped fill the void that they felt after their loss. For instance, Abby shared her need to fill the void she felt after losing her baby. As such, volunteering “helped her heal and gave her a chance to talk about her the baby that she lost. For Abby, *“talking and putting it all out there was therapeutic”* and helped her heal from the passing of her baby.

### *Recommendations to Improve Perinatal Bereavement Care*

Women’s recommendations to improve perinatal bereavement care in Indiana spanned 5 themes namely (1) Perinatal bereavement as a standard of care, (2) Mandatory bereavement education and training for healthcare professionals, (3) More robust bereavement care for early term miscarriage, (4) The importance of follow-up care and mental health support in perinatal bereavement and (5) Lactation education for bereaved mothers who experience late to full term loss. These themes are discussed in detail below.

#### **Theme 1: Perinatal bereavement as a standard of care in all birthing facilities**

A recurring recommendation made by participants for improving perinatal bereavement care in the state of Indiana is the suggestion to make bereavement a standard of care. Women suggested that all birthing facilities within the state be required to provide bereavement care to their patients, regardless of the gestational age of the baby or location of the institution. To this end, Jane shared her thoughts about why she believes perinatal bereavement should be a standard of care in birthing hospitals across the state *“I think it would be real important just to have bereavement across the board. You know, across all of the hospitals in Indiana should all have a standard of care. I think no matter if it’s a rural hospital or a big city, you have to have these*

*kind of services for people, whether it's an early miscarriage or if it's a full term baby that is born stillborn. You have to be able to provide the proper care for them because it is such a loss". Anne, affirms this recommendation and based on her personal experience advocates for molds to be included as part of the bereavement standard of care- "I would fight for it being standard of care, to provide molds to families".*

Additionally, participants suggested incorporating peer support volunteer programs into the perinatal bereavement care of Indiana hospitals. Several participants pointed to the Caring Companions volunteer program as a worthy model to replicate across the state. This would then become part of the perinatal bereavement standard of care, where bereaved parents would receive guidance from volunteer companions who have also experienced baby loss. According to Lisa, the Caring Companion model is a good one to emulate as "*volunteers go through Resolve Through Sharing (RTS) training and become official hospital volunteers who are vetted*". Owing to the companionship offered by volunteers, "*families feel less alone because having someone personable there instead of hospital staff only makes the loss experience less clinical while still in a clinical setting*".

Moreover, participants mentioned the need for hospitals to have a perinatal bereavement room / suite for perinatal loss situations only. This suggestion was made as a result of the unpleasant experience of sharing a hospital room with other women who had a live birth. Abby recounted a particularly difficult moment for her when she shared a hospital room with another mother who had a live birth. While the other mother received her live baby excitedly, her baby was wheeled in covered and hidden from others - "*I shared a room with someone who had a healthy baby and they left me on the labor and delivery floor so I could see people getting their babies. Um, because I was on that floor when they brought my baby to me, they brought him in a*

*crib, but they covered him so that no one would see him. So from the get-go, it was a secret from the very beginning. It was a secret that I had a baby that died. They were hiding him”*. Based on this experience, Abby recommended that birthing hospitals consider creating a private room or suite where families who experience perinatal loss can have their privacy away from the labor and delivery ward - *“If there was any way a hospital could make a special room at the end of the hallway. For those patients or maybe put them on a different floor”*.

## **Theme 2: Mandatory bereavement education and training for healthcare professionals**

Another salient recommendation that was made by study participants is the need to train all emergency department staff on perinatal bereavement care. Although most miscarriages are treated in the Emergency Department (ED), ED staff are the least trained in providing empathetic care to women who are actively bleeding or experiencing the loss of a baby (Engel & Rempel, 2016; Evans, 2012; Merrigan, 2018). Closely related to recommendations for training ED staff was the recommendation to make bereavement education mandatory for hospital staff and health providers, specifically nurses and doctors on the Labor and Delivery floor as well as in the Emergency Department- all spaces within the hospital where perinatal death typically occurs. This is expressed in Liz’s recommendation - *“Um, biggest things for me, um, would be education for all staff that is going to be a part of it, not just the nurses on labor and delivery. I think ED, doctors and nurses need the education, I think, you know, and whether that just be a one-time thing, whether it be some sort of annual, you know, online thing, but give everyone who may come in contact with bereaved families, the education of how to deal with it and how to help the family through it”*.

Lisa affirmed this recommendation and expressed that perinatal bereavement training be made mandatory for nurses during nursing school – *“we need to have perinatal bereavement*

*training for every nurse that goes through nursing school. Because it's like, not even on the docket, it's not even something they teach. And why isn't it part of the medical training when bereavement is an inevitable piece of treating people in the healthcare system?"*

### **Theme 3: More robust bereavement care for early term miscarriage**

Another recommendation made by participants is to provide more support to women and families experiencing a miscarriage. As participants discussed, miscarriage which is typically treated in the ED is often times disregarded or dismissed as ‘no big deal’. While medically, there is minimal care that can be provided by medical staff, ignoring the emotional needs of patients after pregnancy loss is detrimental to women’s mental and psychological health overall. Ruth shared her thoughts on the issue- *“I realize miscarriage is kinda low medically on the totem pole. But at the same time you don't know that that person walking in saying, I'm having vaginal bleeding and I'm pregnant, didn't just spend their last a hundred thousand dollars on IVF and that's their last good embryo”*. Consequently, compassionate bereavement care particularly for early loss remains a priority recommendation for participants in this study.

### **Theme 4: The importance of follow-up care and mental health support in perinatal bereavement**

Several participants commented on the need for follow-up care. This is care provided after women have left the health facility and trying to cope with the loss and grief on their own. Participants discussed that follow-up phone calls and check -ins are crucial and very much needed. While it is typical for bereavement coordinators and nurses to make 1 or 2 follow-up calls to bereaved mothers, participants have suggested multiple and varied means of communication. This recommendation is reflected in Donna’s words- *“I think it's really*

*important that there's a follow-up, that people are calling, just calling to check in on you. I think it needs to be, um, multiple ways and things that are tangible right there that they can click on and find the information and have that folder. I just think that's really important".* Another recommendation which is closely related to following up is the need for mental health services. This was a recurring theme in the study and unsurprisingly, participants strongly recommend that bereaved women and families be connected with mental health services and professional counselling or therapy. Some participants, like Karen even suggested making mental health services a mandatory part of bereavement care-*"I would like to see there be mandatory counseling, whether that is a, um, a support group like I participated in, or if that is private counseling"*. Anne, adds to this recommendation by providing concrete examples of how this should be implemented as part of perinatal bereavement standard of care- *"We need to change the standards of care to include mental health. Like even if it would just be one or two mental health check-ins at, you know, three in six months or six months in one year"*. This would help to improve maternal mental health after perinatal loss.

#### **Theme 5: Lactation education for bereaved mothers who experience late to full term loss**

In the study, participants who experienced stillbirth or infant death reported that they were not given enough information about their lactation options. Karen shares the story about her milk coming in on the day of her baby's funeral which was an unpleasant surprise - *"doctors don't tell mothers of stillbirth that your milk is going to come in. That was a shock. And it came in the day of the funeral for me, that was not a great surprise"*. If the topic came up, most women were advised by doctors, nurses and friends to apply a cold compress to dry up their milk. For instance, Eva's friend, who was also a labor and delivery nurse, advised her to apply a cold compress to dry up her milk after her full-term baby passed away from anencephaly- *"my friend*

*who had been a labor and delivery nurse, also checked in about like, hey, like when your milk comes in and all that. Um, so I wore tight sports bras and I think I even had like cold compresses and just tried for that to go quickly”.*

Consequently, one recommendation made by participants to improve the bereavement care experience following perinatal loss is for health professionals to provide lactation education to women and to list comprehensive options available to them, including milk donation. Karen urged doctors and nurses to be more conscious about providing these services to mothers who experienced a stillbirth or a neonatal death –*“I would like there to be some training for doctors and nurses that address things like milk coming in and being sensitive to those kinds of things that, um, that they know biologically are going to happen that a mother who is in the depths of grief with, or without previous children, just can't think about”*, and called for education around milk donation –*“I wish I had had the foresight to pump and donate to a milk bank because I think that, that would've been very healing to me in itself. My doctors never suggested it to me”*.

## **DISCUSSION**

Bereavement care experiences of Marion County, IN women are generally positive, yet critical aspects of care require further attention. In our study, bereavement nurses played a major role in the positive bereavement care experiences for our study participants. From creating mementos, providing empathetic care, connecting women with local resources, and helping women make critical decisions at the time of their loss, the role of bereavement nurses in perinatal loss cannot be overstated. These findings are in line with prior studies of bereaved parents who have also pointed to the above-mentioned services as particularly helpful for the loss

and grief journey (Gold, 2007; Shakespeare et al., 2019). In addition to the services enumerated, bereaved parents in other studies have indicated that aspects of the perinatal bereavement care that they found to be beneficial were those that provided appropriate psychological support, considered religious diversity, integrated family support, peer groups, self-medication, and traditional remedies (Shakespeare et al., 2019). Additionally, parents appreciated emotional support from health workers who took the time to talk with the family, used humor appropriately, allowed parents to cry, and those who spent sufficient time with the grieving family (Gold, 2007). Tangible care in the form of health workers bending rules to accommodate parents, expanding visiting hours and allowing children to be in the ward, was also perceived to be helpful (Gold, 2007). Last, health workers who provided information and kept parents informed about their treatment plan, explanations as to why the loss occurred, and provided information about what to expect throughout their treatment plan and afterward was also appreciated by bereaved parents (Gold, 2007).

Although the majority of the women in our study reported positive bereavement care experiences, this was not a universal experience, as some participants commented about their negative experiences with bereavement care. Reports that perinatal bereavement care was unavailable or inadequate in some birthing hospitals are an indication that perinatal bereavement may not be a standard of care. Factors such as staffing issues, little to no staff training in bereavement care, and priorities and decisions of hospital administration that fail to acknowledge perinatal bereavement as a real need, could explain the inconsistencies with bereavement care in the county. Although this specific theme has yet to be reported by other existing studies, to our knowledge, this is a novel finding of the current study, which warrants further investigation on a larger scale.

Another theme that emerged from our study regarding bereavement care experiences revolved around the impact of hospital staff attitudes on women's emotional wellbeing. Although these negative experiences were cited less often in our study, they still bear a significant impact on the emotional and psychological well-being of perinatally bereaved mothers. Not surprisingly, negative attitudes of hospital staff are the most frequently cited issue that contributes to the unpleasant bereavement care experiences of bereaved parents (Freeman et al., 2021; Radford & Hughes, 2015). Many bereaved mothers and parents across multiple studies have reported neglect, insensitivity, poor attitudes, and poor communication from health workers (Freeman et al., 2021; Radford & Hughes, 2015; Shakespeare et al., 2019). Systematic reviews of bereavement experiences of women who experienced stillbirth have also reported instances of stigmatization, shame, and blame from health workers, which further contributes to their intense grief and marginalization (Shakespeare et al., 2019).

Furthermore, in our study we found grave disparities in bereavement care for women experiencing early term miscarriage particularly in the first 12 weeks of gestation, compared with later term miscarriage and even stillbirth or neonatal loss. Specifically, we found that participants with early term miscarriage most often did not receive any bereavement care, and the miscarriage was quickly dismissed as 'no big deal'. Similar experiences and sentiments have been documented in other studies of women experiencing early term miscarriages (Baird et al., 2018; Bellhouse et al., 2018; Leis- Newman, 2012; MacWilliams et al., 2016). Much like participants in our study, women have reported that their pain and grief have often been overlooked by health professionals, with words like 'chemical pregnancy', 'just try again', 'it's no big deal', which has left bereaved mothers feeling like they are not allowed to grieve their loss (Baxter-Dunn, 2023; Watson et al., 2019).

Another issue with miscarriage care that we uncovered in our study is the inadequate amount of information given to women and families who are actively experiencing a miscarriage. In the state of Indiana, parents who experience a miscarriage have 2 options to dispose of the baby's remains – a. Through hospital disposition, where the hospital takes care of cremation and disposes ashes in a respectful way, and b. bereaved parents have the option of choosing to bury or cremate with a licensed funeral home (Indiana State Department of Health, 2019; Indiana General Assembly, 2014). Indiana state law also requires hospital staff to inform bereaved parents of all their disposition options both verbally and in written form (Indiana State Department of Health, 2019; Indiana General Assembly, 2014). Sadly, reports from study participants reveal this does not happen often. Because the symptoms of early term miscarriage, usually excessive bleeding or hemorrhage, is often attended to in hospital emergency departments, ED staff rarely provide the required information to bereaved parents. Moreover, in our study, women also reported not receiving any resources, directions or written materials about what to expect when managing their miscarriage at home. The lack of written/ typed information for parents experiencing a miscarriage has also been identified in other studies as a pervasive issue, one that needs to be addressed to improve the bereavement care given to women and parents experiencing a miscarriage (Lee et al., 2023; Larivière-Bastien et al., 2019).

Our finding on the role of peer support bereavement programs as a positive impact on women's grief journey through fostering community, helping with feelings of isolation, serving as a safe space, and helping to resolve personal trauma lend further supporting evidence to the existing body of research. Similar findings have been reported in other studies on bereaved parent's reported benefits of support group attendance (Boyle et al., 2015; Carlson et al., 2012; Diamond & Roose, 2016; Leon, 2008; McCreight, 2007; Umphrey & Cacciatore, 2011). In these

studies, bereaved parents have indicated that attending support groups helped with feelings of isolation as a result of connections made with other grieving parents (Boyle et al., 2015; Carlson et al., 2012; Umphrey & Cacciatore, 2011), provided a space to openly grieve and share feelings without the fear of being judged by people who have little understanding of their experience (Diamond & Roose, 2016; Leon, 2008; McCreight, 2007). Bereaved parents in other studies have also reported that through sharing and listening to other parents' stories, they have learned new and more effective ways of coping with difficult times such as holidays, birthdays, managing emotions with friends and family members who have new babies and difficulties returning to work after the loss (Brown, 2019; Carlson et al., 2012). There is also some documented evidence of support group attendance on maternal mental health, particularly on improved post-traumatic stress (PTSD) in bereaved mothers. A study examining PTSD in a sample of 47 mothers who had experienced stillbirth found that women who participated in local support groups had lower mean scores compared to women who did not attend support groups (Cacciatore, 2007). It is worthy to note that support group attendance did not indicate complete recovery from loss, but rather emphasized the idea that bereaved mothers who were well-connected to appropriate and adequate support systems developed better coping skills to manage the trauma of their loss (Cacciatore, 2007). Furthermore, of 47 women who participated in the study, 39 reported that support groups were the most helpful in dealing with the death of their baby (Cacciatore, 2007).

The second theme that came out in participant interviews on peer support bereavement programs revolved around the positive influence of bereavement volunteering on women's own healing and life purpose. Participants commented on how volunteering to help other bereaved mothers helped them create something positive out of a negative situation, helped them to make

meaning out of their loss and also heal from the loss. In line with the findings from our study, other research studies have also investigated the experiences of parent-peer volunteers and how providing support to others has impacted their own loss journeys. Parent volunteers have similarly commented that the benefits they derived from volunteering are of intrinsic value such as feeling satisfied about their ability to make a difference in the lives of other parents experiencing perinatal loss, being able to honor their dead babies through helping others, and finding meaning to their loss by volunteering (Boyle et al., 2015; Diamond & Roose, 2016). Some reported tangible benefits include the recognition of parent's own personal growth and gaining continued support for their own experience of perinatal loss (Boyle et al., 2015). Existing studies have also investigated parent's motivations to become peer parent volunteers and have found that the desire to help was mostly rooted in the strong belief in the benefits of peer support. Additional motivations include the desire for newly bereaved parents to have access to good support because their own bereavement care was unpleasant, and a way of giving back (Boyle et al., 2015; Diamond & Roose, 2016).

In terms of participant recommendations for improving the existing bereavement care, women unanimously recommended perinatal bereavement as a standard of care. Participants suggested that bereavement programs be implemented in all birthing facilities across the state of Indiana. One suggested component of the bereavement standard of care would include peer volunteer programs like Caring Companions, where veteran bereaved parents would support newly bereaved parents. Another component of the bereavement standard of care suggested by participants was the need to create a bereavement room or suite within the health facility, where families with a loss would be cared for without having to share a room or floor with women with live babies. The importance of a bereavement suite or a private room for loss situations has also

been reiterated by the World Health Organization and discussed in other studies as an area warranting further attention (Siassakos et al., 2018; World Health Organization, 2023).

Another recommendation made by participants is to implement mandatory bereavement education and training for healthcare professionals. In our study, bereaved mothers specified that ED staff, as well as nurses and doctors in the Labor and Delivery departments should be required to enroll in mandatory bereavement training. Some participants even suggested this training be incorporated as part of medical certification or could be included in the medical and nursing school curriculum. Indeed, bereavement training for healthcare professionals has been discussed extensively in the literature (Ellis et al., 2016; Ravaldi et al., 2018; Shakespeare et al., 2019; Shorey et al., 2017). Similar to the recommendations made by our participants, bereaved parents in prior studies have also suggested mandatory training for hospital staff who attend to bereaved mothers and families following the loss of a baby (Aggarwal & Moatti, 2022; Aiyelaagbe et al., 2017; Leitao et al., 2021;). Emergency Department (ED) staff have notoriously been identified as a top priority in addressing perinatal bereavement care. Early term miscarriage, usually occurring within the first trimester, is typically treated in the emergency department, where the focus is kept on physical care rather than emotional and psychological wellbeing (Baird et al., 2018; MacWilliams et al., 2016 ; PUNCHES et al., 2018). Although some ED staff have acknowledged the importance of providing bereavement care and helpful resources like perinatal bereavement websites and perinatal support group information to patients who experience a miscarriage (Merrigan, 2016; Zavotsky et al., 2013), ED staff have also reported not having robust communication skills and knowledge on how to provide empathetic and sensitive bereavement care to their patients (Engel & Rempel, 2016; Evans, 2012 ; Merrigan, 2018). The above

evidence, thus, underscores the importance of bereavement training for healthcare professionals who work to provide any type of perinatal care to women and families.

Furthermore, in our study, we found that women who experienced loss during the first 12 weeks of pregnancy reported receiving no bereavement care. In response to this, participants have recommended more robust bereavement care for early term miscarriage. Bereaved mothers, parents and researchers advocate for equitable care and support for this group (Kuehn, 2021). Recognizing the dire need for bereavement services for miscarriage and early term loss, the LANCET series titled 'Miscarriage Matters' calls for further action and advocates for social change in the treatment of early pregnancy loss (Lancet, 2021).

Participants in our study also indicated the need to improve follow-up care and mental health support for bereaved parents. Follow-up care in the form of bereavement check-in phone calls, emails, memorial events and support groups are documented to have a positive effect on maternal grief and maternal mental health (Atashsokhan et al., 2024; Conroy et al., 2023; Stratton & Lloyd, 2008). These bereavement services are a tool for prevention, first to mitigate the potential negative effects of perinatal grief on maternal mental health and second, to keep bereaved mothers in the continuum of care. While many perinatal bereavement programs have a follow-up component, providers have reported significant challenges staying connected with bereaved families (MacConnell et al., 2013). In many instances, bereavement resources and services are offered at the time of loss, but there is often no follow-up if parents decline the first time. This means that some families fall through the cracks and do not receive bereavement resources because they declined the first time they were asked. Existing research suggests that people may be more inclined to accept services after the initial offer, but because there is little follow-up, it becomes a one-time opportunity (Boyle et al., 2015). Moreover, families may not

be ready at the time its offered (Boyle et al., 2015). Consequently, it is imperative that perinatal bereavement programs develop effective follow-up strategies to better serve bereaved mothers and families.

Lastly, another area within perinatal bereavement care requiring much attention is the lack of lactation advice and support following loss. This topic is often not discussed by health professionals, resulting in shock and a second wave of grief when women begin to lactate following a stillbirth or neonatal loss (Dickens, 2020). Women in prior studies have reported not being presented with comprehensive education regarding lactation after loss, which may result in physical effects such as “breast engorgement, pain and mastitis, and the additional psychological distress of dealing with such symptoms alongside the grief for their baby”(Dickens, 2020, p. 442). For these reasons, participants in our study recommend comprehensive lactation education be provided for mothers experiencing late term loss. Women should be informed about all lactation options that are available to them. Often, women are taught how to suppress milk production, but they are not presented with other options including breastmilk donation (Dickens, 2020). Research shows that milk donation following perinatal loss helps bereaved mothers cope with the grief by gaining recognition and affirming their identities as mothers (Oreg, 2019). The altruistic act of milk donation helps bereaved mothers cope with feelings of guilt as they know that the milk would help save the lives of other babies (Oreg, 2019). Again, bereaved mothers have reported that expressing milk is a way to mourn the loss and create positive memories to replace the negative ones brought on by the baby’s passing (Fernández-Medina et al., 2022).

### *Limitations*

The study has some limitations. First, while this study sheds light on considerations for supporting bereaved mothers who live in Marion County IN, this information cannot be generalized. The experiences of bereavement care discussed in this study are unique to participants and may not apply to all women who reside in Marion County IN. However, the goal of this qualitative study is not for it to be generalizable, but rather to provide an in-depth understanding of the experiences of Marion county, Indiana women in order to learn from it and to inform future interventions and programs (Myers, 2000). Our sample was made up of a homogenous group of Caucasian women; we did not have a diverse sample due to the recruitment strategy employed for the study. For this reason, the experiences described may not hold true for more diverse groups. Most participants in our study experienced their loss or received bereavement support at the same facility in Indianapolis, which we believe may have an impact on participants' bereavement care experiences and the study findings. Additionally, 9 out of 10 of the study participants were connected with bereavement support either by attending support groups or by being a member of the volunteer peer support program. Thus, the experiences of participants discussed in this study may not provide a holistic picture of perinatal bereavement experiences, but rather a subset of possible experiences of perinatally bereaved women. It is possible that bereaved women who seek out these types of support services may be significantly different from the larger community of perinatally bereaved women.

Nonetheless, the findings of this study are important in that they shed light on the gaps in perinatal bereavement care in Marion County, Indiana from first-hand accounts. Again, women's recommendations are useful in designing a more comprehensive response to effectively serve bereaved Indiana families.

#### *Public Health Implications of Research Findings*

Findings of the current study bears significant implications for clinicians, nurses, midwives, public health practitioners and all stakeholders who work to improve maternal and infant health. The recommendations made by bereaved mothers in this study serve as a springboard to design effective perinatal bereavement programs to better serve bereaved parents in Marion County, IN.

For clinicians, nurses, and midwives, the findings of this study underscore the importance of routine and mandatory bereavement training within birthing sites. Reports by bereaved women of negative treatment by hospital staff and reports of little to no bereavement care for women experiencing miscarriage are indications of the need for novel approaches to caring for perinatally bereaved families, irrespective of the gestational age of the baby. Further, recommendations for health providers to give comprehensive lactation education to bereaved mothers experiencing stillbirth or neonatal loss, including options for breastmilk donation, emphasize the need for partnerships with local human milk banks as well as strengthening supports for lactating perinatally bereaved women.

For public health practitioners and stakeholders, findings of this study suggest that perinatal bereavement is not a standard of care across all birthing facilities in Marion County, IN. This reality may also be the case in other Indiana counties. For this reason, it is crucial that public health practitioners and state health entities conduct a needs assessment to determine which Indiana areas, counties and facilities are most in need of support. To ensure that perinatal bereavement is implemented and remains a standard of care, Indiana state health authorities must allocate funds to establishing a state grant that will address the identified issues that pose obstacles to the availability and consistency of perinatal bereavement care across all Indiana birthing sites.

Moreover, the findings of the study underscore the importance of equitable bereavement care for all women who experience perinatal loss, regardless of the gestational age of the baby or the health facility where treatment is provided. We affirm that all women experiencing loss through miscarriage, stillbirth, or neonatal death deserve good, quality, empathetic bereavement care. We believe that by elevating the voices of the women in our study, we promote social justice and advocate for the equitable treatment of this underserved group.

## **CONCLUSION**

Bereavement care experiences of Marion County, IN, women are mixed, as the quality of care varies depending on the facility where the loss occurred, and the availability of a bereavement nurse/staff. Disparities exist based on the type of loss, with early term miscarriage care needing the most attention. Our findings highlight the need for more concerted efforts to improve the care given to women who experience miscarriage. Again, bereavement programs that incorporate peer support components such as parent volunteer supporters (Caring Companions) appear to have a positive impact on women's loss journey. For this reason, it is important that perinatal bereavement programs consider including these elements in existing interventions to better support grieving women and families. Finally, recommendations to standardize perinatal bereavement care in all birthing facilities across the state, mandatory bereavement education and training for healthcare professionals, robust follow-up care and mental health support for bereaved parents, and comprehensive lactation education for bereaved mothers who experience late to full term loss, must be considered when designing perinatal bereavement programs in Marion County IN, and across the state.

## REFERENCES – CHAPTER 4

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## CHAPTER 5: MANUSCRIPT 2

### **Title: Serving Indiana Families after Perinatal Loss – Health Provider Perspectives**

#### **ABSTRACT**

**Background:** Health providers face several challenges when administering bereavement care to families that experience a miscarriage, stillbirth, or a neonatal death. This study sought to (1) examine health provider identified challenges and gaps in perinatal bereavement care in Marion County, IN and, (2) collect health provider recommendations to improve bereavement support in Indiana.

**Methods:** Adopting a critical theoretical framework, we conducted semi-structured interviews with 8 health providers in Marion County, IN. Using a phenomenological approach, interview transcripts were coded, analyzed, and organized into categories and themes.

**Results:** Six overarching challenges were identified by health providers including (1) Challenges with postpartum follow-up and outreach, (2) Financial challenges in post-loss care, (3) Gaps in emergency department bereavement care for miscarriage, (4) Language barriers and difficulties, communication with immigrants, (5) Financial challenges for families without citizenship or documentation, and (6) Cultural nuances in perinatal bereavement practices.

Health provider recommendations to improve bereavement care in Indiana include (1) Creating community-based and culturally inclusive community resources, (2) Maintaining a collaborative bereavement care network, (3) Enhancing follow-up and better connection with mental health services following a loss, (4) Training and education for health staff, and (5) Increasing financial support for loss families.

**Conclusion:** Health provider-identified challenges and recommendations from the current study serve as a first step to inform future studies investigating perinatal bereavement care in Indiana. Study findings will inform future interventions that seek to improve maternal and infant health in the state of Indiana and across the U.S.

**Keywords:** Health provider, Bereavement nurse, FIMR nurse, Bereavement care, Perinatal loss, miscarriage, stillbirth, neonatal death, Indiana, women, immigrant, refugee.

## BACKGROUND

Perinatal loss, which refers to the passing of a baby through a miscarriage, stillbirth or neonatal death (Barfield et al., 2016), continues to be a Public health issue due to the associated effects on maternal mental health (Cacciatore, 2007; Chin et al., 2022; Davoudian et al., 2021; D'Arrigo, 2021; Herbert et al., 2022; Weng et al., 2018), on father's psychological wellbeing (Nguyen et al., 2019), and on the community as a whole (Coomarasamy et al., 2021; Heazell et al., 2016; Lancet, 2021; O'Neil et al., 2021; Quenby et al., 2021). After the loss of a baby, healthcare workers typically provide resources to bereaved parents; this is known as bereavement care. Bereavement care involves a range of tangible, emotional, and psychological support to help bereaved individuals cope with the grief following a loss (Zhuang et al., 2022). Perinatal bereavement is also a tool for prevention because it helps with unresolved maternal grief, and prepares mothers for subsequent pregnancies through managing anxiety that could hinder a safe and healthy pregnancy (Helps et al., 2020). In the subsequent paragraphs, we discuss what perinatal bereavement care services look like in U.S. healthcare settings, prior studies that have examined healthcare worker experiences providing bereavement care to parents following perinatal loss, a justification for the research study, and the research questions that guide the study.

Perinatal bereavement care is primarily provided in health facilities, and in the U.S., it is typically delivered by a bereavement nurse/coordinator or a social worker. These individuals offer meaningful gifts to the bereaved family in the form of mementos that consist of mold of the hands and feet of the baby, handprints, and footprints (Blood & Cacciatore, 2014; Domogalla et al., 2022). Parents are also presented with the opportunity to attend a support group and receive aftercare bereavement services (Domogalla et al., 2022). When possible, bereavement staff

encourage parents to bathe and clothe the baby, engage in religious rituals like naming ceremonies, introduce the baby to extended family, and may keep special clothing and blankets that have come in contact with the baby (Flenady et al., 2014). Memory making remains a central piece in the bereavement care experiences of U.S. women and parents, which reportedly has a significant positive impact on parental grief and coping outcomes (Thornton et al., 2019). Bereavement nurses or social workers consequently facilitate memory making through partnerships with national organizations like Now I Lay Me Down to Sleep, (Now I Lay Me Down to Sleep, n.d.) where volunteers provide bereaved families with free professional portraits of the baby, thus serving as a channel for healing and a way to honor the life of the baby (Limbo & Kobler, 2010; Ramirez et al., 2019; Willer et al., 2020).

Prior studies have examined health worker experiences providing bereavement care to parents following perinatal loss. Owing to the intensity of providing emotional support to bereaved women and families, health workers have reported feeling exhausted, burned out, demotivated, overwhelmed and frustrated (Shorey et al., 2017). These feelings often cause bereavement staff to leave the profession, and consequently, bereavement positions encounter high turnover (Shorey et al., 2017). Again, health workers have also commented on feeling ill-prepared, guilty, and having an internal conflict, all which affect their psychological wellbeing (Shorey et al., 2017). Perhaps the most widely discussed challenge for health workers in serving bereaved parents is the amount of training they have in dealing with perinatal loss (Ellis et al., 2016; Shorey et al., 2017). Generally, little or no experience in dealing with death, junior ranking in any of the healthcare fields directly serving pregnant women, insufficient communication skills, a lack of training in providing bereavement care, and a lack of support from colleagues leave health workers feeling inadequate to provide bereavement care to grieving families (Kelley

& Trinidad, 2012; Shorey et al., 2017; Steen, 2015). While the existing literature on health worker experiences with bereavement care following perinatal loss captures negative feelings and sentiments, some health workers have reported feeling rewarded for being a source of comfort to grieving families (Ellis et al., 2016; Shorey et al., 2017). Some studies have also identified cultural factors impacting health worker experiences providing bereavement care. In certain cultures, such as in China, Hong Kong, Singapore, and Japan, the topic of death and dying is generally accepted as a taboo or forbidden topic and hence viewed as a private family matter (Chan et al., 2005; Fernández-Medina et al., 2022; Gardner, 1999). Consequently, health workers are hesitant to discuss and express emotion with bereaved families; this hinders their ability to accurately assess health needs and provide appropriate care (Gardner, 1999). Further, the scant literature on health worker challenges in serving diverse racial and ethnic populations, particularly immigrant and refugee clients underscores the need for culturally competent bereavement training, more robust strategies to bridge language and interpretation gaps, and concerted efforts to understand and respect the varying cultural and religious differences among such groups (Austin et al., 2021).

Although healthcare provider challenges in serving bereaved parents have been assessed in various countries and in some parts of the U.S., this line of inquiry has yet to be formally studied in the state of Indiana. Indiana has the 9th highest infant mortality rate in the U.S., estimated at 6.75 per 1000, which translates to about 531 children under age 1 dying annually (CDC, 2022), and in 2020 alone, the state recorded 496 fetal deaths and 313 neonatal deaths (IDOH, 2022). Babies born in Marion County are particularly at risk of dying before their first birthday, with mortality rates reported at 7.4 per 1000 births compared with the national average of 6.6 per 1000 births and the Indiana State average of 6.7 per 1000 births (IDOH, 2022). Of the

522 infant deaths recorded in Indiana in 2020, 100 child deaths occurred in Marion County, the highest single contributor by county-level (IDOH, 2022). These high mortality rates leave behind a lot of grieving families who need support to cope with their grief and their mental health. For this reason, it is crucial that we examine the challenges faced by healthcare providers in delivering this much needed care to bereaved parents. To our knowledge, there are no existing studies that have examined health worker challenges and gaps serving bereaved Indiana families. Given the scant literature in this area, we seek to add to the existing body of research. Thus, this study seeks to

(1) examine health provider-identified challenges and gaps in perinatal bereavement care in Marion County, IN and,

(2) collect health provider recommendations to improve bereavement support in Indiana.

### *Theoretical Framework*

The current study is guided by critical theory and draws on the methodological insights from Carspecken's critical ethnography to develop a critical interview study (Carspecken, 1996). The focus of critical research is to identify social inequities and to advocate for positive social change (Carspecken, 1996). Critical theory, therefore, is concerned with promoting equity and social justice for disadvantaged and underserved populations (Carspecken, 1996). In this study, we apply the tenets of critical theory to highlight perinatally bereaved groups that are underserved and disadvantaged. By examining health provider's perspectives, we expose the existing gaps in perinatal bereavement care as the first step in taking action. With the help of health provider recommendations, we advocate for positive social change to improve

bereavement care. Ultimately, health provider recommendations are crucial in designing future interventions that aim to promote social justice and equitable care for underserved bereaved groups. Based on the above, we believe that critical theory serves as the most appropriate theoretical framework for the current study. Thus, critical theory guides the entire research design of the current study and informs the study's research questions.

## **METHODS**

We followed the consolidated Criteria for Reporting Qualitative research (COREQ) guidelines in reporting methodological approaches/ strategies and study findings (Tong et al., 2007). The COREQ is a 32- item checklist that serves as a guide for reporting important aspects of qualitative research, including details about the research team, study methodology, the study's context, data analysis procedures, study findings, and interpretations of these findings (Tong et al., 2007). In this study, the aspects of the COREQ checklist that have been reported below include details about the study's design, the data collection instrument, participant eligibility and sampling strategies, participant recruitment, data collection procedures, information on data saturation, data analysis, and establishing the validity of study findings.

### *Study Design*

We used a phenomenological design for the study. Because phenomenological research describes what participants experienced and how they experienced the phenomenon (Moustakas,

1994), this study sought to describe the challenges faced by health providers who serve perinatally bereaved families, and the resulting recommendations to improve care. The shared phenomenon among providers is the experience of caring for women who have lost a baby through miscarriage, stillbirth, or neonatal death.

### *Instrument*

Interview questions were informed by the existing literature on health provider's experiences serving perinatally bereaved parents (Ellis et al., 2016; Kelley & Trinidad, 2012; Shorey et al., 2017; Steen, 2015). We designed our interview questions to elicit responses that spoke to the study's research questions. As is typical of phenomenological research studies, we used semi-structured interviews to explore health provider reported challenges, gaps, and recommendations. The interview protocol consisted of 4 parts with the following structure:

- a. Background information: We asked about the provider's background, affiliations, and their motivations to provide bereavement care to loss families. This was done to set the stage for the discussion on bereavement care.
- b. Bereavement prompts: We asked providers to share any memorable bereavement care stories that they have, describe the care they typically give to their patients, and any disparities they have noticed in perinatal bereavement care. These questions served to open the dialogue on perinatal bereavement care provided.
- c. Bereavement nurse specific questions: Here, we asked providers about their follow-up strategy, resources that they provide to bereaved patients and family members, and bereavement as a standard of care. This was done to identify gaps in perinatal bereavement care.

d. Intervention prompts: In this section, we asked providers to describe the challenges that they face while serving their patients. Based on their professional experiences, we asked health providers to make recommendations for improving perinatal bereavement care in Indiana.

### *Eligibility and Sampling*

To be able to take part in the study, participants had to be individuals whose work centered on providing direct support to bereaved mothers and families, as well as those professionals who worked to improve maternal, fetal, and infant mortality in Marion County, IN.

### *Recruitment*

Following approval of the study by the Human Subjects Review Board of the author's institution, participants were recruited through purposive sampling methods. First, the researcher established collaborations with personnel from the Fetal-Infant Mortality Review team (FIMR) at the Indiana Department of Health-Division of Fatality Review and Prevention. Next, the researcher attended state FIMR meetings to build rapport with FIMR coordinators and bereavement nurses. With the help of the FIMR program director, the researcher distributed the recruitment flyer through the Indiana State FIMR email listserv. This email listserv includes a large number of providers across the state whose work focuses on improving fetal and infant mortality, such as FIMR coordinators, FIMR nurses, and bereavement nurses. The recruitment flyer contained details about the research study, the purpose for which it was being conducted, and how participants could contribute to the study. Four (4) initial study participants, i.e., nurses working in Marion County were recruited via the FIMR listserv. Two (2) additional providers

were identified and recruited through the help of the Marion County FIMR Coordinator, who expressed interest in helping with the study after receiving the recruitment flyer. Consequently, the Marion County FIMR Coordinator provided the contact information for FIMR nurses and bereavement nurses working in the local hospitals in Marion County, IN. Last, two (2) additional bereavement nurses were subsequently recruited at the local ‘Walk to Remember’, a community event for perinatal loss organized by the Franciscan St. Francis Health in Indianapolis. A total of eight (8) providers participated in the study. The number of participants is appropriate for the study, given that we recruited bereavement nurses from the 5 major birthing hospitals in Marion County, IN. Additionally, we recruited 2 out of 3 FIMR nurses affiliated with the local Marion County Health Department, who work in a bereavement capacity. Thus, our recruitment efforts led to the successful representation of 8 health providers from the 5 main birthing sites in the county. In this way, we believe that our sample is representative of health providers in this field. Further supporting the sufficiency of our sample size are existing studies on perinatal bereavement with 10 or fewer research participants (Aydin et al., 2019; Fenstermacher & Hupcey, 2019; Jonas-Simpson et al., 2013; Kirui & Lister, 2021) that have produced novel insights to inform research and programming in this area of investigation. Moreover, we believe that the participant perspectives and narratives shared in this study lend strong evidence to the prevailing experiences of health professionals who serve perinatally bereaved women and families.

### *Data Collection*

After the recruitment period, the researchers contacted participants and scheduled a time to conduct an interview. The informed consent form was sent via email to participants to review

prior to the scheduled interview date. Participant consent was obtained verbally prior to the start of each interview; verbal consent was captured on the audio recording of each interview and can be verified from the interview transcript. All interviews were conducted via Zoom video conferencing (Zoom, n.d.) or over the telephone, based on participant preference. Interviews lasted between 39 – 136 minutes. Interviews were audio recorded using the Zoom recording feature and transcribed verbatim with an online transcription tool – Descript (Descript, n.d.)

### *Data Saturation*

Data saturation in qualitative studies is the point in the research process when the researcher determines that adequate data has been collected which will help him/her develop a robust and valid understanding of the studied phenomenon (Hennink & Kaiser, 2019). In the current study, data saturation was attained with the 7<sup>th</sup> participant as each subsequent participant repeatedly spoke of similar challenges with follow-up, financial and logistical constraints. We conducted one additional interview with the 8<sup>th</sup> participant to confirm data saturation. Thus, data saturation for the current study was achieved with the 8<sup>th</sup> participant.

### *Data Analysis*

Data analysis followed a 3 step approach described by Creswell (2012), which is widely used by many phenomenologists. The 3 steps include horizontalization, developing clusters of meaning, and providing the essence of the work (Creswell, 2012). The first step was a process known as **horizontalization**, where the researcher read the interview transcripts in order to become familiar with the data (Moustakas, 1994). Data management, including coding and analysis was

performed using the qualitative analysis software MAXQDA 2024 (VERBI Software, 2024).

Working with MAXQDA 2024 helped to organize codes and summarize the study data. Using an inductive approach, the researcher developed a codebook with 43 codes. Next, the researcher and a second coder, independently went through a process of open coding, highlighting significant statements, quotes, and sentences that captured the essence of the studied phenomenon. Thus, each significant statement was highlighted and assigned to the desired code created in the software. The two researchers additionally highlighted relevant quotes that responded to the research questions of the current study.

In the second stage of data analysis, the researcher and the second coder developed ‘clusters of meaning’ from the initial codes generated. To do this, both researchers collaboratively created code groups, reduced these groups into broad categories, and finally deliberated on the salient themes across all transcripts. During this stage, disagreements in coding were resolved through several rounds of discussions until both researchers reached a consensus (Chinh et al., 2019). The final stage involved both researchers developing appropriate wording for each theme and selecting quotes to support each theme and sub-theme (Creswell, 2012).

The third step of the analysis process involved compiling a comprehensive report of the ‘essence’ of the phenomenon, detailing the deeper meanings, understandings, and commonalities as well as divergences in participant experiences of the studied phenomenon.

*Establishing validity of study findings*

The validity and credibility of study findings were established through peer debriefing. The first peer debriefer, who is the FIMR program director, provided guidance on the interpretation of research findings from a provider perspective. The second peer debriefer, an external individual who is an expert in critical qualitative research, substantiated the interpretations of research findings, calling into question the researcher’s personal biases and assumptions. With the help of the 2 peer debriefers, the findings of the current study were validated.

## RESULTS

### *Participant Description*

We explored health provider’s perspectives of bereavement care among 8 bereavement/FIMR nurses who work in Marion County, IN. Our sample comprised 6 bereavement nurses and 2 FIMR nurses. Provider ages ranged from 33 years to 61 years. Providers reported working with the local health department as a FIMR nurse or as a bereavement nurse at a local birthing facility/hospital. The average length of time working in the bereavement position was 12 years (range 2-28 years). Details of participant characteristics are provided in Table 4.

Table 4. Participant characteristics showing health provider's age, position, and length of time as a bereavement care provider.

Participant	Age	Position	Time in position (Years)
Ruby	46	FIMR nurse	7
Betty	33	FIMR nurse	2
Lucy	61	Bereavement nurse, retired	38
Chloe	56	Bereavement nurse	7

Kate	49	Bereavement nurse	24
Maya	38	Bereavement nurse, former	4
Samantha	54	Bereavement nurse	12
Naomi	50	Bereavement nurse	2

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All participant names in this study are pseudonyms to preserve the confidentiality and anonymity of respondent's identities

### *Format for Reporting Study Findings*

In reporting the findings of the current study, the researcher will discuss findings by themes organized according to each of the 2 study research questions. Thus, in this section, the researcher discusses provider-identified challenges and gaps in perinatal bereavement care and provider recommendations to improve perinatal bereavement care in Indiana.

### *Challenges and Gaps in Perinatal Bereavement Care*

We identified 6 overarching challenges and gaps reported by health providers. The first 3 themes relate to general challenges and gaps while serving bereaved parents, which include (1) Challenges with postpartum follow-up and outreach, (2) Financial challenges in post-loss care, and (3) Gaps in emergency department bereavement care for miscarriage. The last 3 themes focus on unique challenges and gaps that health providers encounter while serving immigrant and refugee populations. These include (4) Language barriers and difficulties with communication (interpretation), (5) Financial challenges in post-loss care for families without citizenship or documentation, and (6) Cultural nuances in perinatal bereavement practices. We discuss these themes in detail below.

## Theme 1: Challenges with postpartum follow-up and outreach

In our study, health providers described the challenges they face when attempting to follow-up with patients after they have left the health facility. While providers report having the goals and intentions to follow up with each patient at least a few times following the loss of a baby, it is often near impossible to follow through. Samantha, a bereavement nurse indicated that - *“My goal originally was to see the patient in the hospital, make a follow up call within two weeks, one month, two month, three month, six month, and one year. Well, that does not happen. I'm not gonna lie to you. That does not happen”*. Naomi, another bereavement nurse commented- *“Everybody at least gets the one phone call...”*. One major factor that contributes to the challenges with follow-up is the sheer volume of patients that providers report needing to ~~having~~ ~~to~~ follow up with. Because there is a high number of women experiencing perinatal loss who require bereavement care each week, providers are unable to keep up with the volume of patients they have to care for daily, and this affects their ability to make follow-up phone calls and check-ins with bereaved families. Samantha describes this in her own words - *“honestly, the volume of patients we have. Um, oftentimes when I am in a given week and I'm helping take care of X number of patients this week, my brain in the back is thinking about the girl from last month, and that was particularly having a hard time. And so we try very hard to reach out. Um, but it's really hard to keep up with because every month it just piles on as you can see, you know, that just stacks”*.

Another obstacle to following up with patients is difficulty contacting families due to changes in the patient's phone number and/or home address. The providers in our study have commented about how constant changes in patient's mailing addresses and phone numbers significantly impact their ability to reach out and provide bereavement resources after they have

left the health facility. In this regard, while some providers have definitively expressed their preference for communicating via email, obtaining accurate patient contact information continues to be an issue. For instance, Chloe discusses the challenges she faces in obtaining accurate contact information for some of her patients - *“...we ask for their emails, but about half of the people I don't have emails for when I first encounter them. And so I can't start with sending everything by email, but that's where I would like it to eventually go. It would reach people, I mean, people move more than they change their emails, and so I've had issues where it's been six months, but I'm getting mail returned to me because they've moved. And the post office only forwards it for so long”*.

## **Theme 2: Financial challenges in post-loss care**

Health providers in this study reported that financial costs impact their ability to care for their patients. According to the health providers in this study, the biggest financial burden is brought on by the Indiana state policy, which specifies that all fetal deaths that occur at 20 weeks or greater must either be cremated or buried with a licensed funeral home. In addition to this, parents are responsible for all costs associated with the private disposition. Again, if the baby is born alive, regardless of gestational age, parents are also required to do private disposition and bear all associated costs. Kate provides further details about the law – *“Any baby over 20 weeks or any baby born alive, the parents are responsible for doing their own cremation or burial. Even if it's like an 18-weeker that comes out, it's not gonna breathe cuz it doesn't have any lungs, but it's heart might beat for a few, two minutes or five minutes. Um, yes, that's considered a live birth and the parents are responsible for choosing a funeral home and doing their own cremation or burial”*. Providers have reported that the cost involved in private disposition

required by Indiana law is prohibitive for many families. Lucy, explains that in her experience, one of the biggest challenges in serving bereaved families is the cost associated with disposition of the baby's remains - "*The big need is paying for the funerals or the care of the aftercare for the baby. Uh, I mean, families are young a lot of times, with no means to care for the baby. It's just a huge burden*". In many cases, this additional financial cost poses a real burden for families with limited resources - "*when I think of challenges in my program, the first thing that comes to mind is families having to pay \$300-500 dollars for cremation and they can't keep their lights on*" - Samantha.

Consequently, health providers, who in this instance become the bearers of bad news, often feel the burden of assisting families to find more affordable options for private disposition. Naomi confirms this by adding that although there are a few non-profits that offer assistance for burials and cremations, the challenge in trying to find extra sources of funding for families persists. In some cases, health providers have offered their own resources to help reduce the burden on bereaved families - "*I personally know bereavement nurses and chaplains who have taken care of things on their own and out of their own pockets*" - Naomi.

Moreover, the cost of mental health services to deal with the grief after perinatal loss is another challenge to serving perinatally bereaved families. In some cases, women who require further counseling to cope with the loss have to pay out of pocket for private therapy, which may not be economically feasible but remains an essential component of perinatal bereavement care. Ruby explains that the cost of private counseling may be prohibitive for many bereaved mothers - "*Some of our women who are not financially independent are definitely having access issues because afterwards, if they want to have any type of counseling, they have to pay out of pocket, which is typically not very affordable. I mean, most mental health counselors that I've reviewed*

*lately, the minimum is going to be \$60 and those are practically impossible to find, because they are already full. And typically, the cost is around \$100 to \$120 an hour. So it's definitely cost prohibitive to you know, to like pay independently at Marion County for mental health services”.*

### **Theme 3: Gaps in emergency department bereavement care for miscarriage**

A salient gap identified by health providers is the lack of adequate bereavement care and resources provided for women who experience a miscarriage and are treated in hospital Emergency Departments (EDs). Providers in our study confirmed that miscarriages, particularly first trimester losses, are treated in the ED – *“...the early pregnancy losses, they go to the emergency department. Some of the local hospitals, their Labor & Delivery departments only see pregnancies that are 16 to 20 weeks or over. Other than that, they go to the emergency department”*- Naomi. Additionally, health providers also report that while these early losses are cared for in the hospital Emergency Departments, EDs do not have any resources for women experiencing a miscarriage. For instance, Chloe shares her knowledge about how pregnancy loss is treated in the hospital EDs– *“I can tell you for certain that emergency departments in general don't have resources. Women that come into the emergency department and they miscarried... They, they do really good at physical aftercare instructions but they don't understand when it comes to bereavement and disposition”.*

In the same vein, another gap that occurs with early term pregnancy loss is the lack of information given to patients in the emergency department. Providers have reported that, in many instances, patients and families are not informed that they have a choice regarding disposition. For those families experiencing early term loss who can afford it and want to keep

the ashes of their baby as mementos or have them buried, they can opt out of the hospital disposition. This information, however often does not get communicated to parents and as such families agree to hospital disposition thinking that this is the only option available – “ *Women that come to the emergency department don't know they have a choice that they could bury their baby privately if they wanted to. They don't know that they have a choice that they could cremate their baby privately and have the ashes themselves. The baby goes to pathology and goes for hospital burial; the hospital has disposition in a humane manner. But the families don't even know they have a choice*”- Chloe.

### **Challenges Serving Immigrant and Refugee Groups**

In addition to describing the general challenges and gaps they face when serving perinatally bereaved families, health providers also commented on the unique challenges they encounter while providing care to immigrant and refugee groups.

#### **Theme 4: Language barriers and difficulties with communication (interpretation)**

One of the greatest challenges reported by health providers who serve perinatally bereaved immigrant and refugee groups is the language barrier. While mainstream bereavement care appears to support English speakers very well, this is not the same for non-English speakers or those patients for whom English is not a first language. Ruby attests to this fact by stating that generally, the bereavement care offered to patients “*is really great at supporting English speakers. It is not very good at supporting any other language*”. This is evident in the struggle to locate interpreters for the different languages.

Another challenge revolves around the reliability of the translation provided, as the health provider has no way of knowing if the translation is accurate or if the patient truly understands what is being communicated to them. In this regard, Chloe explains how she manages the language barrier by employing the services of an interpreter over the phone – *“I don't always have an interpreter in person, so we'll have to use an iPad or we get somebody over the phone. I'm very clear on my language as to what we're doing so that the interpreter knows and then we go from there. But I know sometimes things are getting lost in translation”*. Relatedly, the difficulties with translating words and phrases that do not exist in the target language also poses another obstacle with communication for health providers. Betty shares anecdotally that *“ it's a real challenge to know whether patients understand what interpreters are telling them. We'll get a lot of the Burmese moms, and how do you explain in a language that doesn't have a word for autopsy, genetic screening, genetic malformation, you know, how do you explain like doing a stillbirth workup when they don't really have those kind of words in their language?”*.

Although less often cited, the gender of the interpreter also impacts the quality of the translation which makes it difficult for providers to give appropriate care to their immigrant and refugee patients. Because the medical interpreter field is male-dominated, it is sometimes difficult to obtain pertinent information from women owing to shyness or not wanting to discuss personal and intimate issues in front of a man. Chloe, a bereavement nurse at one of the local birthing hospitals, describes her experience with this issue – *“The hard part I have is a lot of my interpreters are male. And it's very difficult to get any information out of anyone. I mean, even to ask something simple about are you having much cramping or bleeding now after your miscarriage? You know, you miscarried two days ago. How, how are you doing with cramping*

*and bleeding? The response is I'm fine. You know, because they don't wanna say anything in front of a man”.*

### **Theme 5: Financial challenges in post-loss care for families without citizenship or documentation**

Although the Indiana state policy on private disposition at 20 weeks or greater brings on financial challenges to Indiana families alike, this burden is felt even more by immigrant and refugee families residing in Indiana. This is because while there is some financial assistance for families at the town trustee's office, these funds are not provided to immigrants and refugees without legal US status – *“there is financial assistance through the township trustee office, but if you don't have citizenship, legal ID, Social security number, you don't get those services”* – Samantha. Another provider, Naomi, confirms this reality as a significant challenge that she must manage when serving non-U.S. citizens – *“the trustee's office a lot of times can provide assistance, but if they [patients] are not legal citizens, the township cannot, they're not able to help them. So then there's that challenge”*. This indicates an additional access barrier for immigrants and refugees even when assistance is available, but do not qualify to receive it due to their immigration status.

### **Theme 6: Cultural Nuances in Perinatal Bereavement Practices**

Providers have also reported challenges navigating cultural and religious differences in how perinatal loss is treated and understood. This impacts the amount and quality of bereavement care that they are able to provide. For instance, in some cultures, mementos and

keepsakes of the deceased baby is a taboo. For this reason, parents are not too keen on receiving mementos of the baby. Naomi describes her general observations working with some immigrant groups – *“I feel like people who are from other countries. Um, I feel there's certain cultures where, I don't know if they feel like it's taboo to have like photos and stuff like that. Um, or you don't treat, you know dead bodies like that. I definitely have seen like in the African culture, I feel like some of those are like, God took care of it, and that's what it was supposed to be. And I'm gonna move on from this and I don't need to ponder on this and, um, we're gonna move forward”*. In such situations, providers are unsure what kinds of bereavement services are appropriate to offer to families.

Again, some cultures prohibit parents from talking about the baby and dwelling on the grief brought on by loss. In these cases, the bereaved parents turn down the opportunity to attend support group and may refuse to accept any additional support information. Maya relays her experience with specific immigrant groups – *“We did get a lot of, um, Punjabi and they were Sikhs and um Hindus. Um, so we would have a lot of Indian immigrant families, but this population never came to support groups ever and didn't want any material, didn't want mementos”*. Consequently, health providers find it hard to connect bereaved immigrant and refugee groups to mental health services.

Nonetheless, health providers recounted stories of how they have helped to respect the cultural and religious differences of their patients. For instance, Lucy talks about how she helped a Hindu family send off their baby in a way that brought them peace– *“I had, I think they were Hindu. Um, but they said we need to have the room all white. And I'm like, White. White. I have sheets. So I went and I just brought them tons of sheets and, um, they covered the room with the sheets and they did not invite me into whatever that, um, was that they needed to do. So I don't*

*know, but I know that they had peace after that experience*". Again, providers shared their experiences assisting families with religious requirements for cremations, such as negotiating with the funeral home to have the father push the button on the crematory or placing baby's ashes in a moving water towards Mecca. These stories highlight the dedication of health providers to their patients and their desire to respect different cultural and religious rituals while providing perinatal bereavement care to diverse populations.

### *Provider Recommendations to Improve Bereavement Care*

Health provider's recommendations to improve perinatal bereavement care in Indiana spanned 5 themes namely (1) Community-based and culturally inclusive community resources, (2) Maintaining a collaborative bereavement care network, (3) Enhanced follow-up and better connection with mental health services following loss, (4) Training and education for health staff, and (5) Increased financial support for loss families. These themes are discussed in detail below.

### **Theme 1: Community-based and culturally inclusive community resources**

Health providers in this study have identified the need for community resources for people of different cultures, faiths, and languages. Because Marion County is increasingly becoming more diverse as it is home to people of many different backgrounds, health providers recommend the development of local grassroots organizations and resources that may better serve individual groups. For Samantha, it would be a dream come true *"to have community*

*resources for different cultures and faiths and languages communication, different languages where we have community resources that are well known to people to offer support”.*

Related to the recommendation for community-based resources, health providers also recommend increasing representation within the perinatal bereavement field. Through our interviews, health providers related that although they serve families from varying backgrounds, the composition of patients who typically attend support groups is homogenous, usually Caucasian women. Health providers intimated that recruiting bereavement staff who look like and can relate to diverse perinatally bereaved patients would increase trust and help connect patients to available resources. For instance, Ruby shares anecdotally that the women she serves are seeking support from people they can identify with –“ *the women I'm talking to, they're looking for more of that I feel like I know you, I feel like you're my friend and I feel like we could understand each other and support each other*”. With this realization in mind, health providers have recommended that community members be trained to take up some of the roles within perinatal bereavement; this would increase trust among local communities and would also reduce the burden on families and on healthcare staff.

## **Theme 2: Maintaining a collaborative bereavement care network**

Another recommendation made by health providers is the importance of creating and maintaining a collaborative network of bereavement professionals within the county and even in the state of Indiana. Through this network, providers can share resources and make referrals to resources that they otherwise may not be able to provide through their own health institution. Maya, who is a bereavement nurse at a local birthing hospital, affirms the need for a

bereavement committee and discusses the importance of creating one within the county and for the state - *“there needs to be a bereavement committee. Within the city of Indianapolis, we had what we called a city coalition where all of the bereavement nurses in the major hospitals were kind of in a network. So if we had questions, we could just send a group message and be like, Hey, I need a Spanish speaking support group. I have a Spanish speaking family, and we don't have that here without getting an interpreter, but I know hospital X has a lot of Spanish speaking patients. If somebody can't make it to my Tuesday night on the South side support group, maybe they can make it to hospital Y on the North side. We sat down and tried to make sure that we had support groups on different nights and different weeks. I would like to see that back together”*.

To complement the above recommendation, health providers also highlighted the need for more frequent support group meetings for their patients. Typically, health facilities that offer bereavement hold support group meetings once a month. This often causes access issues for patients with scheduling conflicts. For this reason, providers have indicated the need for more varied time and day options for support group meetings occurring within and around Marion County.

### **Theme 3: Enhanced follow-up and better connection with mental health services following loss**

In response to the identified challenges and gaps, health providers call for a more robust system of follow-up and outreach for patients. The health providers in our study consistently recognize the importance of follow-up care, like Kate who reports that *“follow up is really*

*important. And that making sure that patients are okay is crucial*". Another issue that is deemed a top priority is connecting bereaved families with relevant mental health services, and in Chloe's expert opinion it is imperative to *"have counselors out there that are trained in perinatal bereavement, because just going to a generalized grief counselor, it's not the same grief when you've lost a baby as it is when you've lost your spouse, or your older child or your parent or your grandparent, it's not the same because it's such an isolated loss"*. Consequently, improving access to appropriate mental health care for bereaved women requires much needed attention within the state.

#### **Theme 4: Training and education for health staff**

Further, health providers in our study also recommend that all hospital staff who serve women and families experiencing perinatal loss must be trained in bereavement care. Particularly, providers suggest that personnel working in Labor and Delivery units as well as Emergency Departments have to be trained on perinatal bereavement care. Chloe shares her ideas on how training should be organized – *"If I have all the money and all the resources, every hospital that has an emergency department gets training. Every hospital that delivers babies gets more training. Every hospital that delivers babies must have a bereavement nurse navigator or bereavement coordinator or some sort of person in that role in their facility. And then every nurse that works labor and delivery or emergency department has the ability to attend trainings for bereavement so that the bedside nurses learn what they don't know. I mean, I would start with education. I think that's huge"*.

Taking this a step further, health providers in our study have suggested that bereavement training be made mandatory for hospital staff, particularly nurses. Anecdotally, some providers have reported staying away from patients who experience the loss of a baby for fear of saying the

wrong thing – *“for most nursing staff the biggest fear is they don't know what to say and the fear is, I'm gonna say the wrong thing and hurt them even more”* – Samantha. For this reason, providers recommend that all nursing staff, especially new nurses, be trained in perinatal bereavement, possibly during orientation sessions, to help them develop skills that will help serve their bereaved patients – *“staff engagement and training is like an absolute must, and it needs to be done early on. It needs to be mandatory classes, like while you're on orientation. In my experience, all the nurses that take care of bereavement patients are nurses that have been there for a few years. So these brand new nurses aren't getting exposed to it at all”* – Maya.

#### **Theme 5: Increased financial support for loss families**

In response to the financial challenges identified for post-loss care, providers call for more funding to assist bereaved families. Samantha suggests grant funding to support these efforts – *“So that is a huge area that has always been like a dream of mine to have some kind of foundational fund or grant fund where we could help patients with burial and cremation. That's something in the future that I hope we can establish at some point in time. Because that's probably the biggest one, is having to tell people they have to do this and they don't have the resources to do it”*. Increased funding in this area would help many families honor the life of their baby in a way that they choose, rather than what they can only afford – *“I'm talking about helping families very specifically so they can have the service that they want for their babies. Many people don't choose what they would choose if they have the funding to do it. And what I mean by that is I think there are many patients who would bury their baby instead of do a cremation, but they can't afford it. So they just accept it has to be a cremation”* - Samantha.

Another recommendation that has been made by health providers is a change in the Indiana state policy that requires families of deceased babies who are either born alive or born at 20 weeks and older to be buried or cremated by a licensed funeral home. Providers have discussed the extreme financial burden that the policy bears on families, and have suggested a policy change where these babies could be included in hospital disposition, unless otherwise desired by the parents. Chloe discusses her ideas on policy change – *“I would love to change a couple of state laws. One of those state laws is if my baby is less than 20 weeks’ gestation, but is born with a heart rate or born breathing, you have to go through a funeral home and you have to pay to have your baby cremated or buried yourself, and that is a financial hardship on so many people. Why can we not allow the hospital to take care of that baby with the other babies that were going to cremate? That would be no cost to them. Why should it matter if that baby took a breath and lived an hour? Why should that matter? ...And the other law I would like to change is the hospital isn't allowed to take care of common burial for a baby that was 20 weeks or greater even if the baby was stillborn. Why not? It's not any anymore ashes. It's not any more space. It's not any more expense if the family does not want to. Why should it matter that the baby was stillborn at 21 weeks instead of 19 weeks? The law says that in order to do hospital burial, the baby has to be 19 weeks, 6 days or less, and born dead. If you're born alive and too early, too bad, have to use a funeral home... I don't think that's fair”* – Chloe. Thus, revising the state policies regarding dispositions where parents could opt into hospital cremation would significantly reduce the financial burden on bereaved parents, which leaves them to focus on honoring their baby in a way that they desire.

## DISCUSSION

Health providers face several challenges while serving bereaved women and families following the loss of their baby. From our study, it is evident that the volume of patients significantly impacts health provider's ability to adequately follow up with their bereaved patients. Anecdotally, hospital bereavement nurses, in many cases, may be the only staff working with perinatally bereaved families and, consequently, may be overwhelmed with all the associated responsibilities. Often, the bereavement nurse may have shared responsibilities as both a floor nurse and her role as the bereavement nurse, which places extra demands on the workload (Raymond et al., 2017). Consequently, providers have little time for follow-up and to check in with their bereaved patients because of the multiple responsibilities that they may be juggling. Again, due to the observed frequent changes in patient contact information particularly, for immigrant and refugee groups, it becomes almost impossible to offer follow-up care to bereaved patients. Our findings, are novel in that they offer real insight into the day-to-day challenges of health providers which directly affects the quality of bereavement care provided to bereaved families. This finding, to the best of our knowledge, has yet to be identified and discussed in any prior studies on perinatal bereavement care. Nonetheless, challenges with follow-up, particularly for immigrant and refugee groups, have been documented in a research brief by the U.S. Department of Health and Human Services and remains a prominent barrier to accessing healthcare services (Pereira et al., 2012).

In our study, we uncovered that financial constraints significantly impacts health provider's ability to effectively serve their bereaved patients. The extreme financial hardship brought on by burial and cremation cost, which are mandated by the Indiana state law, remains a crucial factor in perinatal bereavement care (Indiana State Department of Health, 2019; Indiana

General Assembly, 2014). Our findings are supported by existing studies, and although there are differences in policies related to parental responsibility when it comes to fetal disposition in the U.S. and globally, financial costs is a frequently cited challenge for many bereaved parents (Heazell et al., 2016). Researchers estimate the associated costs to range between \$469 and \$11,719 (Heazell et al., 2016). Owing to the unexpected financial burden placed on families, health providers sometimes are put in the precarious situation of helping families fund these unanticipated costs themselves. The quote from Theme 2 where providers have had to dig into “*their own pockets*” to help bereaved families shows just how dire the financial burden is to warrant such an altruistic act. Further, similar to our findings, researchers also report that the associated costs of burials and cremations influence parents’ choices for final funeral rites, where they opt for the most cost-effective option rather than their own preferences of how they wish to say goodbye to their baby (Heazell et al., 2016). This bears a significant emotional and mental toll on bereaved parents, and subsequently, health providers must help connect them with scarce and costly mental health services which may be prohibitive for low-income families. Exacerbating this further are financial challenges related to serving immigrant and refugee patients without citizenship or legal documentation. Indiana is home to an estimated 350,000 immigrants and refugees with about 92,000 identified as undocumented residents (National Immigration Forum, 2019). While health providers have reported that there is some financial assistance for bereaved parents at the local trustees office in Marion County (Marion County Indiana Trustee’s Office, n.d.), these funds are reserved for people with legal US citizenship. Consequently, families without the required documentation have limited options for support with post-loss care. These realities pose access barriers for this underserved group and further bears implications for health equity efforts.

A third gap in perinatal bereavement care in Marion County, IN that is reported by health providers is the extreme lack of resources provided to parents experiencing early pregnancy loss i.e. miscarriage in the Emergency Department (ED). Similar to findings from our study, prior research has found that ED staff often provide little to no bereavement resources to patients experiencing a miscarriage ( Larivière-Bastien et al., 2019 ; Lee et al., 2023). Another issue that has yet to be discussed in the literature, to our knowledge, is the fact that often ED staff neglect to inform women and families of all their disposition options. In Indiana, hospitals are required to take care of common disposition for any fetus that is less than 20 weeks old and born dead (Indiana State Department of Health, 2019; Indiana General Assembly, 2014). Although this is the general rule, parents can opt out of this by choosing to arrange final rites privately at their own cost (Indiana State Department of Health, 2019; Indiana General Assembly, 2014). Unfortunately, ED staff have consistently failed to inform parents of these options, leaving bereaved families who experience miscarriage with no physical reminders/ mementos of their baby.

Language barriers continue to be a significant challenge for many health providers who provide perinatal bereavement care to immigrant and refugee patients. While the existing evidence supports the knowledge that mainstream bereavement care adequately serves English-speaking patients, the same cannot be said for patients who are non- English speaking or for whom English is not a first language. Not surprisingly, health providers in a recent study have identified language barriers as one of the most challenging aspects of their work with immigrant and refugee patients (Austin et al., 2021). Translation services, though available, may not always be reliable. Again, from our study, we uncovered that additional considerations, such as the gender of the interpreter, may also influence the quality of patient's interactions. In some

cultures and religions, it is highly frowned upon or even forbidden to discuss topics related to female reproduction and sexual health openly and with the opposite sex (Ayesh, 2022). As such, male interpreters may pose a significant barrier for bereaved women, which may prevent them from receiving adequate bereavement care following perinatal loss.

Furthermore, challenges related to cultural and religious differences have been discussed by health providers in our study. Perinatal bereavement care in many non-western cultures looks quite different from what is practiced in the U.S. particularly regarding picture taking, holding, seeing, and naming the baby (Shakespeare et al., 2019). For instance, in some Eastern and Western African cultures, it is a taboo for parents to see the dead baby (Ayebare et al., 2021; Adebayo et al., 2019; Attachie et al., 2016). Additionally, women are not permitted to mourn or cry over their babies for fear that they may become barren or have recurrent losses (Attachie et al., 2016; Ayebare et al., 2021; Adebayo et al., 2019). Again, in some Asian cultures, particularly in Taiwanese culture, death is considered a bad omen and thus discussions pertaining to the latter are forbidden. Mothers are also prevented from seeing and holding the baby to prevent any future harm to subsequent pregnancies (Tseng et al., 2018). Consequently, health providers find it challenging to provide culturally appropriate care to bereaved parents, particularly when it comes to making critical decisions about final rites. It is also difficult to connect women with mental health services because of the lack of communication around the death of the baby and the mother's reluctance to mourn or dwell on the passing of the child.

Regarding recommendations, health providers in our study strongly recommend community-based and culturally inclusive resources for bereaved families. Owing to the identified gaps and challenges that providers face when serving patients with diverse backgrounds, it is important that local communities develop culturally relevant resources to help

bereaved families navigate the difficult time. Again, providers have suggested building a collaborative bereavement network to facilitate the easy exchange of resources and information between hospital systems. Indeed, provider collaborations have proven to be beneficial for both patients and professionals, evidence primarily documented within the medical field (Scheinrock & Korenda, 2017). Provider collaboratives typically comprise a group of independent yet aligned professionals, hospitals or health systems who come together to pursue common goals (Scheinrock & Korenda, 2017). These types of collaboratives have been found to increase access to care in the face of geographic limitations, promote easy sharing of critical information among group members, and serves as a platform for continuous learning (Scheinrock & Korenda, 2017).

Furthermore, providers also recommend perinatal bereavement training for healthcare staff who work in labor and delivery departments and in the emergency department. These findings are supported by existing studies examining health providers' needs in providing perinatal bereavement care (Shorey et al., 2017). Reviews of about 30 research papers underscored health provider's desire for more education and training in perinatal bereavement care (Shorey et al., 2017). Taking this a step further, providers in our study have also recommended that these trainings be made mandatory, be included as part of onboarding and orientation for new nurses, and for perinatal bereavement education to be included in the nursing school curriculum. Not surprisingly, results from a recent study evaluating the confidence levels of student midwives after a bereavement training workshop reported increases in bereavement support skills, and bereavement support knowledge of student participants (Doherty et al., 2018). Last, provider recommendations to address the identified financial challenges point to changes in the existing Indiana policies on fetal disposition and advocate for increased financial assistance for bereaved families. While there are some local non-profit organizations that assist families

with funeral and cremation costs (Love, Lucas, n.d.; Remembering Rowan, n.d.), these institutions have limited resources. The funds provided are a temporary solution to a permanent problem. Consequently, recommendations to change or modify the existing policy so that parents have the option to choose hospital disposition will significantly reduce the financial burden on bereaved families.

### *Limitations*

A limitation of the current study is the small sample size resulting from our targeted recruitment strategy. Again, our sample is not representative of all health providers and professionals who do bereavement work in Marion County, IN. Another limitation is that our study findings may not be generalizable to other Indiana counties and U.S. states. While the providers in our study shared their experiences with delivering bereavement care within their county of jurisdiction, these experiences may not hold true for other bereavement providers in different geographic locations within the state and across the country.

Nonetheless, our study has many strengths. First, our research findings lay bare the challenges and gaps in perinatal bereavement care that have yet to be discussed by other prior studies. These findings, thus, add to the literature on perinatal bereavement care. Again, our study findings respond to a gap in the literature on provider challenges serving immigrant and refugee patients. Because this area of investigation is severely understudied, our findings are an important and novel contribution to the field. Finally, the provider recommendations discussed in our study will serve to inform future programs on perinatal bereavement care in the U.S.

## *Public Health Implications of Research Findings*

The findings of the current study bear significant implications for health providers, policymakers, local communities, public health practitioners, and all stakeholders who work to improve infant mortality in Indiana, and in the U.S. For health providers, the recommendation to build collaborative networks is important to consider as it would imply easy access to shareable resources and reduce work burden and challenges. Again, our study findings underscore the need to build partnerships between health facilities and local community organizations. For instance, the identified challenges with language barriers and interpretation could be addressed by training community members to bridge the gap by serving as translators in health facilities. This will also serve to increase representation within the perinatal bereavement field.

For policymakers, our findings shed light on the adverse financial toll of state policy on bereaved families. Policymakers must re-evaluate the existing policies and adjust accordingly based on the recommendations of those who are directly affected by them, i.e., bereaved parents and bereavement care providers. Finally, public health practitioners must design interventions that consider the unique backgrounds of diverse populations. It is widely accepted within social and behavioral health that one size does not fit all (Alegria et al., 2010; Barrera et al., 2013), and our findings lend evidence to this. While mainstream perinatal bereavement care may be sufficient for some populations, it may be inadequate for others. For this reason, further research into understanding the different cultural and religious nuances of perinatal bereavement is necessary to provide affirming and respectful care to all populations. Future studies in this area should seek to understand the varying religious and cultural needs of diverse populations following perinatal loss. These findings will help to inform the creation of future programs for perinatally bereaved parents of diverse racial and ethnic groups.

## CONCLUSION

This research study sheds light on provider reported challenges and gaps in perinatal bereavement care in Marion County, IN. The findings of the study respond to a gap in the literature on bereavement care at the local level, and to our knowledge, this is the first study to examine provider reported gaps and challenges in perinatal bereavement care in Indiana. Further, this study adds to the scant literature on provider reported challenges and gaps serving immigrant and refugee groups in the U.S. This is a very understudied area that warrants further investigation as public health is population health, and immigrants and refugees form a significant and essential part of the U.S. population. We believe that the provider recommendations made will serve as a first step toward improving care and protecting maternal mental health in Marion County, IN. We hope that these findings inform future interventions that seek to improve maternal and infant health in the state of Indiana and across the U.S.

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## CHAPTER SIX : CONCLUSIONS, FUTURE RESEARCH, AND LESSONS LEARNED

Perinatal loss, the death of a baby through a miscarriage, stillbirth, or a neonatal death, remains a public health issue due to the associated adverse outcomes on maternal mental health. To counteract these negative effects, bereavement care services have been created and designed to protect women's psychological and emotional health after the loss of a baby. Although bereavement care has been studied on a national scale, few studies have toed this line of investigation at the local level. Because perinatal bereavement care is severely understudied in Indiana, I aimed to fill the research gap by exploring bereavement care experiences of Marion County IN women. I also sought to understand how participation in peer support programs impacted women's journey with loss. Additionally, I investigated health provider – identified challenges and gaps in bereavement care. Finally, I collected recommendations from both bereaved women and health providers on ways to improve the existing perinatal bereavement services for Indiana families. The findings of the research study are discussed in detail in Chapters 4 & 5 of this dissertation. A brief discussion and conclusions of study findings are presented in the subsequent paragraphs.

First, this research study affirmed that overall, bereaved mothers report positive experiences with their bereavement care following the loss of their baby. A key factor in promoting these positive experiences is the pivotal role played by the bereavement staff. Although several women in our study reported having positive experiences with the bereavement care, this was not a universal experience as some bereaved mothers recounted negative events that they had experienced with their bereavement care. Relatedly, a novel finding from this theme which has yet to be discussed in other studies is the realization that perinatal bereavement care is not a standard of care across all birthing facilities. Several factors may account for the

reported inconsistencies in the availability of perinatal bereavement care, which warrants further investigation.

Not surprisingly, findings of this study also confirmed that women's emotional wellbeing continues to be impacted by negative attitudes of hospital staff. This is a widely reported issue across several studies, an area that requires further attention.

Again, this research study uncovered grave disparities in bereavement care for women experiencing early term miscarriage particularly within the first 12 weeks of gestation, compared to later term losses. Specifically, I found that women who experienced a loss earlier in the pregnancy did not receive any bereavement care and their grief was often dismissed. Relatedly, I found that women experiencing a miscarriage who are treated in hospital emergency departments do not receive comprehensive information about their disposition options, though this is required by Indiana state law. This is another novel finding from the study which identifies a gap in the existing care and would inform future interventions.

In recognizing the critical role of peer support programs as part of perinatal bereavement care, two major themes were discussed. The first, focused on the positive impacts of shared experiences in bereavement support groups such as finding community, resolving feelings of isolation and trauma from the loss as well as offering a safe space to discuss the loss experience. The second theme related to finding healing and purpose after the loss of the baby through volunteering to help other bereaved parents (bereavement volunteerism). Findings of the study suggests that bereaved mothers used volunteering as a way to make something positive out of a negative situation and to find meaning in their loss.

Regarding health provider's perspectives, reported challenges included difficulty following up with patients resulting from frequent changes in contact information. While this finding has yet to be discussed in other national level studies, I believe that this may be a more generalized issue for local-level providers and warrants further investigation. Another novel finding of this study comes from the Indiana state law that requires parents to bear all financial costs related to disposition if the baby is born 20 weeks or older, or if they are born alive. This law brings on significant financial burden to many bereaved Indiana families, and often limits parent's choice on how they would like to say goodbye to their baby as opposed to what they can afford.

Similar to findings reported by bereaved mothers, health providers also commented on the gaps in emergency department bereavement care for miscarriage patients. Thus, the evidence affirms the need for more robust bereavement care training and intervention in hospital emergency departments.

In addition to the general challenges discussed, health providers also reported unique difficulties that they face when serving immigrant and refugee populations including language barriers and challenges with interpretation, difficulty in locating external funding for burial and cremation to help undocumented families and those without citizenship. Moreover, health providers experience challenges while trying to accommodate the various cultural nuances in perinatal bereavement care for immigrant and refugee patients.

Regarding recommendations to improve the existing perinatal bereavement care, both health providers and bereaved mothers made similar recommendations including making bereavement education and training mandatory for healthcare professionals particularly ER staff and nurses, having more robust bereavement care for early term miscarriage, and enhancing

follow-up and mental health support. Some unique recommendations made by bereaved mothers included implementing perinatal bereavement as a standard of care in all Indiana birthing facilities, and requiring health professionals to provide comprehensive lactation education to mothers who experience late to full term losses because their bodies would naturally still produce milk despite the loss. Health providers also suggested creating community-based, culturally inclusive resources for patients of diverse backgrounds, building a collaborative bereavement network, and increasing financial support for loss families.

The above-mentioned findings of this dissertation research study contributes to the literature by supporting existing research in perinatal bereavement, and further adds novel findings to the scant literature on local level perspectives, thereby filling an identified gap in the field of bereavement research.

## IMPLICATIONS OF STUDY FINDINGS

In line with the tenets of critical research, this study provides evidence that will inform future interventions and programming in perinatal bereavement care. First and foremost, the study findings underscore the importance of equitable bereavement care for all women who experience perinatal loss, regardless of the gestational age of the baby or the health facility where treatment is provided. I affirm that all women experiencing loss through miscarriage, stillbirth or neonatal death deserve good, quality, empathetic bereavement care. I believe that by elevating the voices of the women in our study, we promote social justice and advocate for the equitable treatment for this underserved group.

My findings also bear significant implications for health providers including clinicians, nurses, midwives, as well as policy makers, local communities, public health practitioners and all stakeholders who work to improve maternal and infant health. For health providers, women's reports of negative treatment are concerning and require the creation of protocols that will eliminate these occurrences. In addition to creating new protocols, health providers including nurses and ED staff must undergo routine training in bereavement care as this would reduce the care burden on bereavement staff. Further, provider recommendations to create a collaborative bereavement network is an important one to consider as it would imply easy access to sharable resources and reduced work burden. Moreover, my study findings underscore the need to build partnerships between health facilities and local community organizations. Establishing collaborations with local communities serves to build trust and also to increase representation within the perinatal bereavement field.

For policy makers, my findings shed light on the adverse financial toll of state policy on bereaved families. Policy makers must re-evaluate the existing policies and adjust accordingly based on the recommendations of those who are directly affected by them.

Finally, public health practitioners must design programs that consider the unique backgrounds of diverse populations. This research study underscores the importance of providing affirming and respectful care to all population, regardless of race, ethnicity, religion, or immigration status.

#### SUGGESTIONS FOR FUTURE RESEARCH

Future studies may explore differences in perinatal bereavement care experiences of diverse bereaved women who have not participated in peer support program such as caring

companions. Studies could also investigate the role of hospital administration and health facility priorities on women's experiences with perinatal bereavement care and on maternal health. Further, future studies could explore health provider challenges as they relate to patient follow-up and connection with mental health services. Again, further research into understanding the different cultural and religious nuances of perinatal bereavement is necessary to provide affirming and respectful care to all populations. Future studies in this area should seek to understand the varying religious and cultural needs of diverse populations following perinatal loss. These findings will help to inform the creation of future programs for perinatally bereaved parents of diverse racial and ethnic groups.

## LESSONS LEARNED

Throughout this dissertation study, I have learned some lessons along the way that I would like to share. First, I learned that as a researcher it is of the utmost importance to establish collaborations and networks early on, preferable prior to the start of the project. This helps build trust, but also facilitates learning for the researcher, especially when they have an outsider perspective. Coming into this project without much knowledge about perinatal bereavement outside of the academic literature, it was very important for me to learn as much as possible from the experts – women who had lived experience of perinatal loss, and health providers who serve these women and families on a daily basis. I am grateful that I was able to sit in on FIMR meetings to learn about the FIMR case review process. I am also grateful to the women who were willing to share their experiences and stories with me.

Another lesson that I learned in this process is to be genuine and true to my values and beliefs. As a researcher who affirms the tenets of critical theory, I strongly believe that research should not be conducted just for the mere sake of it, but rather should be done to help the less privileged and the underserved. In this regard, I learned that people respond well to those that they believe have a genuine desire to help and give back to the community, rather than just to take away for personal gain. These principles helped me immensely with recruitment and with data collection. By being genuine and open with my participants about my intentions and goals for this study, they also in turn responded with openness and a deep desire to contribute in whatever way they could. It is my dream, thus, that findings of this study would inform future programming in perinatal bereavement care, as this is such an overlooked area within maternal health. I would love to take this information back with me to my own community in Ghana, and explore how perinatal bereavement care can be implemented or improved in ways that are affirming for women, while still respecting the cultural nuances within society.

Finally, through this study I learned the value of community. I learned that having a support system when the storms of life hit, is crucial for our wellbeing. From women's stories of loss, to meeting other bereaved mothers who gave support and served as mentors, to ultimately becoming a source of support to others, shows the full circle of what community truly means. I learned from the Caring Companions that we can be a community for people we don't know, just by being there for each other in our own small way. By sharing our stories, bringing to bare the inequities, and shedding light on what's wrong in our world, we take a step further toward improving conditions for others to come.

## **Appendix A- Email message to recruit health professionals in Indiana**

### Recruitment email for health professionals (bereavement coordinators/nurses)

Bereavement services after perinatal loss, miscarriage or stillbirth are effective public health strategies to improve mental health and future reproductive decision making of women and families. In Indiana, the availability of bereavement services varies across the state. This research study therefore examines the scope of available bereavement services and hopes to collect recommendations on programming that ultimately improves maternal, fetal and infant mortality in Indiana.

You are invited to participate in a **60 minute interview** about your experiences (work, position, personal loss, non-profit) with bereavement support services in Indiana.

Who we want to hear from:

- Health professionals whose work centers on improving maternal, fetal and infant mortality in Indiana
- Administrators of fetal and perinatal loss support groups

If you are interested in sharing your perspectives on how bereavement support can be improved in Indiana, please reply to this email with your availability and contact information. A member from the research team will be in touch with you.

# Bereavement support study

Bereavement services after a perinatal loss are effective public health strategies to improve mental health and future reproductive decision-making of women and families. This study examines bereavement services in Indiana and hopes to collect recommendations on programming that ultimately improves maternal, fetal, and infant mortality in Indiana.

## Who we want to hear from

- Health professionals whose work centers on improving maternal, fetal, and infant mortality in Indiana
- Administrators of fetal and perinatal loss support groups

## What would you do?

A 60-minute Interview via


- Phone
- Zoom



whatever is most convenient for you



Interested in adding your voice and sharing your experience with bereavement support services after perinatal loss in Indiana, please contact:

Frederica Jackson  
Indiana University School of Public Health

 email 

 phone 

**Appendix C – A Walk to Remember community event flyer**

5/30/23, 3:37 PM 2022 A Walk to Remember - Indianapolis- Franciscan Health | Sarah T Bolton Park, Beech Grove, IN | Sat October 8, 2022

☰

## 2022 A Walk to Remember -Indianapolis- Franciscan Health



37TH ANNUAL  
FRANCISCAN HEALTH  
**WALK TO REMEMBER**  
SATURDAY,  
OCTOBER 8, 2022

<https://goallevts.com/e/2022-a-walk-to-remember-indianapolis-franciscan-health-E200023434076926> 1/5

**Date**

Sat Oct 08 2022 at 09:30 am to 01:00 pm

**Location**

Sarah T Bolton Park, 1300 Churchman Ave,Beech Grove,IN,United States, Beech Grove, United States

**Organizer**

Amos' Anchors

Franciscan Health will host its 37th annual Walk to Remember.

This citywide event includes hundreds of families from around central Indiana who have lost children through miscarriage, stillbirth or newborn death and will come together to remember their babies in a service of music, poetry and reading of the infants' names.

The memorial service begins at 11 AM.

The event is free, but your online registration is required to ensure your infant(s) and family information is included in the memorial service program.

To have your baby's name and family information included in the program, please register by midnight Friday, September 23, EST.

Register [HERE](#):

<http://events.r20.constantcontact.com/register/event?oeidk=a07ej9r4pw2b3e7a033&llr=mbdr5elab>

In person registration begins at 9:30 AM at Sarah T. Bolton Park.

Sarah T. Bolton Park

1300 Churchman Avenue



## **Appendix D – Recruitment Email – Bereaved mothers**

### Recruitment text message for women who have experienced perinatal loss

The loss of an infant/fetus can be an extremely difficult and painful experience for women and families. Often, the pain and grief associated with such loss is overlooked, understated and minimized. This research study seeks to examine existing bereavement services and resources that are available to Indiana women and families who are/ have experienced perinatal loss. We hope to collect recommendations to improve existing resources.

#### **What will you be asked to do:**

You are invited to participate in a **60-minute interview** about your experience with bereavement support services in Indiana.

Who we want to hear from:

- Indiana women who have experienced miscarriage, stillbirth or neonatal loss in the last 30 years
- Immigrant and refugee women who have experienced miscarriage, stillbirth or neonatal loss while living in Indiana.

If you are interested in adding your voice and sharing your experience with bereavement support services after fetal/ perinatal loss in Indiana, please contact:

Frederica Jackson

Indiana University School of Public Health

[email](#)

phone

# Bereavement support study

*We share in your sorrow and hope to  
learn from you*

## Study purpose

To examine bereavement support resources provided to Indiana women after perinatal loss

## Who can participate

- Indiana women who have experienced miscarriage, stillbirth or neonatal loss in the last 30 years
- Immigrant and refugee women who have experienced miscarriage, stillbirth or neonatal loss while living in Indiana

## What will you do

Participate in a 60-minute interview about your experiences with bereavement support services in Indiana

Interested in participating? Please Contact

**Frederica Jackson**  
**Indiana University School of Public health**

email  
phone

PROTOCOLS



## APPROVAL LETTER

**To: Obeng, Cecilia**

**Protocol #: 14851**

**Protocol Title: Bereavement support for perinatal Loss in Indiana**

**Type of Submission: Initial**

**Level of Review: Exempt**

**Approval Date: Monday, July 18th 2022 Expiration Date: no date provided**

**\*If Expiration Date = "No date provided," this research does not require annual renewal; thus there is no expiration date.**

**The Indiana University HRPP approved the above-referenced submission. Conduct of this study is subject to the [IU HRPP Policies](#), as applicable.**

**Additional Notes:**

**This research is exempt under the following category:**

**-Category 2(ii)**

**Documents approved with this submission:**

### Attachments

Data Collection Instrument    Bereavement and loss\_interview protocol.7.12.22.pdf

Informed Consent Statement    Informed consent\_Bereavement support for fetal and perinatal loss\_6.29.22.pdf

Recruitment Materials            Recruitment docs\_ Bereavement support for perinatal loss in Indiana\_7.13.22.pdf

Recruitment Materials            Flyer\_Bereavement support study.pdf

You should retain a copy of this letter and all associated approved study documents in your research records.

If you have any questions or require further information, please contact the HRPP via email at [irb@iu.edu](mailto:irb@iu.edu) or via phone at (317) 274-8289.

## CURRICULUM VITAE

**FREDERICA JACKSON, MA, MPH, PhD**

**Email: [fjackso@iu.edu](mailto:fjackso@iu.edu)**

### **Profile**

I have 6 years of professional experience in Public Health and 4 years' experience in the Maternal and Child Health field. I possess a Master of Public Health Degree, and have expertise in the scientific research process, and in communicating research findings through peer reviewed publications, and at professional conferences. I have excellent communication, interpersonal and organizational skills. Other relevant experiences include supervising and mentoring students and peers, as well as fostering collaborations with diverse organizations.

### **Education**

- |           |       |   |
|-----------|-------|---|
| Aug 2024  | Ph.D. | <b>Indiana University- Bloomington</b> , School of Public Health.<br><b>Major:</b> Health Behavior<br><b>Minor:</b> Inquiry Methodology<br><b>Dissertation:</b> Perinatal loss – Bereavement Care Experiences of Indiana Women and Health Provider Perspectives |
| May 2020  | MPH   | <b>Ohio University</b> , Social and Public Health.  |
| May 2017  | MA    | <b>Ohio University</b> , International Development Studies. Major in International Women's Health.  |
| June 2014 | BA    | <b>University of Ghana</b> , Double Major in Sociology & Spanish.   |

### **Research Experience**

- |               |  |
|---------------|--|
| August 2021 – | <b>Graduate Research Assistant</b> , IU SPH, Department of Applied Health Science. |
|---------------|--|

Under the mentorship of Director, Maternal and Child Health Program

PI: Cecilia S Obeng, PhD.

- Collaborate on research projects in Maternal & Child Health
- Develop surveys for mixed methods research projects
- Develop interview guides for qualitative research projects
- Assist with data collection and data analysis
- Disseminate research findings in peer-reviewed manuscripts and at professional conferences.
- Assist with MCH grant applications

January 2021 – **Research Assistant**, Project UNITE.

PIs: Alison Rachel Greene, PhD; Catherine Sherwood- Laughlin, HSD.

- Conducted in-depth one-on-one qualitative interviews
- Assisted with Qualitative data analysis – coding, theme generation
- Assist with UNITE grant applications
- Disseminate research findings at professional conferences
- Collaborate on preparing peer-review manuscripts

August 2020 – 2021 **Graduate Research Associate**, IU Abortion Attitudes Project (DAMSS)

PIs: Kristen N Jozkowski, PhD; Brandon L Crawford, PhD.

- Created and designed Abortion Attitudes Project website - DAMSS
- Assisted with survey development – Spanish translation team
- Prepared peer-reviewed manuscripts
- Disseminated research findings at professional conferences
- Assisted with data collection and data analysis

August 2018 – 2020 **Research Assistant**, Reproductive and Sexual Health Initiative (RSHI) at Ohio University.

PI: Caroline Kingori, PhD.

- Assisted with STI/ HIV resource information distribution and awareness among college population
- Collected primary data for STI Holzer study
- Supervised undergraduate student volunteers during primary data collection

- Analyzed primary and secondary data using statistical analytic software
- Presented research findings at professional conferences
- Prepared and published peer-reviewed manuscript

### **Peer Reviewed Publications**

1. LaRoche K.J., Jozkowski K. N., Crawford B. L. & **Jackson F.** Can someone be both pro-life and pro-choice? Results from a national survey of US adults. Perspectives on Sexual and Reproductive Health. 2024. <https://doi.org/10.1111/psrh.12262>
2. Obeng, C.S., **Jackson, F.**, Brandenburg, D. et al. Black/African American Women’s Woes: Women’s Perspectives of Black/African American Maternal Mortality in the USA. J. Racial and Ethnic Health Disparities. 2023. <https://doi.org/10.1007/s40615-023-01883-0>
3. **Jackson, F.**, Obeng, C.S., Greene, A.R. et al. Untold Narratives: Perceptions of Human Milk Banking and Donor Human Milk Among Ghanaian Immigrant Women Living in the United States. J. Racial and Ethnic Health Disparities (2023). <https://doi.org/10.1007/s40615-023-01860-7>
4. Sakyi KS, Hurley EA, Kanyangarara M, Owusu PG, Sowah LA, Lartey M, **Jackson F**, Sacks E. Over forty percent of women living with HIV report interruption in antiretroviral therapy during intrapartum and early postpartum inpatient stay: findings from five hospitals in Ghana. AIDS care. 2024 Jan 2;36(1):139-45.
5. Obeng C, **Jackson F**, Amissah-Essel S, Nsiah-Asamoah C, Perry CA, Gonzalez Casanova I, Obeng-Gyasi E. Women's perspectives on human milk banking in Ghana: results from a cross-sectional study. Frontiers in Public Health. 2023;11:1128375.
6. **Jackson, F.**, Obeng, C., Golzarri Arroyo, L., Heinrich, A., Byrd, J. & Obeng- Gyasi, E. Men’s breastfeeding perceptions: A need for targeted intervention among male sub-populations. International Public Health Journal. 2023; 15(2):203-211.
7. **Jackson F**, Haile ZT. Association between educational attainment and risky sexual behavior among Ghanaian female youth. African Health Sciences. 2023;23(1):301-8.
8. Baney L, Greene A, Sherwood-Laughlin C, Beckmeyer J, Crawford BL, **Jackson F**, Greathouse L, Sangmo D, Ward M, Kavaya S. “It Was Just Really Hard to Be Pregnant in a Smaller Town...”: Pregnant and Parenting Teenagers’ Perspectives of Social Support in Their Rural Communities. International Journal of Environmental Research and Public Health. 2022;19(24):16906.

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10. Valdez, D, Jozkowski, KN, Montenegro, MS, Crawford, BL, **Jackson, F**. Identifying accurate pro-choice and pro-life identity labels in Spanish: Social media insights and implications for comparative survey research. *Perspect Sex Reprod Health*. 2022; 1- 11. doi:10.1363/psrh.12208
11. **Jackson F**, Obeng C. Perceptions of Human Milk Banks as a Response to the US Infant Formula Shortage: A Mixed Methods Study of US Mothers. *Women*. 2022; 2(3):218-230. <https://doi.org/10.3390/women2030022>
12. Obeng C, Amissah-Essel S, **Jackson F**, Obeng-Gyasi E. Preschool environment: Teacher experiences during the Covid-19 pandemic in Ghana. *International Journal of Environmental Research and Public Health*. 2022;19(12):7286.
13. Gebre H, Ghamli S, **Jackson F**, Chavan B, Kingori C. Knowledge, perception and utilization of cervical cancer screening and Human Papillomavirus (HPV) vaccination among immigrants and refugees in Central Ohio. *The Columbia University Journal of Global Health*. 2021;11(1).

### **Conference presentations**

- Jackson, F.**, Obeng, C. (2023, November 11 – 15). *Factors accounting for COVID-19 vaccine hesitancy in mothers of children aged 6 months to 5 years*. [Poster presentation]. American Public Health Association 2023 Annual Meeting and Expo. Atlanta, Georgia.
- Jackson, F.**, Obeng, C. (2023, October, 11- 13). *Perinatal bereavement care for minority populations: provider challenges, gaps and future directions*. [Poster presentation]. Ohio Society of Public Health Education (OSOPHE) Health Educators Institute Annual conference. Lore City, Ohio.
- Sangmo, D., **Jackson, F.**, Baney, L., Kavaya, S., Beckmeyer, J., Greene, A., Sherwood-Laughlin, C., Greathouse, L., Terrel, B., Ward, M., Trudeau, K., Ehudin, P., Menser, J. (2022, May 11- 13). *Accepted but not Acceptable, Disappointing but Celebrated: Exploring Shifting and Contradictory Perceptions of Teen Pregnancy and Parenthood in Rural Communities*. [Oral presentation]. Indiana University Center for Rural Engagement 2022 Conference. French Lick, IN.
- Jackson, F.**, Montenegro, M., Lo, WJ., Mercantonio, T., Crawford B., Jozkowski, K., & Turner R. (2021, October 23-27). *Examining social attitudes toward government's*

*involvement in abortion*. [RoundTable presentation]. American Public Health Association Annual meeting. Denver, Colorado.

Ward, M., Sherwood-Laughlin, C., Greene, A., Beckmeyer, J., Sangmo, D., Kavaya, S., Baney, L., **Jackson, F.** (2021, October 23-27). *Leveraging community-based participatory research to overcome COVID-19 related data collection challenges in two rural communities*. [RoundTable presentation]. American Public Health Association Annual meeting. Denver, Colorado.

Sangmo, D., Kavaya, S., Terrel, B., **Jackson, F.**, Ward, M., Baney, L., Greene, A., Sherwood-Laughlin, C., Greathouse, L., Beckmeyer, J. (2021, May 10-13). *Holding hands: Strategies to bridge outsider-insider dynamics in CBPR & considerations when working with rural communities*. [Oral presentation]. Indiana University Center for Rural Engagement 2021 Virtual Conference.

**Jackson, F.** & Haile, Z. (2021, March 11-14). *Association between educational attainment and risky sexual behavior among Ghanaian female youth* [Poster Presentation]. Consortium of Universities for Global Health 2021 Virtual conference.  
<https://cugh.confex.com/cugh/2021/poster/eposterview.cgi?eposterid=126>

**Jackson, F.**, Avornyo D., Saeed O., Kingori C., Borrasca H., Martin N., Dixon B. & McGee C. (2019, November 2-6). *Attitudes towards safe sex practices among college students: Implications for sexual health intervention*. [RoundTable presentation]. American Public Health Association Annual meeting.

**Jackson F.**, Kinsey T., Arnold T. & Nicks S. (2019, April 18). *Depression & Anxiety among women in Appalachia*. [Poster Presentation]. OHIO Student Expo

### **Invited Talks and lectures**

**Jackson, F.** *Human milk banking among African immigrants living in the US: Perceptions, influences, considerations*. Delivered to Indiana Department of Health (IDOH) Fatality Review & Prevention – Diversity Equity & Inclusion team. March 2023.

**Jackson, F.** *International Women's Health*. Delivered to students enrolled in the Women's Health Course at the Indiana University School of Public Health. Spring 22, Fall 23 & Spring 23.

### **Teaching Experience**

## **Indiana University**

Aug 2021 -  
May 2024

**Associate Instructor**, Stress Prevention & Management (SPH H- 180)

- Taught 180 undergraduate students in Fall 21, Spring 22 & Fall 22.

**Associate Instructor**, Personal Health (SPH H-263)

- Taught 345 undergraduate students in Spring 23, Fall 23 & Spring 24.

## **Ohio University**

Aug 2015 – May 2017

**Teaching Assistant**, Elementary Spanish I (SPAN 101)

- Instructor of Record, Department of Modern Languages
- Taught 150 undergraduate students in Fall 15, Spring 16, Fall 16, Spring 17, Summer 17.

## **Industry experience**

Oct 2023 – May 2024 **Perinatal Research Intern**, Indiana Department of Health (IDOH)

- Designed and conducted surveys to investigate health provider gaps in perinatal bereavement care
- Created reports and research briefs based on research findings
- Investigated approaches to support the mental health needs of families who experience the death of an infant
- Collaborated on interventions to safeguard the mental well-being of mothers who experience perinatal loss.

Aug – Dec 2019

**Public Health Intern**, Athens City-County Health Department (ACCHD)

- Assisted with PHAB accreditation process
- Updated medical reserve corps volunteer contact list
- Assisted with data collection for Athens harm reduction clinic
- Planned and organized health education programs
- Assisted with CHANGE tool assessment

## **Additional Training and Professional Development**

- October 24, 2023 **Pregnancy, Infant loss, and Maternal Mental Health** Webinar. Maternal Mental Health Leadership Alliance. Speakers: Adrienne Griffen, Kay Matthews (Shades of Blue project), Jessica Brooks-Woods, Jamie Zahlaway Belsito. 1 hour continuing education.
- August 31, 2023 **Predatory Marketing of Formula in Black communities.** Speakers: Dr. Ifeyinwa Asiodu (Moderator), Brooke Gilliam (CGBI), Mona Liza Hamlin (ChristianaCare), Dr. Kimarie Bugg (ROSE). 1 hour continuing education.
- June 7, 2023 **Count the Kicks Webinar.** Anthem and the Indiana Minority Health Coalition. 1 hour continuing education.
- May 25, 2023 **Understanding PTSD and Postpartum Depression** panel Discussion. Indiana University School of Medicine. 1 hour continuing education.
- May 22, 2023 **Maternal Health: Engaging Doulas & Midwives to Improve Birth Outcomes.** Beacon Public Health. 1.5 hours continuing education.
- January 12, 2023 **Perinatal Bereavement Training.** Indiana Department of Health, Fatality Review and Prevention. 2 hours continuing education.
- October 26, 2022 **#ClearTheCrib Safe Sleep Webinar.** Prevent Child injury & trainees for Child Injury Prevention. 1 hour continuing education.
- July 26, 2022 **Sudden Unexpected Infant death (SUID).** Indiana Department Of Health, Fetal & Infant Mortality Review post conference. 1 hour continuing education.

### **Fellowships, Scholarships & Awards**

- Fa & Sp 2024 **Indiana University SPH Marian Godeke Miller Scholarship-\$5000**  
SPH Award – Awarded to graduate students in the School of Public Health who are pursuing a Ph.D. and have a minimum GPA of 3.0 on a 4.0 scale.

- Fa & Sp 2023      **Indiana University SPH Equity and Justice Scholarship -\$2500**  
SPH Award – Awarded to undergraduate or graduate student in the School of Public Health-Bloomington who are studying or have demonstrated an interest in public health topics focusing on stigmatization, stress, violence prevention, and underrepresentation in minority and vulnerable populations.
- Fa & Sp 2023      **Indiana University SPH Mohammed R. Torabi Scholarship recipient -\$1000**  
SPH Award – Awarded to undergraduate or graduate student in the School of Public Health who is an international student and with a minimum GPA of 3.2 on a 4.0 scale.
- Sp & Su 2022      **Indiana University SPH Maternal and Child Health fellowship recipient -\$2000**  
Maternal and Child Health Program

### **Professional Service**

#### **Professional memberships:**

Ohio SOPHE  
American Public Health Association

#### **Journal Reviews:**

Journal of Racial and Ethnic Health Disparities  
BMC Pediatrics  
Preventive Medicine  
PLOS One

### **Skills & Certifications**

Fluent in Spanish. Diploma of Spanish as a Foreign Language: B2 level. Cervantes Institute  
Experience with Statistical software R programming, SAS, STATA, SPSS  
Proficient with qualitative analysis software ATLAS.ti., MAXQDA, Dedoose.  
Grant Writing & Program Evaluation Certificate.

### **References**

Available upon Request