An Evaluation of a Perinatal Bereavement Treatment Program for Infant Loss: Risk Factors, Treatment, and Healing

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AN EVALUATION OF A PERINATAL BEREAVEMENT TREATMENT PROGRAM FOR INFANT LOSS: RISK FACTORS, TREATMENT, AND HEALING

by

Mary Hilgeman Neal

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Dedication

For Hannah, for being patient and loving me through this journey. Being your mother is a precious blessing that I hope to always make my #1 priority.

For Davey, for also being patient and loving me through this journey. While you did not always understand my intense love for school, you waited up for me on most of those late nights and that helped more than you know.

For my future students, it has been a long and worthwhile road to get here, and I hope you feel seen, heard, and important.
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Abstract

One in five mothers experience a perinatal mood or anxiety disorder (PMAD), and parents who have suffered infant loss are more at risk of experiencing mental health symptoms than other new parents. There are numerous risk factors for perinatal women developing a mood or anxiety disorder, including a history of depression, lack of support, and negative childhood experiences. This study followed more than 1,000 mothers who participated in an integrated behavioral health perinatal bereavement family support program in the Southeast region of the United States from 2015–2023. Mothers who have suffered from infant loss were found to have a statistically significant relationship with a large effect size between certain risk factors, including depression, anger, and guilt, and PMAD symptoms on the Edinburgh Postnatal Depression Scale (EPDS) at the one-month mark after the loss. Moderate to high risk levels were also statistically significant with a medium effect size with higher EPDS scores. Lastly, certain risk factors indicated a greater or less likelihood to participate in therapy after infant loss. Those with depression were four times more likely to participate in therapy. Mothers with anxiety and guilt were twice as likely to engage in therapy services, and those with anger were almost twice as likely to participate in therapy. While those with addiction were three times less likely to get therapeutic support following a miscarriage or infant loss. Those who did not have depression were also less likely to participate in therapy. This bereavement family support program better sets parents up for healthy grieving, recovery, and resilience building after the profound loss of an infant. Through providing training on grief and trauma informed bereavement care, proper screening and identification of risk factors for mental illness and complicated grief, and providing timely treatment, healthcare providers can positively impact parents and their whole families, including any surviving loved ones that are impacted by the loss. This study seeks to bring awareness,
promote education, and encourage advocacy for bereaved perinatal parents integrated behavioral health screening and treatment needs to implement a universal standard of care in hospitals and healthcare settings that treat these families.
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CHAPTER ONE: BACKGROUND AND INTRODUCTION

This quantitative study sought to understand parent bereavement after infant loss, risk level and factors for mental illness symptoms developing, and a mother’s likelihood of engaging in therapy for her grief by studying an existing bereavement program. This study looked at risk level (low versus moderate/high), risk factors (depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress) for symptoms of perinatal mood and anxiety disorders (PMAD), treatment for the first year after the loss, and participant’s total scores on the Edinburgh Postnatal Depression Scale (EPDS). EPDS scores are collected one month after the miscarriage or stillbirth. In the United States, a miscarriage is considered the loss of a baby prior to being 20 weeks pregnant, while a stillbirth is the loss of a baby at 20 weeks pregnant or after (CDC, 2022). Annually, there are 24,000 stillborn babies in the U.S., which is about 1 in 100 pregnancies that reach 20 weeks or later (MacDorman & Gregory, 2015).

In hospital and community settings that do not have a screening or bereavement standard of care in place, parents who suffer from infant loss may not be referred to treatment for PMADs. The term ‘standard of care’ refers to the standards that physicians are held to for evaluating and performing care for patients by the legal system (Moffett & Moore, 2011). PMADs are the number one cause of pregnancy-related deaths and are preventable with access to screening and mental health treatment (Trost et al., 2021). One in five to seven mothers will develop PMADs during their perinatal experience (PSI, 2023; Mughal et al., 2022). Parents who experience pregnancy loss are at risk for significant depression, anxiety, and post-traumatic stress (Jacob et al., 2019; Farren et al., 2018; Reardon, 2018; Sullins, 2016). Thus, standardized perinatal bereavement care should be routinely offered to all parents (Cole et al., 2020).
Statement of Problem

Despite the alarming rate of PMADs, there is still a lack of consensus on the nature of screening parents, which can impact mothers and families from getting needed mental health treatment even after a loss as significant as a child. Pediatricians, Primary Care Physicians (PCP), and Obstetrics (OB) agree that postpartum depression screening and treatment is important; however, there is no consensus on screening best practices, including parents who have suffered a miscarriage or stillbirth. The American College of Obstetricians and Gynecologists (ACOG) recommend providers should screen for mental health symptoms during the 6-week postpartum visit and the Annals of Family Medicine recommend screening at the 6- and 12-month postpartum appointments (ACOG, 2018; Earls, 2010). Postpartum Support International’s (PSI’s) (2019) recommendations for screening include the first prenatal visit, at least once in the second trimester, at least once in the third trimester, at the 6-week postpartum OB visit, 6- and 12-month OB and PCP visits, and the 3-, 9-, and 12-month pediatrician appointments for parents with live children. Other suggestions for screening best practices during the perinatal period would be when hormone fluctuations typically occur post-nursing, starting the menstrual cycle, and starting birth control (PSI, 2019).

The perinatal period also includes parents who have suffered a loss, although they can be overlooked for screenings, including not having the opportunity at the pediatrician’s office (the provider who typically meets with a new parent most frequently). When mental health screenings do not occur, this can impact the entire family, including living children in the home, if the mothers’ mental health needs are not met (Earls, 2010). Similarly, maternal (mothers’) postpartum depression is also linked to higher rates of paternal (fathers’) depression (Goodman, 2004; Ramchandani et al., 2005) and may be comorbid with marital discord, divorce, domestic
violence, substance abuse, and child abuse and neglect (McLennan & Kotelchuck, 2000). One in 10 fathers suffer from postpartum depression (PSI, 2022) and up to 18% develop a diagnosable anxiety disorder (Leach et al., 2016).

Research indicates that perinatal depression is underdiagnosed and undertreated (Earls, 2010). In Gavin et al.’s (2015) study, 40% of parents were detected and diagnosed with perinatal depression and only 60% got treatment. However, 68% of mothers who discontinued psychiatric medication during pregnancy had symptoms relapse during their postpartum experience (Cohen, 2006). Perinatal depression remains the most under diagnosed obstetric complication (Earls, 2010). One in five to seven women experience a perinatal mood disorder with 19.3% of these women experiencing thoughts to harm themselves (Wisner et al., 2013).

Additionally, parents are at high risk for complicated grieving after the profound loss of losing a child (Van Aerde, 2001). Complicated grief is the condition of ruminating about the circumstances surrounding a death, worrying about the aftermath of a death, or excessive avoidance of any reminders about the death (Shear, 2012). Complicated grief occurs in about 7% of people who have suffered a loss (Shear, 2012). People who suffer from complicated grief have a hard time understanding that the death is final and thus engage in excessive avoidance of reminders of the loss, and can experience fluctuating between intense emotions (Shear, 2012).

Research further supports that the death of a child can be the most intense, difficult, and stressful type of loss, and family members are a higher risk for depression and anxiety for almost a decade following the death (Kreicbergs et al., 2004; Lannen et al., 2008). Lannen and colleagues (2008) found that parents with unresolved grief report significantly worse mental and physical health symptoms, including mothers having increased doctor visits and taking sick leave and fathers reporting significant sleep disturbance.
Purpose and Research Questions

In 2020, there were 21,000 stillbirths reported in the United States (CDC, 2022). Women of color are more than twice as likely to experience a stillbirth (CDC, 2022). One in five mothers experience a perinatal mood or anxiety disorder (PSI, 2023), and parents who have suffered infant loss are more at risk of experiencing mental health symptoms than other new parents (Farren et al., 2018); however, there is a gap in the literature regarding risk factors, mental health screening, and engagement in therapy for mothers who experience infant loss. For this study, the following research questions will be analyzed using archival data from 2015 – 2023 from the Butterfly’s Embrace Family Support Program (BEFSP), a bereavement treatment program from a rural county hospital in the Southeast region of the United States.

Research Questions

1. What is the relationship between participant risk level (low or moderate/high) and postpartum mood and anxiety symptoms, as measured by the EPDS, for participants enrolled in a bereavement treatment program for infant loss?

2. What is the relationship between a participant’s risk factors (depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress) and postpartum mood and anxiety symptoms, as measured by the EPDS, for participants enrolled in a bereavement treatment program for infant loss?

3. What is the relationship between a participant’s risk factors (depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress), mother’s age, gestational age, and whether the participant engages in therapy?
The BEFSP labeled risk factors as low, moderate, and high-risk categories. If a bereaved mother has moderate or high-risk factors, she is given therapy referrals. The identified risk factors indicate a higher likelihood of developing PMADs. Low risk factors are: (a) previous bereavements, including unresolved or complicated relationships, death of a significant person in the last year, and complicated grief with death over the last three years; and (b) social support system and relationships, including social isolation, spiritual/cultural distress, conflictual relationship issues within family system. The moderate risk factors are: (a) concurrent stressors: work, including unemployed, at-risk; and (b) concurrent stressors: insufficient resources, including housing, childcare, income, divorce, recent relocation, children in the home, and health concerns post-delivery. High risk factors are: (a) health-mental illness, including depression, anxiety, psychosis, bipolar disorder, and panic attack; (b) health-disability, including developmental, physical, and communication; (c) coping-addiction issues, including drug, alcohol, sex; (d) coping-suicidal ideation, including considered, self-expressed plan, prior attempts; (e) coping-heightened emotional states, including anger, guilt, disorganized; and (f) coping-relationship style, including anxious personality and avoidant personality.

Statement of Potential Significance

This quantitative study aims to understand how screening for risk level, risk factors, and utilizing therapy impacts PMADS in bereaved parents after infant loss to identify needs and shed light for healthcare providers working with these families. If screening and therapy reduce PMAD symptoms in these parents, then education and advocacy can be promoted to place a greater importance on mental health screening and treatment accessibility. If certain risk factors impact healing from loss and contribute to PMAD symptoms, then a greater emphasis can be placed on supporting bereaved parents with these specific stressors and diagnoses. This study
will examine how a standard of care at one hospital impacts bereaved parents in a significant way, with the intention of implementing an infant loss bereavement standard of care. The following definitions are included throughout this report.

**Definitions**

**Complicated grief**: The excessive worrying about the death and avoidance of reminders about the death (Shear, 2012).

**Edinburgh Postnatal Depression Scale (EPDS)**: A screening tool used to assess postpartum depression, anxiety, and suicidal symptoms. The EPDS (Cox et al., 1987) has 10 questions with a scale of 1 to 3, with a maximum score of 30. Parents who report above a 10 are likely to be suffering from a depressive illness of varying severity and number 10 on the scale assesses for suicidal ideation. This study looks at scores on the EPDS for these participants.

**Miscarriage**: Infant loss prior to 20 weeks pregnant/gestational age (CDC, 2022).

**Perinatal period**: The time frame of Pregnancy to Postpartum one year.

**Perinatal Mood and Anxiety Disorders (PMADs)**: DSM-V diagnosable mood or anxiety disorders during pregnancy or postpartum up to 1 year after the birth or pregnancy loss (PSI, 2022).

**Postpartum Support International (PSI)**: The leading international organization for resources, training, and support groups for Perinatal mental health clients and providers.

**Posttraumatic Growth**: Defined as “positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (Calhoun & Tedeschi, 2001, p. 157).

**Standard of care**: Standards physicians are held to for evaluating and performing care for patients (Moffett & Moore, 2011).
Stillbirth: The death or loss of an infant 20 weeks pregnant or after, before or during delivery (CDC, 2022).
CHAPTER TWO: LITERATURE REVIEW

This literature review includes research on perinatal mood and anxiety disorders, risk factors, perinatal screening, COVID-19 influences, grief after infant loss, posttraumatic growth, bereavement treatment, and information on the Butterfly’s Embrace Family Support Program. This research identifies gaps in screening, treatment, and evaluation practices to support the perinatal bereaved parent population. The literature supports that this quantitative study can help to shed light on how to best support bereaved parents of infant loss with grief support and their mental health. Additionally, posttraumatic growth after a loss as significant as one’s infant sets a theoretical basis for this study.

**Perinatal Mood and Anxiety Disorders**

The perinatal period encompasses pregnancy to one year postpartum, during which mental health problems are recognized as a major public health issue (Buist et al., 2005), and are linked to poor outcomes for women, their partners, and their children (Murray et al., 2003). Research shows that if women with perinatal mental health problems can access treatment, then symptoms can be minimized (Armstrong et al., 2002; Kemp et al., 2011; Shaw et al., 2006). There is a myriad of risk factors for a perinatal woman developing a mood or anxiety disorder, including a history of depression, lack of support, and negative childhood experiences (Austin et al., 2005, 2011; Bernazzani et al., 2005; Carroll et al., 2005; Howard et al., 2007).

Sixty to 80% of new mothers experience what has been coined “baby blues,” (PSI, 2019) and this statistic does not include the mothers who do not get to bring their baby home with them. Major Unipolar Depression with peripartum onset is the only diagnosable postpartum mental illness related disorder in the DSM-V, and this diagnosis is the only mention of PMADs in the DSM-V. Persistent Complex Bereavement Disorder (PCBD) was added in the fifth
update of the DSM for the first time, but as a special condition, meaning more research is needed to understand this topic (American Psychiatric Association, 2013; Weir, 2018).

Prolonged grief disorder was added to the DSM-5-Test Revision in 2022, which is “the intense yearning or longing for the deceased (often with intense sorrow and emotional pain) and preoccupation with thoughts or memories of the deceased” (APA, 2022).

For mothers in the perinatal period even without experiencing infant loss, the prevalence for prenatal (i.e., pregnancy) anxiety symptoms are 15.8% (Fairbrother et al., 2016) and postpartum (i.e., after childbirth) anxiety is between 8-20% (Farr et al., 2014). New fathers’ risk of experiencing anxiety disorders is 4.1 to 16% in the prenatal period and 2.4 to 18% in the postnatal (i.e., after childbirth) period (Leach et al., 2016). Perinatal women are also at risk for other mental health diagnoses, with a 1.5-2x greater risk for obsessive-compulsive disorder (OCD) onset than the general population (Uguz et al., 2011). Thirty percent of women have perinatal OCD onset (Forray et al., 2010), meaning they are having diagnosable symptoms of OCD for the first time during their pregnancy and/or postpartum experience.

Perinatal OCD thoughts are intrusive thoughts, images, impulses, or urges that are unwanted, cause the parent distress, and pop into the parent’s mind without their control (Challacombe et al., 2019). There may be tremendous guilt and shame about the thoughts (PSI, 2019), and the thoughts can be repetitive and impair the parent’s functioning (Challacombe et al., 2019). Selective Serotonin Reuptake Inhibitors can help to reduce intrusive thoughts, but providers must inquire about scary or unusual thoughts for the parent to initiate treatment (PSI, 2019). Healthcare providers need to better understand the severity, prevalence, and range of PMAD symptoms to better support these women and their families.
Perinatal psychosis is among the most serious of PMAD symptoms, can be life threatening, and needs to be screened for as early as possible. When the parent has perinatal psychosis, they do not recognize that the intrusive thoughts and images they get are not normal, and they may be experiencing delusional thoughts (PSI, 2019). The parent may seem to have diminished anxiety when having thoughts and behaviors and have no insight that the thoughts are being distorted. Sadly, the mother may think her thoughts to harm the baby are reasonable and she may feel tempted to act on the thoughts (PSI, 2019). Perinatal psychosis effects 1-2 in 1,000 women with five percent committing suicide and 4.5% committing infanticide (Brockington, 2017; Monzon et al., 2014). Fifty percent of mothers who develop psychosis had no previous mental health inpatient admissions (Valdimarsdottir et al., 2009). Perinatal psychosis onset is within two weeks of the birth for 65% of new parents (Monzon et al., 2014). If a parent is not screened and thus not given resources or referred to treatment post a loss, they may not access qualified help for perinatal mood disorder, anxiety disorder, obsessive-compulsive disorder, or psychosis.

**Risk Factors**

The literature identifies risk factors for PMADs during pregnancy, including anxiety, life stressors, history of mental health problems, poor support, unplanned pregnancies, intimate partner violence, and smoking, and risk factors in postpartum including depression or anxiety during pregnancy, stressful life events, traumatic birth, preterm birth or neonatal intensive care stays, poor support, history of mental health problems, and breastfeeding issues (Lancaster et al., 2010; Robertson et al., 2004). Additionally, parents report depressive symptoms and high pregnancy anxiety in subsequent pregnancies after loss, with mothers reporting more mental health symptoms than their partners (Armstrong, 2002). Mothers also report greater
hypervigilance, feeling vulnerable, and fear in subsequent pregnancies that extends to other areas of their lives too, such as fear of losing their marriage, loved ones, or thoughts about their own death (Wright, 2010).

**Perinatal Screening**

Despite PMADs being the third leading cause of maternal death there continues to be a lack of consensus on when and how often to screen parents with living and deceased children for mental health symptoms. Pediatricians, primary care physicians (PCP), and obstetrics gynecologist (ObGyn) agree that postpartum depression screening is important; however, there is a range of different recommendations given to practicing physicians. The American Academy of Pediatrics recommends screening at the 1-, 2-, 4-, and 6-month appointments; the American College of Obstetricians and Gynecologists (ACOG) state providers should screen at the postpartum appointment, and the Annals of Family Medicine recommend primary care physicians screen at the 6- and 12-month postpartum visits (Earls, 2010; ACOG, 2018). Contrary to these recommendations, PSI (2019) recommends screening at the first prenatal visit, at least once in the second trimester, at least once in the third trimester, at the 6-week postpartum OB visit, 6- and 12-month OB and PCP visits, and the 3-, 9-, and 12-month pediatrician appointments. Postpartum Support International (2019) also recommends screening when hormone fluctuations can occur post-nursing, the first menstrual cycle after pregnancy, and when re-starting birth control after pregnancy. Thus, PSI (2019) recommends parents should be screened by all health care providers that see perinatal parents.

Pregnant and postpartum women meet with a variety of healthcare providers during the perinatal time frame, including PCPs, ObGyn, and pediatricians; yet many do not get screened or referred for treatment for PMADs. Mothers with unmet mental health needs impact the whole
family. For example, maternal depression impacts attachment and bonding, as well as the infant’s cognitive, social-emotional development, and behavior (Earls, 2010) for parents with living children. Research indicates that postpartum depression in mothers is linked with higher rates of paternal depression (Goodman, 2004; Ramchandani et al., 2005) and comorbid with marital discord, divorce, domestic violence, substance abuse, and child abuse and neglect (McLennan & Kotelchuck, 2000).

Despite these concerns, less than half of Pediatricians screen for maternal depression according to a 2013 American Academy of Pediatrics Periodic Survey (Kerker et al., 2016), and 68% of mothers who discontinued psychiatric medication during pregnancy had symptoms relapse (Cohen, 2006). Meanwhile, more than 400,000 babies are born to depressed mothers in the U.S. every year, and perinatal depression remains the most underdiagnosed obstetric complication (Earls, 2010). According to Earls (2010), pregnant people experience a variety of common screenings that represent frequent diagnoses in pregnancy, including gestational hypertension (present in 6-8% of pregnancies), pre-eclampsia (present in 6-8% of pregnancies), and gestational diabetes (representing 6% of pregnancies). Among all these diagnoses, perinatal mood, and anxiety disorders (PMADs) are the most common with a prevalence of 21%; however, they are not universally screened for at physician offices (Earls, 2010). Untreated postpartum depression can cause an increase in medical care costs, inappropriate medical care, early discontinuation of breastfeeding, family dysfunction, and adversely affect early infant brain development (Earls, 2010). One in five to seven women experience PMADs with 19.3% of these women experiencing suicidal thoughts (Wisner et al, 2013).

In terms of screening practices, Gavin et al. (2005) completed a systemic review of the research and determined that more research was needed because the best time and location for
screening was not clear due to the small number of available studies. If PMAD onset begins before 6 weeks, then the ObGyn office is the ideal place to screen. However, if the perinatal mental health concern starts after 6 weeks, then family or internal medicine healthcare providers need to screen parents (Gavin et al., 2005), including those who have suffered infant loss.

Overall, researchers support screening for PMADs in doctors’ offices, serving as a helpful reference point indicating the importance and necessity for screening. For example, Viswanathan et al. (2021) conducted a systemic review of 164 studies on perinatal pharmacologic interventions in the United States to weigh the benefits versus harm. The study indicated that untreated mental disorders impact the mother and living child, but more research is still needed on utilizing pharmacological interventions during the perinatal period. Viswanathan et al. (2021) recommended parents make informed decisions about treatment choices with their healthcare providers. Thus, perinatal mental health screening must take place for families to be able to have these important conversations with providers. If symptoms can be treated sooner, then a bereaved parent can be set up for greater success in their grief journey.

Additionally, in 2020, Australian researchers completed a systemic metanalysis on longitudinal data from 2000-2017 on perinatal mental health screening practices (Moss et al., 2020). The study gathered data on whether 7,566 mothers were asked about emotional well-being by a healthcare provider, and concluded that screening is not universally occurring, even if the parent is considered to be in a high-risk category (Moss et al., 2020). If parents in high-risk categories, including those who had reported emotional distress, are not being screened, then this increases the case for all parents to be screened universally so that no mothers fall through the cracks of accessing treatment and suffer more than necessary.
In Kingston et al.’s (2014) survey of 1,207 Canadian women, participants strongly agreed or agreed that mental health screening should occur in the prenatal (63% of participants) and postpartum (73% of participants) period; that their first choice would be seeking help or support from a family doctor; and preferred treatment would be talking to a physician, midwife, or obtaining counseling. Family doctors are often the most trusted by women in terms of discussing their mental health, therefore, it is imperative that family doctors open the door to these conversations through standardized screening procedures. In Honikman et al.’s (2012) case study of a Perinatal Mental Health Project (PMHP) in South Africa, 90% of women were offered mental health screening during antenatal care in a maternity clinic over a three-year period, and 32% of these women qualified for referrals to counseling. The PMHP model shows a best practice approach to the integration of mental health and primary care for perinatal women. One in five to seven women experience a perinatal mood disorder within the first year of giving birth, yet many women are not diagnosed or treated (PSI, 2023; Austin et al., 2008; Dennis & Allen, 2008). Standardized screenings, as well as improved education and advocacy need to occur for families to access better healthcare during the perinatal period.

**COVID-19 Influences**

Even prior to the COVID-19 pandemic, 45% of new Mothers considered their childbirth experience as traumatic (Beck et al., 2018). Additionally, 10-20% of women who knew they were pregnant reported miscarriage or infant loss (Beck et al., 2018; March of Dimes, 2023). There were 80,242 live births in Tennessee in 2019 for women between the ages of 15 to 44 years old (Tennessee Department of Health, 2019). Birth rates were down at the start of the pandemic, but a recent study predicted there would be a COVID surge in birth rates in the summer and fall of 2021 (Mostafavi, 2021). This bump in births did play out, and by the end
of 2021, births were up 6.2%, with the populations with the greatest increase being first time mothers and mothers under the age of 25 years old (Zorthian, 2022).

The COVID-19 pandemic unavoidably influenced women’s healthcare experiences post March 2020. Frederiksen et al.’s (2021) survey indicates that women were more likely to have gone without healthcare or initiated mental health treatment during the pandemic compared to men. Yet, 51% of women and 34% of men reported that the pandemic had negatively impacted their mental health due to worry and stress (Frederiksen et al., 2021). Eight percent of women ages 18-25, 7% of women ages 26-35, and 3% of women 36 - 49 state that they postponed or were not able to access birth control during the COVID-19 pandemic, which could have resulted in sexual health-related infections and unintended pregnancies (Frederickson et al., 2021). With women experiencing inaccessible health care services due to concerns of COVID-19 exposure or risk, health conditions worsening as a result, and barriers to telemedicine (Frederickson et al., 2021), the pandemic has further impacted women’s perinatal healthcare experiences, including feelings and stress related to healthcare appointments and decisions leading up to their miscarriage and infant loss.

The importance of adequate screening, detection, prevention, and treatment of parents’ mental health concerns impacts parenting and the mental, behavioral, and social health of children (National Research Council & Institute of Medicine, 2009) before, during, and after the COVID-19 pandemic. Consistent and successful screening and evaluation continues to be a challenge for healthcare providers which negatively impacts families (National Research Council & Institute of Medicine, 2009). Perinatal mental health screening after a loss is imperative for parents who are at risk for prolonged and significant grief responses.
Grief After Infant Loss

Grief can significantly impact the health of those who have experienced loss. Some people may require acute interventions, advanced cardiac care, or even die themselves (de Groot & Kollen, 2013; Eckerd et al., 2016; Masterson et al., 2015; Prigerson et al., 2009). There are on average 60 million global deaths a year, and for every person who dies, it is approximated that an average of four to 10 people will have severe grief as a result (Parliamentary Committee on Palliative & Compassionate Care, 2011; United Nations, 2013). Yet, parental grief from infant loss is frequently not recognized or attended to by healthcare providers. Mothers and fathers can be left feeling isolated and alone in their time of crisis and after (Londa, 2010). Parents even report experiencing pressure or a feeling of responsibility to comfort others when they find out their baby has died (Wright, 2010).

A qualitative study by Dyson and While (1998) found that perinatal death is considered a significant loss and the impact on women and their families is felt for years, with bereaved women still reporting yearning and sadness 14 years after their loss. Swanson (2000) found perinatal loss impacted women of all ages. Yet, those most at risk for clinical depression after perinatal loss are women who report high personal significance to the miscarriage, poor social support, low emotional strengths, poor coping skills, lower incomes, and women who do not get pregnant or give birth within one year of their loss (Swanson, 2000). Flach et al. (2021) identified complicated grief risk factors for mothers after the loss of a baby, including history with mental illness, history of other pregnancy losses, and social pressure to get pregnant again quickly after the loss. Brier (2004) reviewed the literature and found a significant percentage of women have increased anxiety for six months after a miscarriage, with an elevated risk for
clinically diagnosable symptoms of obsessive-compulsive disorder and posttraumatic stress disorder.

Each year, many families experience complicated grief through infant loss. One million perinatal Americans suffer the loss of an expected child every year (CDC, 2014; Ventura et al., 2009), which may be an underestimation as only clinically diagnosed pregnancies are counted (Wright, 2005). Yet, there is still a lack of consistent terminology, research findings, and evidenced-based health care provided for perinatal parents (Wright, 2011). Many women do not speak or share about their experience of pregnancy loss in their lifetime, and healthcare providers are often not aware of the significant impact on the woman’s mental health after the loss (Wright, 2011). They may experience mental health symptoms for many years (Flach et al., 2021) and not get the support that they need (Dyson & White, 1998). In medical settings, a woman’s reproductive history is often taken, including miscarriages and still births, but her mental health related to these experiences is usually not asked about in these appointments (Wright, 2011).

If mental health assessments are not administered after perinatal loss, then parents cannot be properly supported during this significant time (Wright, 2011). Having positive and sensitive interactions with healthcare providers can help parents cope better with losses (Abbound & Liamputtong, 2005). A recent systemic literature review by Lamon et al. (2022) showed mothers experiencing higher levels of depressive and post-traumatic stress symptoms after perinatal loss compared to their partners. While women will continue to grieve their loss throughout their lives, anniversaries can be particularly hard, including the baby’s due date and Mother’s Day (Wright, 2010). Domogalla et al. (2022) advocate healthcare providers have an ethical obligation to provide bereavement support services for all mothers (regardless of where delivered, including
rural areas) after perinatal and infant loss. Treatment in the early stages after loss may prevent chronic grief conditions (Weir, 2018).

**Posttraumatic Growth**

After a major life event, significant positive psychological change can occur and is referred to as posttraumatic growth (Calhoun & Tedeschi, 2001). This change can occur from trying to make sense of their world after a crisis or significant loss, which can strengthen relationships, enhance spiritual practices, highlight one’s strengths, and understand that events are not always in one’s control (Ryninks et al., 2022). Flach et al. (2021) found in a systematic review that the experience of losing a baby can result in posttraumatic growth. A classic grounded theory qualitative study of 19 women’s experiences after pregnancy loss found women eventually reached a point of transcendence from their suffering into a new, permanent, and changed view of the world, to find meaning from the pain, and to rely on others for support (Wright, 2010). Krosch and Shakespeare-Finch (2017) also studied women’s experiences after perinatal loss and found moderate posttraumatic growth levels.

Ryninks et al.’s (2022) study looked at posttraumatic growth in mothers who had experienced a stillbirth compared to those who experienced an early miscarriage and found that mothers who experienced a stillbirth had significantly more posttraumatic stress symptoms, perinatal grief, willingness to self-disclose, ruminating thoughts (i.e., intrusive, and deliberate), and higher posttraumatic growth levels. There were no significant differences in ethnicity, marital status, education, employment, if currently pregnant, or having had previous pregnancy losses between the mothers; however, they recommend interventions that encourage self-disclosure, and challenge assumptive beliefs and ruminating thoughts (Ryninks et al., 2022). Ryninks et al. (2022) also recommend advocacy for needed societal change regarding shame and
stigma around perinatal losses, and the need to change attitudes and encourage disclosing losses for healing. Protective factors against developing complicated grief after infant loss are having another living child, quality specialized grief healthcare services, and social support from partners, community support, and spiritually (Flach et al., 2021). Unfortunately, specialized perinatal bereavement treatment is not yet an automatic standard of care in hospital or outpatient settings.

**Bereavement Treatment**

Despite hospice bereavement being offered in most hospitals, maternal-fetal medicine bereavement programs are still not universally offered (Cole et al., 2020). Wilson et al. (2021) completed a research review of reports from 2000 – 2018 on bereavement program evaluations that ranged from using self-devised questionnaires (59.1% of the reports), qualitative interviews (36.4%), or grief inventories or depression scales (40.9%). Wilson et al. (2021) found that 77% of the reports that used evaluative data were typically collected once at the end of program completion, and that formal bereavement program evaluations are not consistent or standardized. These reports are “potentially unlikely to provide the type and quality of information needed to retain, improve, expand, or abandon programs” (Wilson et al., 2021, p. 831). Forty-four of the studies had multiple support components to the bereavement programs and 37 offered a single component to the program, including group counseling, individual counseling, education on grief, memorials, or social components that were offered by peers, volunteers, or paid staff for one or more bereaved family members (Wilson et al., 2021).

Of the bereavement programs studied, a few encompassed supports for the loss of a child with three programs specifically focused on infant loss treatment (Wilson et al., 2021). The treatment approach in the programs for child loss varied, including written support to take home
after a child died in the hospital, phone follow up from a peer support person (Aho et al., 2014), memory creation, sympathy cards, mailings, at least one phone call check in, a memorial service, local counseling or group work (deJong-Berg & Kane, 2006), and phone support from hospital-based nurses after child cancer deaths (Darbyshire et al., 2013). Another bereavement program used photography for memory making for parents whose children died in a pediatric ICU (Michelson et al., 2013). While meeting individual bereavement needs is important, the child loss bereavement programs studied did not have a standardized evaluation process in place to compare what was helping and what was not compared to other bereavement programs.

Out of all of the programs in the study that were offering bereavement care, two quantitative studies were conducted to evaluate if the specific bereavement resources being offered were helpful. Raitio et al. (2015) gave 83 mothers a grief intervention (support package, peer support contact, and health-care provider contact) and 53 mothers were in a control group, with a background questionnaire and the Hogan Grief Reactions Checklist given at six-months after losing a child. The intervention resources included grief education information and a phone call one week after the child’s death and one home visit (Raitio et al., 2015). Secondly, an evaluation of a pre-death support program for sixteen parents of currently ill or deceased children that offered peer support and services, a two-day memorial at the hospital, a legacy board that included postings about the children, an education packet, videos, and a holiday condolence card, asked the parents to provide feedback. Parents reported that most of the support program was useful but some of the provided readings were not utilized (Snaman et al., 2017).

The studies that specifically looked at infant loss bereavement programs showed varied treatment approaches. Any education or treatment that was offered was found to be helpful in reducing mental health symptoms compared to control groups (Wilson et al., 2021). First,
Murray et al. (2000) assessed 79 mothers and 65 fathers for mental health symptoms and adjustment after infant death, with an experimental group who received resources and contact with a trained grief worker, and a control group at three points: four to six weeks after the loss, six-months after the loss, and 15-months after loss. Resources and grief support were effective at reducing parents’ distress, especially for those who were identified as high risk for grieving difficulties (Murray et al., 2000). The parents were identified as low- or high-risk for complicated grieving based on factors including, lack of social support, ambivalence with baby, traumatic circumstances of the death, difficult life circumstances, a history of difficulty coping, problematic individual characteristics, and a poor relationship within the nuclear family (Murray et al., 2000). The intervention program tracked total number of contacts and total hours of contacts in the program with low-risk parents getting 3.96 contacts on average ($SD = 3.04$) over 2.78 hours ($SD = 2.52$), and high-risk parents getting 8.19 contacts ($SD = 6.40$) for 7.89 hours ($SD = 7.49$). The BEFSP uses risk level categories (low, moderate, or high) to determine how quickly the team follows up with the parent after the loss, and the need for a therapy referral.

Another program, with similarities to BEFSP, offered resources to all members of the family that were grieving perinatal loss. Roose and Blanford (2011) used a mixed-methods survey to study a hospital-based perinatal loss bereavement program for parents, grandparents, and siblings that evaluated if a mix of inpatient and outpatient services helped whole families grieve. Perinatal bereavement program education and support services were useful for family member’s own grieving, as well as supporting each other’s grieving which confirmed that intergenerational services can be beneficial for supporting parents and their families (Roose & Blanford, 2011). This study supports the idea that offering wrap-around services to the whole
family can benefit grieving parents and should be offered as part of the standard of care in perinatal bereavement programs.

Lastly, Kersting et al.’s (2013) quantitative study used the Brief Symptom Inventory, Inventory of Complicated Grief, and the Impact of Event Scale Revised to evaluate a five-week internet-based bereavement intervention for parents who had suffered pregnancy loss. The parents who participated in treatment showed reduced symptoms of prolonged grief, depression, anxiety, and posttraumatic stress compared to a wait list control group, and the approach was deemed feasible and cost-effective. Researchers suggested the need for further evaluation and routine evaluation of low-threshold internet health interventions. With these evaluations being a decade old, and perinatal bereavement program evaluations still not being universally conducted, the need for education, awareness, and advocacy is clear. Notably, Neimeyer (2010) cautions that some grieving participants can be harmed by bereavement programs, so evaluation of these programs is essential. Valks et al. (2005) recommended that bereavement program evaluations should routinely occur but found only 10% of programs in Australia being evaluated after a survey of 99 programs. Currently, there are no set standard of care or accountability requirements in place for bereavement programs in any country, which makes it difficult to compare programs effectiveness (Wilson et al., 2021).

In other infant bereavement studies, parents have reported being the most dissatisfied with post-perinatal loss interventions when nursing staff were inattentive to needs or not sensitive about their loss (Lasker & Toedter, 1994), and when their feelings were not recognized or validated (Davis et al., 1998). Pregnancy loss grief can be misunderstood by providers, including how impactful the loss is on the parents, as well as not being aware of their own reactions to the death of an infant, which may contribute to unsupportive nursing care (Davis et
Kavanaugh and Moro (2006) recommended nurses be trained in grief theories, taught to avoid jargon, engage in memento making, and follow up with the parent post hospital discharge.

Bereavement programs can be founded by hospital staff that see an unmet need. For example, in 1982 at Massachusetts General Hospital for Children, two nurses started bereavement support resources for parents who lost their infants in the NICU after getting to know these grieving families intimately while caring for their dying babies (Reilly-Smorawski et al., 2002). This 14-year program that lasted until 1996 consisted of sending a sympathy card, a phone follow up call three weeks after the infant’s death, and a 12 week couples support group to process their grief together as a couple, make connections with other grieving parents, and prepare for hard anniversaries that occur in the first year after the loss, including Mothers and Fathers’ Days, and major holidays (Reilly-Smorawski, 2002). The couples typically started the support group about three to five months after their loss, when extended family and friends were less present, and given a safe space to grieve openly with others who understood and were also displaying grief responses (Reilly-Smorawski, 2002).

Parents reported improved functioning as the weeks progressed and improvement was visibility noticeable to hospital personnel as mothers started wearing makeup and making effort regarding their appearance, while fathers participated more and could be heard laughing and making future plans (Reilly-Smorawski, 2002). Parents were given a qualitative evaluation tool at week 11 out of 12 and reported being able to more freely talk to their spouse and loved ones about their grief, ability to get through hard moments easier knowing they would have the group time to process what they needed to, being more understanding of the differences in the way their spouse was grieving compared to their own, and finding comfort in the similarities of the
grieving experiences of the other parents with their own experiences (Reilly-Smorawski et al., 2002).

This program did not continue after the two nurses running the program left the hospital to pursue advanced education on bereavement counseling. Yet, some recommended take-aways include the importance of memory making experiences, training NICU staff on compassionate care practices, visits from the hospital chaplain, telephone follow ups, bereavement support for both parents, and an annual memorial service (Reilly-Smorawski et al., 2002). All of these are incorporated in the Butterfly’s Embrace Family Support Program (BEFSP).

**Butterfly’s Embrace Family Support Program**

As of April 2023, 1,098 mothers have been supported in their grieving and offered bereavement care in the BEFSP program. The program was initially called the Butterfly’s Embrace Bereavement Program when it was founded in 2015. The name has since been changed to the Butterfly’s Embrace Family Support Program (BEFSP) as of 2022 to decrease the stigma around accessing mental health care and to properly identify the wraparound services that are now being offered to the whole family. There are now four BEFSP team members whose positions are dedicated to perinatal bereavement care for parents.

The BEFSP intervenes with parents from the moment the loss is expected to occur, including identification in the emergency room department, in inpatient or hospice admissions, and acceptance of community referrals. Once the hospital knows there is going to be or there has been an infant death, a flag is notated in the electronic medical record and a picture of a butterfly, the program’s logo, is placed on the hospital room door. Hospital staff receive grief training by the BEFSP staff, and every hospital employee that enters the room knows the infant has died in order to provide individualized, trauma-informed compassionate care.
Mothers are assessed for risk factors, at the initial consult and ongoing during the year they are in the program, which are labeled into low, moderate, and high-risk categories. These risk categories have been developed by the BEFSP clinical experience and judgment. Low risk factors are: (a) previous bereavements, including unresolved or complicated relationships, death of a significant person in the last year, and complicated grief with death over the last three years; and (b) social support system and relationships, including social isolation, spiritual/cultural distress, and conflictual relationship issues within family system. Moderate risk factors are: (a) concurrent stressors – work, including unemployed, and at-risk; and (b) concurrent stressors – insufficient resources, including housing, childcare, income, divorce, recent relocation, children in the home, and health concerns post-delivery. High risk factors are: (a) health-mental illness, including depression, anxiety, psychosis, bipolar disorder, and panic attack; (b) health-disability, including developmental, physical, and communication; (c) coping-addiction issues, including drug, alcohol, and sex; (d) coping-suicidal ideation, including considered, self-expressed plan, and prior attempts; (e) coping-heightened emotional states, including anger, guilt, and disorganized; and (f) coping-relationship style, including anxious personality and avoidant personality.

Staff in the BEFSP are trained by the family support team leader that the team may only get a “snapshot” of the mother during the hospital stay and are encouraged to use the full assessment (e.g., initial meeting, history in hospital records, staff interactions, and follow up phone call) with the family to make a determination on risk level and to re-evaluate the risk level during the initial phone call of bereavement care, in case something was missed initially. Examples from the family support team leader on how this determination is made, include: (a) If a mother has a mental health diagnosis and a history of drug use, but has the
resources and ability to seek help, re-start therapy, etc. this will lessen her final risk factor determination; (b) If the mother has no history of mental health issues or drug use, but is “at-risk” due to a limited support system, financial issues, or chronic health issues, these would be reasons her risk level would be higher.

Mothers are screened using the EPDS at one-month post loss. Based on the risk factors assessment and EPDS scores, mothers are offered therapy sessions paid for by BEFSP foundation up to $500. Most therapy providers that the program refers to have agreed to reduce their session fees to $100 or less so mothers are able to get up to five sessions, typically at no cost to the mother. Therapists are told to offer three sessions to the mother initially, but if needed can provide up to five sessions or until the $500 mark is met with the foundation’s money. Therapists provide additional referrals or sessions if needed after the free services, which are then billed to the parent, insurance is billed, or other non-profit services offered.

Conclusion

This study was conducted to understand the gap in the research for how specific risk factors impact perinatal bereaved mothers’ PMAD symptoms and participation in therapy. Bereavement programs, like the BEFSP, if available and accessible, help parents suffering from grief (Shah et al., 2013; Wilson et al., 2018; Wilson & Playfair, 2016). The literature highlights a significant need for standardized routine bereavement programs to support perinatal parents (Cole et al., 2020). Mental health treatment and support can provide benefit and relief for bereaved parents at risk of developing PMADs; however, there is a lack of standardized care, perinatal mental health screening practices, and evaluations of the bereavement programs that do exist, making it impossible to know what aspects of these programs are most useful for parents.
The purpose of this study was to better understand if utilizing individual mental health therapy can provide some relief of PMAD symptoms and posttraumatic growth for these impacted bereaved parents. The research questions were as follows. First, what is the relationship between participant risk level (low or moderate/high) and postpartum mood and anxiety symptoms, as measured by the EPDS, for participants enrolled in a bereavement treatment program for infant loss? Second, what is the relationship between a participant’s risk factors (depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress) and postpartum mood and anxiety symptoms, as measured by the EPDS, for participants enrolled in a bereavement treatment program for infant loss? Third, what is the relationship between a participant’s risk factors (depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress), mother’s age, gestational age, and whether the participant engages in therapy?
CHAPTER THREE: METHODOLOGY

The study evaluated mental health symptom reduction of participants in the BEFSP, a perinatal bereavement program that works with parents in the Southeastern region of the United States. Participation in the program begins the moment hospital staff identifies a loss is expected to occur or has occurred, whether in hospice, the emergency department, inpatient, or from a community provider referral. After identification, the BEFSP is notified, and they initiate contact with the family. Parents are given the EPDS at the one-month mark post infant loss; however, this study focused solely on maternal responses to the assessment. The mother’s risk factors were compared to see if certain risk factors impacted perinatal mental health healing.

Study Design

Overview

This quantitative non-experimental, longitudinal study used archival, de-identified data from a 123-bed community hospital in Jackson, Tennessee. Jackson is a small city with a population of 68,205 (United States Census, 2020) in the Southeast Region of the United States. Jackson-Madison County General Hospital is part of the West Tennessee Healthcare network that serves a large surrounding rural area in West Tennessee. The BEFSP has been serving bereaved parents since 2015 and the EPDS has been routinely and more consistently administered since 2020.

Justification/Rationale for Design

This study used a quantitative, non-experimental design due to the nature of examining a pre-existing dataset collected by the BEFSP team from 2015 to 2023. Descriptive statistics and pre-bereavement risk factors were available for mothers since 2015, and the EPDS scores were consistently collected since 2020 for the inpatient mothers, Emergency department, and
community referral mothers. This study was non-experimental due to it being unethical to have a control group and to withhold treatment from bereaved parents anticipating or having experienced miscarriage or infant loss. Non-experimental designs use retrospective review of medical records without the need to expose the participants to something new or different, as in an intervention that a control group would not have access to in the experiment (Novosel, 2022).

The researcher chose this research design and to use archival data due to the hospital team collecting data since 2015 on their program, but due to not having a researcher on the team, had not closely looked at relationships in the variables or implemented a systematic way to implement improvements and changes. The BEFSP offers perinatal bereavement support and hospice care for these families about an hour from the researcher’s city. The hospitals in the larger city where the researcher lives do not provide perinatal bereavement treatment and grief informed care. The hospital team and the researcher hope to spread to other cities and areas what other hospitals can do to better identify and support infant loss bereaved families. Through this study’s results, there are suggestions for the team to better focus their time and effort on certain participant variables and increased data collection to focus on the participants most in need, additionally, with a better understanding of who is willing or not willing to participate in therapy.

**Goal of the Study**

The goal of this study was to evaluate a perinatal bereavement treatment program to determine what factors influence mental health after infant loss. Specifically, this study examined BEFSP-determined risk levels and pre-bereavement risk factors influence on perinatal bereaved mothers’ PMAD symptoms. It also explored if a mother chooses to engage in therapy services after infant loss. This study was conducted with the hope of spreading awareness, education, and
advocacy for perinatal bereaved parents to be screened for postpartum mental illness symptoms immediately and ongoing after infant loss to better support grieving families.

Participants

Participants included in this study presented to the outpatient surgery center, the hospital emergency room, were admitted to the hospital inpatient floor, participated in the inpatient hospice program, or were referred from the community. Participants included mothers who had suffered infant loss from 2015 until 2023. All participants had experienced a miscarriage or still birth to have taken part in the Butterfly Embrace Perinatal Bereavement/BEFSP and to be a participant in this study.

The BEFSP provided maternal data on a population of 1,098 mothers. However, not all participants participated in all aspects of the program being studied and thus sample sizes will vary depending on who participated in which aspect of the program being studied. The researcher controlled for missing data by using the default option in SPSS to exclude cases listwise if a case was incomplete. The researcher studied participants’ assigned risk levels by the BEFSP team, the risk factors that made up the risk levels, and relationships to EPDS scores at the one-month mark post loss. The researcher also studied if certain risk factors predict if a participant is more likely to engage in therapy post infant loss.

For the first research question, the sample included 198 mothers who participated in the EPDS and had an assigned risk level of low, moderate, or high. For research question two, the sample included 190 mothers who participated in the EPDS administration and had assigned risk factors that were assessed for and provided in the data set to the researcher. For the third research question, the sample included 669 mothers in the data set that had assigned risk factors and information regarding therapy participation, including if the mother had either participated in
therapy or did not participate. Thus, sample data was available for 61% of the total population of 1,098 mothers from the dataset. There were 431 missing cases from the dataset, where therapy information was not available; therefore, the analysis was comprised of 669 participants with available data.

**Setting of the Study**

The participants in this study utilized services in the BEFSP and were patients at the Jackson-Madison County General Hospital or outpatient surgery center in Jackson, Tennessee.

**Sample Selection Procedures**

The Perinatal Bereavement Program started in 2015 with demographics and pre-bereavement risk factors collected and identified for the mothers. Edinburgh Postnatal Depression Scale scores were consistently offered at the one-month mark starting in 2020 for the inpatient, hospice, outpatient surgery center, and emergency room patients.

**Demographic Information**

Demographics included the mother’s age in years, race, ethnicity, gestational age of the pregnancy at the loss, and medical diagnosis (if one was identified) at the time of the loss. Mothers who had a miscarriage or infant loss and participated in the BEFSP from 2015 to 2023 were included in this study. Pregnancy type (e.g., singleton, twins, or triplets), referral type (e.g., inpatient, emergency department, outpatient surgery center, community referral), mother’s age, date of death, gestational age (by weeks), infant age (by weeks), diagnosis (e.g., fetal death, neonatal death, etc.), risk level and risk factors were all provided in the archival data set. Additionally, the researcher coded if the loss was pre or post the pandemic start of March 2020. EPDS overall scores, including the individual test item scores were provided, as well as if the participant engaged in therapy, and if they did, how many sessions were attended.
Mothers’ ages were listed in years. Of the 1,098 total participants, there were 986 participants who had the mother’s age available. There was a mean age of 28, median of 27, and $SD$ of 5.93. The minimum age for the participants was 14, and the oldest mother was 44. The mothers’ ethnicities were self-reported and available from the hospital medical record. Race/ethnicity was coded, African American or Black = one, White = two, Chinese = three, Hispanic or Latino = four, Other = five. There were 369 African American or Black participants (35%), 632 White participants (61%), one Chinese participant (0.1%), 28 Hispanic or Latino participants (3%), and 11 Other Race/ethnicity (1%).

Medical information that was provided included the date of death (DOD), gestational age which was how far along in the pregnancy the mother was at the time of the infant’s death, and the neonatal death or infant age which was how old the infant was at the time of death. Neonatal deaths occurred after a live birth. DX stands for diagnosis and categorizes infant death types. The majority of infants were labeled in the medical chart as fetal death (i.e., during pregnancy) or neonatal death (i.e., after a live birth). Diagnosis codes included: one = Miscarriage, two = Fetal death, three = Neonatal, four = SIDS, five = Fetal death/hospice, six = Other. There were 53 miscarriages (5%), 875 fetal deaths (81%), 114 neonatal deaths (10%), 18 SIDS deaths (2%), 21 hospice deaths (2%), and three listed as other.

For the gestational age at death or infant death in weeks, the time was rounded up if it was more than four days, so for example one-week, four days was rounded up to two weeks. If the time was three-days or less than it was rounded down, so for example two-weeks, three-days was recorded as two-weeks. The researcher deleted one outlier participant from December 2021 with a date of death as 14 years ago, because there was no other information on the participant or infant. There were 951 available gestational (i.e., pregnancy-related deaths) ages, provided by
weeks, and 49 infant (i.e., after a live birth but later died) ages (by weeks). The average gestational age in weeks was 19, median was 18, with a SD of 10.05. The maximum gestational age was 42 weeks. The mean infant age at death in weeks was 15, with a median of 8, and SD of 26.56. The minimum age in weeks was 1 week post birth, and the maximum age that was included in the study was 156 weeks.

The type of pregnancy was also provided, with one being a singleton pregnancy loss, two was a twin loss, and three indicated a triplet loss. There were 1,073 singleton losses (98% of the infant losses), 21 twin losses, and four triplet losses, for a total of 1,098 total infant losses. Inpatient referrals to the BEFSP, including hospice inpatient patients, were coded as one, emergency department patients (i.e., participants not admitted to the hospital but came through the emergency room) were coded as two, outpatient surgery center patients were coded as three, and community referrals were coded as four. There were 709 inpatient participants (69%), 211 emergency department participants (21%), 103 outpatient surgery center participants (10%), and two community referral participants in the BEFSP program. All participants who had a miscarriage or infant loss, regardless of referral type were included, due to the nature of the significance of the loss and the variables being studied.

Risk levels were listed into low, moderate, and high-risk categories, with low coded as a one, moderate as a two, and high as a three. Moderate and high were later combined due to low participant numbers in the high category. Of the participants, 669 (77%) were categorized by the BEFSP team as low risk, 176 (21%) were listed as moderate risk, and 21 (12%) were listed as high risk for developing mental illness symptoms post infant loss. Once moderate and high were combined there were 197 in the moderate/high category (33%).
The categories for the pre-bereavement risk factors were depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress. Risk factors that are considered high risk are depression, anxiety, panic, disability, addiction, anger, and guilt. Marking the patient as high risk means follow up within 72 hours of discharge and continued follow up weekly until risk decreases. The risk factors that are considered moderate risk are complicated grief and spiritual distress. Moderate risk flags the BEFSP team to follow up within two weeks of discharge.

The EPDS score was the total participant’s score on the EPDS administration taken one month after the infant’s death. The EPDS directions ask the participant to indicate how she has been feeling in the past 7 days (Cox et al., 1987). Questions one – 10 responses, scored on a zero - three scale for the EPDS administration were also listed. The total possible score is 30, with a participant score of 10 or higher indicating possible depression, and above 13 possibly indicating varying severity of a depressive illness, according to the scoring chart for the EPDS (Cox et al., 1987). See Appendix F for scoring directions for the EPDS.

For the EPDS scores there were 199 (18%) participants’ scores available that agreed to participate in the EPDS at the one-month mark post loss. The mean score was 14.64 out of 30, median was 14.00, and the SD was 6.14. The maximum score was 28 out of 30, and the minimum score was 0. Of the 199 participants, 159 scored a 10 or higher (80% of participants), and 107 scored a 14 or higher (54%) indicating the participants had depressive symptoms severe enough to being clinically diagnosed with depression at one month post loss. The most common response total by 19 participants was 18 out of 30, and the second most common by 17 participants was 11 out of 30 points on the EPDS administration. One hundred and seven of these mothers participated in therapy.
Therapy was listed as a zero = no therapy, one = yes, the patient had therapy, if the patient was referred to therapy and utilized it, then the number of sessions is recorded. Approximately 15% or 168 mothers participated in therapy from the total sample. However, the number of sessions that were participated in was not available for every participant. There were 406 therapy sessions provided to participants that were available to the researcher, with a mean of 3.20, median of 3 sessions, and a $SD$ of 1.20. Therapy sessions were listed if the participant was referred, attended, and then the therapist billed the BEFSP for the sessions and that information was recorded in the BEFSP case file. The available minimum number of therapy sessions participated in was 1, and the maximum was 6.

The dataset used for this study included a total of $N = 1,098$ participants; however, data was not available for all variables. For example, only 986 of the mothers included in the study provided their age. Descriptive statistics for all available data for the primary variables of interest are provided in Table 1.

**Table 1**

*Descriptive Statistics for Full Sample*

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Mean</th>
<th>Median</th>
<th>SD</th>
<th>Min.</th>
<th>Max.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother's Age</td>
<td>986</td>
<td>27.83</td>
<td>27.00</td>
<td>5.93</td>
<td>14</td>
<td>44</td>
</tr>
<tr>
<td>G Age (weeks)</td>
<td>951</td>
<td>19.05</td>
<td>18.00</td>
<td>10.05</td>
<td>0</td>
<td>42</td>
</tr>
<tr>
<td>Infant age at death (weeks)</td>
<td>49</td>
<td>14.71</td>
<td>8.00</td>
<td>26.56</td>
<td>1</td>
<td>156</td>
</tr>
<tr>
<td>Infant age at death gestation</td>
<td>49</td>
<td>54.71</td>
<td>48.00</td>
<td>26.56</td>
<td>41</td>
<td>196</td>
</tr>
<tr>
<td>EPDS score</td>
<td>199</td>
<td>14.64</td>
<td>14.00</td>
<td>6.14</td>
<td>0</td>
<td>28</td>
</tr>
<tr>
<td>Number of therapy sessions</td>
<td>406</td>
<td>3.20</td>
<td>3.00</td>
<td>1.20</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>

Frequencies for each risk factor, as reported by the participants, are presented in Table 2. For these factors, most participants reported more than one risk factor.
Table 2

Risk Factor Statistics for Full Sample

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>191</td>
<td>667</td>
</tr>
<tr>
<td>Anxiety</td>
<td>278</td>
<td>580</td>
</tr>
<tr>
<td>Panic</td>
<td>31</td>
<td>827</td>
</tr>
<tr>
<td>Disability</td>
<td>30</td>
<td>828</td>
</tr>
<tr>
<td>Addiction</td>
<td>66</td>
<td>792</td>
</tr>
<tr>
<td>Anger</td>
<td>119</td>
<td>714</td>
</tr>
<tr>
<td>Guilt</td>
<td>371</td>
<td>487</td>
</tr>
<tr>
<td>Stressors</td>
<td>508</td>
<td>349</td>
</tr>
<tr>
<td>Complicated Grief</td>
<td>332</td>
<td>526</td>
</tr>
<tr>
<td>Spiritual Distress</td>
<td>89</td>
<td>769</td>
</tr>
</tbody>
</table>

Inclusion/Exclusion

Over 1,000 mothers had taken part in the bereavement program from 2015 – 2023. All 1,098 mothers who had taken part in the BEFSP were included in the study (see Figure 1 for flowchart of BEFSP services for total population), including hospital inpatient, hospice, emergency department, outpatient surgery center, and community referrals. All mothers experienced a miscarriage or infant loss and had been offered support services. The variables studied in this research included the assessment of risk level, risk factors, therapy sessions, and EPDS scores. Although bereavement supports services for fathers began in 2022, fathers were excluded from the study because there was not enough data collected yet that was available for the hospital to share at the time of this study.

This study worked with secondary data only and incomplete cases were anticipated. Not all of the 1,098 mothers took part in the full resources and protocols in the treatment program. There was missing data when participants did not utilize all of the available services. Sample sizes for the three research questions differed due to missing data for this reason. The researcher used IBM SPSS Statistics (version 28.0.1.1) to run the analyses which controlled for missing
data, and ran analyses only on complete cases, and ignored any missing data. The default option for missing values was used in SPSS, so that incomplete cases were excluded listwise.

**Figure 1**

*Flowchart: Services for BEFSP Participants*

**Instruments and Measures**

**Theoretical Basis for the Selection of the Instrument**

The bereavement family support program team administered a risk assessment at the one-month mark to identify risk factors for PMADs for all consenting participants. Inpatient
participants were additionally screened for PMADS, including depressive, anxious, and suicidal thoughts, three times while in the program, including at one-month, six-months, and close to the one-year anniversary of the loss. The EPDS was attempted at these three intervals with inpatient mothers who experienced a loss since 2020 and who gave consent to participate in treatment. The EPDS was used to identify postpartum mental health symptoms for mothers who could benefit from therapy and extra support.

**Risk Factors**

An assessment was conducted at the time of the infant loss and again at the one-month mark post loss to assess for pre-bereavement risk factors and used to determine if the patient was referred to therapy sessions that were paid for by the Foundation up to $500. If certain risk factors were determined, then the mothers were offered therapy sessions with no charge for the patient. The mothers were given referrals to in-person or virtual therapy sessions to therapists in the community and private practice settings. The hospital contracted with therapists in the community to provide this service for the program patients.

The following risk factors were identified as important by the BEFSP. Risk factors were divided into three categories: low, moderate, or high. Low risk factors were: (a) previous bereavements, including unresolved or complicated relationships, death of a significant person in the last year, and complicated grief with death over the last three years; and (b) social support system and relationships, including social isolation, spiritual/cultural distress, and conflictual relationship issues within family system. Moderate risk factors were: (a) concurrent stressors – work, including unemployed, and at-risk; and (b) concurrent stressors – insufficient resources, including housing, childcare, income, divorce, recent relocation, children in the home, and health concerns post-delivery. High risk factors were: (a) health-mental illness, including depression,
anxiety, psychosis, bipolar disorder, and panic attack; (b) health-disability, including developmental, physical, and communication; (c) coping-addiction issues, including drug, alcohol, and sex; (d) coping-suicidal ideation, including considered, self-expressed plan, and prior attempts; (e) coping-heightened emotional states, including anger, guilt, and disorganized; and (f) coping-relationship style, including anxious personality and avoidant personality.

If moderate or high-risk factors were identified, therapy referrals were given. Risk assessments incorporated a holistic point of view that included physical, mental, social, emotional, and spiritual aspects of the mother’s life. The family support team leader described the program’s approach as being all-inclusive and individualized for the patients. Risk assessments were done while the parents were at the hospital and during the initial phone calls of the bereavement care. The BEFSP staff used the back of the initial contact record to label the risk factors divided into severity level and color coded. High-risk required immediate follow up with the mother and family within 72 hours of discharge from the hospital (ER, hospice, or inpatient). The family support team leader shared that there is typically a mental health diagnosis or previous trauma from recurrent losses, or the mother may have a drug history. With a high-risk determination, the staff have been trained that the expectation was an immediate referral for therapy, and crisis intervention or an appointment was scheduled with the mother’s ObGyn to discuss medications for anxiety, depression, or other mental illness symptoms.

The designation of moderate risk required follow up within two weeks of discharge from the hospital. The trained hospital bereavement team was encouraged that this level was indicated using “the gut-feeling” too. If the team members were unable to spend a lot of time at the bedside with the mother or if a mother was quiet, reserved, or did not open up but a team member felt like something was off, then the mother was marked as moderate risk until a more
definitive assessment was achieved. An indication of moderate risk ensured timely and appropriate follow-up was provided. If a mother was low risk the BEFSP followed the set standard of care timeline for follow up care.

**Edinburgh Postnatal Depression Scale**

The EPDS was given at one-month post infant loss as an initial screening. Recently, the BFEPS program instituted a six-month and one-year EPDS administration; however, due to small sample sizes, only the one-month EPDS was included in the present study. The EPDS (Cox et al., 1987) has 10 questions with a scale of one to three, with a maximum score of 30 (see Appendix F). Parents who reported above a 10 are likely to be suffering from a depressive illness of varying severity and number 10 on the scale assesses for suicidal ideation.

The Edinburgh Postnatal Depression Scale is used for measuring the construct of Perinatal Depression and was used by the BEFSP. There are 10 items on the EPDS focused on the psychological symptoms of depression with each scored on a four-point rating scale from zero to three points for each of the items. The EPDS is the most commonly used screening assessment for perinatal depression (Srisurapanont et al., 2023), with a sensitivity range of 0.60 (specificity 0.97) to 0.96 (specificity 0.45) for major depression, and 0.31 (specificity 0.99) to 0.91 (specificity 0.67) for major or minor depression (Hewitt et al., 2009).

Boyce et al. (1993) studied the EPDS validation for an Australian sample of 103 postpartum women with infants younger than six-months who were interviewed using the Diagnostic Interview Schedule and completed the Edinburgh Postnatal Depression Scale (EPDS). The study showed good validity for the EPDS regarding sensitivity, specificity, and positive predictive values for identifying major depression. Spearman correlations were used to study concurrent validity and the EPDS, the General Health Questionnaire (GHQ), and the Pitt
scale were highly correlated. The study concluded that EPDS is considered to be a useful measure for predicting postpartum depression.

Srisurapanont et al. (2023) studied the EPDS’s convergent validity compared to the Patient Health Questionnaire (PHQ-9) in perinatal women based on functioning level or disability and construct correlations using the World Health Organization (WHO) Disability Assessment Schedule as the reference standard. Functional disability versus non-disability refers to whether perinatal individuals are experiencing significant trouble in being able to complete their daily activities or are able to function normally for themselves, regarding: (a) understanding and communication, (b) self-care, (c) mobility, (d) interpersonal relationships, (e) work and household roles, and (f) community and civic roles or participation (Ustun et al., 2010). Understanding a parent’s functioning level during the Perinatal period helps to determine if the individual meets criteria for a diagnosable mental disorder (Ustun & Kennedy, 2009; Vazquez-Barquero, 2009), and thus should be referred for treatment. Studying the EPDS’s convergent validity evaluates the accuracy of the EPDS as a screening tool for diagnosis by studying the correlation between scores on the EPDS and the PHQ-9 that measures the same construct, depression (Abma et al., 2016).

The EPDS was found to have good internal consistency reliability for pregnant participants with a Cronbach’s alpha of 0.80 compared to 0.83 for the PHQ-9; and the EPDS and PHQ-9 were found to be significantly correlated with a $r_s$ of 0.73 (Srisurapanont et al., 2023). For the postpartum participants, the EPDS was found to have good internal consistency with a Cronbach’s alpha of 0.82, compared to the PHQ-9 of 0.85; and the EPDS and PHQ-9 were found to be significantly and moderately correlated with a $r_s$ of 0.66. Both scales showed good correlations with disability and moderate accuracy at differentiating between functional disability
and non-disability, which supports the scales’ ability to diagnose perinatal depression for participants with high scores on either questionnaire (Srisurapanont et al., 2023).

**Procedures**

The hospital Institutional Review Board (IRB) and the University of Memphis IRB process were both approved prior to accessing the deidentified, archival data from the BEFSP’s bereavement files. The hospital provided a letter waiving the need for an IRB due to the data being a deidentified, archival dataset. The University of Memphis expedited IRB was also approved and waived.

Due to the nature of the data being mental health related, not all of the variables being studied were a part of the hospital’s electronic medical record. The patients in the BEFSP had a bereavement medical record number assigned to them and a separate spreadsheet that was kept for organization of nonmedical variables. The spreadsheet serves as the program electronic file and includes scanned copies of the patients’ assessments and progress notes. A paper file is kept with other important patient information, including financial support families have received from the Foundation for funeral costs and therapy sessions. For the purposes of this study, the Family Support Team Lead/Certified Bereavement Counselor, uploaded the de-identified paper files and assessment information into the bereavement program spreadsheet in order to deidentify the variables and shared with the researcher. Due to the nature of secondary data, not all of the 1,098 cases were complete. IBM SPSS Statistics (version 28.0.1.1) only runs analyses on complete cases and ignores missing data. The researcher used the default option in SPSS for missing cases and incomplete cases were excluded listwise.
**Data Collection**

Deidentified, archival data was retrieved from a regional hospital in the southeastern region of the US. Data was retrieved from the BEFSP’s spreadsheet database. Patients were given an identification number that was used for data sharing and all Health Insurance Portability and Accountability Act compliant identifiable information on patients was not shared. The deidentified data was given to the researcher for data analysis after the hospital IRB process was approved and the University of Memphis IRB process had been waived.

**Data Analysis**

*Power Analysis*

The researcher ran an a priori G*Power statistical analysis (Faul et al., 2009) for a multiple linear regression to determine the needed sample size with five predictors and a medium effect size (0.15), power of .80, and alpha of .05. The recommendation was that at least 92 participants were required for the individual analyses, which was met for all three samples in this study.

*Data Analysis Plan*

The hospital and the University of Memphis IRB approved the study and waived the need for an IRB review. After the University of Memphis IRB was approved, the data was requested and shared with the researcher. The purpose of the study and research questions were verified with the existing available data, then regression analyses ran to look at relationships in risk level, risk factors, therapy participation, and PMAD symptoms measured by the EPDS one month post infant loss.
**Research Question #1**

Due to the nature of the variables, a linear regression was run in SPSS for research question #1 to see if the categorical variable, risk level (low versus moderate/high) predicted the variability in EPDS scores at the one-month mark post loss. Participants are labeled as being low, moderate, or high risk for acute mental illness or grief symptoms and the level determines how quickly the BEFSP team follows up with the participant and what type of care the participant is referred to for support (i.e. therapy, medication evaluation, timely follow up phone check-ins). The moderate and high-risk levels were combined for the regression after descriptive statistics were run and showed low participant numbers in the high-risk category.

The descriptive statistics included the mean, standard deviation, divided out by each group, and for the total sample. The assumptions that were tested were Linearity, homoscedasticity, normality of residuals, and independence. Scatterplot graphs were used to check the assumption of linearity, by choosing Graph and Chart Builder. The categorical variables were dummy coded. The relationship was evaluated as follows:

\[ \text{EPDS} = \alpha + \beta_1 \text{RiskLevel} \]

In equation 1, \( \alpha \) was the constant, \( \beta_1 \) was the effect of risk level on EPDS scores. Expanding on this analysis, research question #2 broke down the risk components further and studied the risk factors that make up the risk levels.

**Research Question #2**

For research question #2 a second linear regression was run for risk factors (depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress) on EPDS scores, at the one-month mark post loss. The descriptive statistics included the mean and standard deviations, divided out by each group, and by the total sample. The
assumptions that were tested were Linearity, homoscedasticity, normality of residuals, and independence. Scatterplot graphs were used to check the assumption of linearity, by choosing Graph and Chart Builder. The categorical variables were dummy coded. The relationship was evaluated as follows:

$$\text{EPDS} = \alpha + \beta_1 \text{Depression} + \beta_2 \text{Anxiety} + \beta_3 \text{Panic} + \beta_4 \text{Disability} + \beta_5 \text{Addiction}$$

$$+ \beta_6 \text{Anger} + \beta_7 \text{Guilt} + \beta_8 \text{Stressors} + \beta_9 \text{Complicated Grief}$$

$$+ \beta_{10} \text{Spiritual Distress}$$

In equation 2, \( \alpha \) was the constant, \( \beta_1 \) was the effect of Depression on EPDS scores, \( \beta_2 \) was the effect of Anxiety on EPDS scores, \( \beta_3 \) was the effect of Panic on EPDS scores, \( \beta_4 \) was the effect of Disability on EPDS scores, \( \beta_5 \) was the effect of Addiction on EPDS scores, \( \beta_6 \) was the effect of Anger on EPDS scores, \( \beta_7 \) was the effect of Guilt on EPDS scores, \( \beta_8 \) was the effect of Stressors on EPDS scores, \( \beta_9 \) was the effect of Complicated Grief on EPDS scores, and \( \beta_{10} \) was the effect of Spiritual Distress on EPDS scores.

**Research Question #3**

The researcher ran a logistic regression to see if risk factors (depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress) had a relationship with therapy (whether someone participated in therapy). Additionally, the researcher wanted to know if specific risk factors predicted whether a participant engaged in therapy. The descriptive statistics included the mean and standard deviations, divided out by each group, and by the total sample. The assumptions that were tested were Linearity, homoscedasticity, normality of residuals, and independence. Scatterplot graphs were used to check the assumption of linearity, by utilizing Graph and Chart Builder. The categorical variables were dummy coded.
The relationships were evaluated as follows:

\[ \text{Therapy} = \alpha + \beta_1 \text{RiskFactors} + \beta_2 \text{MothersAge} + \beta_3 \text{GestationalAge} \]

In equation 3, \( \alpha \) was the constant, \( \beta_1 \) was the effect of a vector of risk factors on therapy participation, \( \beta_2 \) was the effect of mother’s age on therapy participation, and \( \beta_3 \) was the effect of gestational age on therapy participation.
CHAPTER FOUR: RESULTS

This research study used secondary data and not all cases were complete within the dataset, because not all items were collected on all participants. The program was voluntary, and consent was obtained at each step for inclusion in the mental health screening and support measures. The researcher ran descriptives for the total sample size and then had three smaller sample sizes for each research question. For this reason, there is variance in the sample sizes that were analyzed, depending on the research question. Not all participants provided data for all items that were analyzed, so the default option for linear regression in SPSS (exclude cases listwise) was used so that only complete cases were included in each analysis.

Research Question 1

The first research question was, what is the relationship between participant risk level (low or moderate/high) and postpartum mood and anxiety symptoms, as measured by the EPDS, for participants enrolled in a bereavement treatment program for infant loss? Although \( N = 1,098 \) participants who were included in the full dataset for this study (had experienced a miscarriage or infant loss and participated in the BEFSP), for research question #1, \( N = 198 \) participants who completed the EPDS and had a risk level identified for them (See Table 3 and Figure 2).

Table 3

Descriptive Statistics for Research Question 1

<table>
<thead>
<tr>
<th></th>
<th>( N )</th>
<th>( Mean )</th>
<th>( SD )</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPDS score</td>
<td>198</td>
<td>14.63</td>
<td>6.15</td>
</tr>
<tr>
<td>Risk Level (Low)</td>
<td>136</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk Level (Moderate)</td>
<td>51</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk Level (High)</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk Level (Moderate/High)</td>
<td>62</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Summary of First Linear Regression Analysis**

A linear regression analysis was conducted using IBM SPSS Statistics (version 28.0.1.1) to determine if risk level (low versus moderate/high) was predictive of EPDS scores. The primary assumptions were assessed for the first linear regression model, which determined if a prediction was valid and the amount of variance in EPDS scores that were explained by risk level (Laerd Statistics, 2015). There was a significant linear relationship between risk level and EPDS scores.
scores, \( r(196) = .37, p < .001 \). See Figure 3 for a scatterplot of the relationship between risk level and EPDS score.

![Scatterplot: Risk Level as a Predictor for Research Question One](image)

**Figure 3**

*Scatterplot: Risk Level as a Predictor for Research Question One*

The value of the Durbin-Watson statistic = 2.002, which demonstrated that the adjacent residuals in the regression model were not correlated (Laerd Statistics, 2015). The Durbin-Watson statistic being close to 2 is preferable, with results less than 1 or larger than 3 being a potential cause for concern because it may indicate autocorrelation of the residuals, thus invalidating standard errors and/or tests for significance (Field, 2018). There were no significant outliers (Field, 2018; Laerd Statistics, 2015). No cases had a standardized residual greater than \( \pm 3 \) standard deviations, therefore there was no need to remove any cases from the analysis.

Homoscedasticity was also tested and indicated that error variance remained constant across both values of the risk level (Field, 2018; Laerd Statistics, 2015). SPSS was used to plot the standardized residual values against the standardized predicted values. Based on a visual inspection of the scatterplot, the residuals appeared to be fairly evenly spread (see Figure 4). This
scatterplot indicated that the residuals variance was homoscedastic. Thus, the ordinary least squares method for the regression analysis was viable, and the homoscedasticity assumption passed (Field, 2018; Laerd Statistics, 2015). Figure 5 shows a histogram of the standardized residuals that were approximately normally distributed, and that the normality of the standardized residuals and the assumptions were met (Field, 2018; Laerd Statistics, 2015).

**Figure 4**

*Normal P-P Plot: Standardized Residuals for Research Question One*

**Figure 5**

*Histogram: Standardized Residuals for Research Question One*
The participants’ EPDS total scores were out of a maximum possible score of 30. The null hypothesis was rejected. The regression model explained approximately 13.0% of the variance in EPDS scores and was statistically significant, $F(1, 196) = 30.56, p < .001, R^2 = .14, R^2\text{ adjusted} = .13$. Risk level was a statistically significant predictor of EPDS scores, $\beta = 4.86, t(197) = 5.53, p < .001$ with a medium effect size ($f^2 = 0.16$), based on Cohen’s (1988) criteria.

**Research Question 2**

The second research question was, what is the relationship between a participant’s risk factors (e.g., depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress) and postpartum mood and anxiety symptoms, as measured by the EPDS, for participants enrolled in a bereavement treatment program for infant loss? This analysis expands on research question #1, as the risk factors inform the identified risk level. Although $N = 1,098$ participants who had experienced a miscarriage or infant loss and participated in the BEFSP were included in the full dataset for this study, the number of cases for this analysis was $n = 190$ participants who had an EPDS score, and risk factors identified (See Figure 6). The researcher used the default option for missing values in SPSS with incomplete cases excluded listwise and only complete cases included.
Figure 6
Flow Chart: Research Question Two Participants

Summary of Second Linear Regression Analysis

A linear regression analysis was conducted using IBM SPSS Statistics (version 28.0.1.1) to determine if specific risk factors, including depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress are predictive of EPDS scores. The primary assumptions were assessed for the second linear regression model, which determined if a prediction was valid and the amount of variance in EPDS scores explained by risk factors, depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress (Laerd Statistics, 2015). In the presence of the other risk factors there was a significant predictive relationship for three of the risk factors, depression, anger, and guilt.
and EPDS scores; depression = \( r(179) = .22, p = .007 \), anger = \( r(179) = .19, p = .011 \), and guilt = \( r(179) = .22, p = .009 \) (see Table 4).

The value of the Durbin-Watson statistic = 2.10, which demonstrated that the adjacent residuals in the regression model were not correlated (Laerd Statistics, 2015). The Durbin-Watson statistic being close to 2 is preferable, with results less than 1 or larger than 3 being a potential cause for concern because it may indicate autocorrelation of the residuals, thus invalidating standard errors and/or tests for significance (Field, 2018). There were no highly significant outliers (Field, 2018; Laerd Statistics, 2015). No cases had a standardized residual greater than ±3 standard deviations, therefore there was no need to remove any cases from the analysis.

Homoscedasticity was assessed using SPSS to plot the standardized residual values against the standardized predicted values (Field, 2018; Laerd Statistics, 2015). Some error variance was observed based on a visual inspection of the scatterplot. The residuals appeared to have a slight fan (Figure 7), which indicated that the residuals variance may not be homoscedastic.

![Scatterplot: Standardized Residuals for Research Question Two](image)

**Figure 7**

*Scatterplot: Standardized Residuals for Research Question Two*
Thus, the ordinary least squares method for the regression analysis may not be viable (Field, 1018; Laerd Statistics, 2015). The researcher ran a weighted linear regression next to compare results. See Figure 8 for a histogram of the standardized residuals that were approximately normally distributed, and normality of the standardized residuals and the assumptions were met (Field, 2018; Laerd Statistics, 2015).

![Histogram: Standardized Residuals for Research Question Two](image)

**Figure 8**

*Histogram: Standardized Residuals for Research Question Two*

The null hypothesis was rejected. The regression model explained approximately 19.0% of the variance in the EPDS scores and was statistically significant, $F_{(10,179)} = 5.43$, $p < .001$, $R^2 = .23$, $R^2$ adjusted = .19, and the effect size ($t^2 = 0.30$) was large. In the presence of the other risk factors, depression, anger, and guilt were statistically significant predictors of EPDS scores. A large effect size is an important indicator. Even though 70% of the variability is not explained, 30% is significant in terms of being able to explain human behavior. Co-efficient values for each predictor variable are presented in Table 4, and a plot of the standardized residuals shown in Figure 9.
Table 4

Coefficients for Research Question Two

<table>
<thead>
<tr>
<th>Model</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
</tr>
<tr>
<td>1</td>
<td>(Constant)</td>
<td>12.29</td>
<td>.83</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>2.81</td>
<td>1.04</td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
<td>6.70</td>
<td>1.09</td>
</tr>
<tr>
<td></td>
<td>Panic</td>
<td>1.41</td>
<td>1.83</td>
</tr>
<tr>
<td></td>
<td>Disability</td>
<td>-1.19</td>
<td>2.05</td>
</tr>
<tr>
<td></td>
<td>Addiction</td>
<td>3.55</td>
<td>2.71</td>
</tr>
<tr>
<td></td>
<td>Anger</td>
<td>3.30</td>
<td>1.28</td>
</tr>
<tr>
<td></td>
<td>Guilt</td>
<td>2.81</td>
<td>1.06</td>
</tr>
<tr>
<td></td>
<td>Stressors</td>
<td>-1.64</td>
<td>1.17</td>
</tr>
<tr>
<td></td>
<td>Complicated Grief</td>
<td>-0.46</td>
<td>1.04</td>
</tr>
<tr>
<td></td>
<td>Spiritual Distress</td>
<td>2.14</td>
<td>1.59</td>
</tr>
</tbody>
</table>

Note. ** <.001; *<.05
a. Dependent Variable: EPDS Score

Figure 9

Normal P-P Plot: Standardized Residuals for Research Question Two
Weighted Linear Regression Analysis

After a visual inspection of the residual scatterplot for research question two revealed some evidence of fanning of the residuals, and slight heteroscedasticity, the regression was rerun using a WLS weighted variable. This procedure was added to determine if rerunning the regression with the weighted variable would correct the violation of homoscedasticity, since this is a primary assumption for regression. If residuals do not evenly spread out and are different in peak, then results do not have homoscedasticity (Laerd, 2015). A comparison of the results from both analyses for RQ #2 indicated that the results were equivalent, meaning the initial results were not biased and can be trusted. The results were stable across both linear regression analyses. Homoscedasticity did not change the results, however, the weighted linear regression explained slightly more of the variability, approximately 23.1% of the variance in EPDS scores, up from 19.0%. Co-efficient values for each predictor variable for the weighted linear regression are presented in Table 5.
Table 5

Coefficients for Research Question Two - Weighted

<table>
<thead>
<tr>
<th>Model</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
</tr>
<tr>
<td>1</td>
<td>(Constant)</td>
<td>12.24</td>
<td>.86</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>2.80</td>
<td>.99</td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
<td>.60</td>
<td>1.08</td>
</tr>
<tr>
<td></td>
<td>Panic</td>
<td>1.73</td>
<td>1.55</td>
</tr>
<tr>
<td></td>
<td>Disability</td>
<td>-.95</td>
<td>2.02</td>
</tr>
<tr>
<td></td>
<td>Addiction</td>
<td>3.46</td>
<td>2.07</td>
</tr>
<tr>
<td></td>
<td>Anger</td>
<td>3.16</td>
<td>1.13</td>
</tr>
<tr>
<td></td>
<td>Guilt</td>
<td>2.70</td>
<td>1.05</td>
</tr>
<tr>
<td></td>
<td>Stressors</td>
<td>-1.39</td>
<td>1.18</td>
</tr>
<tr>
<td></td>
<td>Complicated Grief</td>
<td>-1.46</td>
<td>1.02</td>
</tr>
<tr>
<td></td>
<td>Spiritual Distress</td>
<td>1.80</td>
<td>1.39</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14.24</td>
<td>1.11</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.83</td>
<td>.08*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1.67</td>
<td>.12**</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.58</td>
<td>.21*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.79</td>
<td>.20**</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1.54</td>
<td>-.10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1.18</td>
<td>-.18</td>
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<tr>
<td></td>
<td></td>
<td>2.58</td>
<td>-.04</td>
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<td></td>
<td></td>
<td>2.79</td>
<td>-1.18</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1.54</td>
<td>-1.40</td>
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<td></td>
<td></td>
<td>2.58</td>
<td>-1.40</td>
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<td></td>
<td></td>
<td>2.79</td>
<td>1.29</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.58</td>
<td>3.65</td>
</tr>
</tbody>
</table>

Note. ** <.001; * < .05

a. Dependent Variable: EPDS Score
b. Weighted Least Squares Regression – Weighted by Weight

Research Question 3

The third research question was, what is the relationship between a participant’s risk factors (depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress), mother’s age, gestational age, and whether the participant engages in therapy?

Summary of Binary Logistic Regression

Although $N = 1,098$ participants who were included in the full dataset for this study, only 669 were included in this analysis that had both risk factors and if the participant engaged in therapy (yes or no). Mother’s age and gestational age were added to this analysis. The frequencies of the participants’ risk factors included: 51 had addiction, 97 had anger, 235 had anxiety, 270 had complicated grief, 162 had depression, 24 had a disability, 306 experienced guilt, 22 experienced panic, 74 had spiritual distress, and 430 had other stressors. Overall, 150
participants (22%) engaged in therapy, and 519 (78%) did not participate post infant loss (See Figure 10 for flowchart of participants).

**Figure 10**

*Flow Chart: Research Question Three*

The researcher ran a binary logistic regression using IBM SPSS Statistics (version 28.0.1.1) to predict whether someone participated in therapy (yes or no) from a participant’s risk factors including, Depression, Anxiety, Panic, Disability, Addiction, Anger, Guilt, Stressors, Complicated Grief, and Spiritual Distress. The null hypothesis was rejected. The model
explained approximately 31.2.0% (Nagelkerke $R^2$) of the variance in EPDS scores and correctly classified 83.3% of cases (See Table 6). The Cox and Snell $R^2$ explained approximately 20.5%.

The regression model was statistically significant, $\chi^2(12) = 153.211, p < .001$. Sensitivity was 44.0%, specificity was 94.6%, positive predictive value was 70.2% and negative predictive value was 85.47%. From these results, the researcher is better able to tell who is less likely to do therapy, but not as well who will do therapy. Of the twelve predictor variables, five were statistically significant: depression ($p < .001$), anxiety ($p = .006$), addiction ($p = .005$), anger ($p = .036$), and guilt ($p = .008$), as seen in Table 7. Addiction is a reversed Exp(B), or odds ratio value, meaning participants with addiction are less likely to engage in therapy.

**Table 5**

*Classification Table for Research Question Three*

<table>
<thead>
<tr>
<th>Observed</th>
<th>Predicted</th>
<th>Percentage correct</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No therapy</td>
<td>Therapy</td>
</tr>
<tr>
<td>No therapy</td>
<td>No</td>
<td>491</td>
</tr>
<tr>
<td>Therapy</td>
<td>Yes</td>
<td>84</td>
</tr>
<tr>
<td>Overall percentage</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a. The cut value is .500
### Table 6

*Logistic Regression: Variables in the Equation*

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>S.E.</th>
<th>Wald</th>
<th>Exp (B)</th>
<th>95% C.I. for EXP(B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>1.39**</td>
<td>.27</td>
<td>26.86</td>
<td>4.03</td>
<td>2.38 - 6.84</td>
</tr>
<tr>
<td>Anxiety</td>
<td>.77*</td>
<td>.28</td>
<td>7.65</td>
<td>2.17</td>
<td>1.25 - 3.74</td>
</tr>
<tr>
<td>Panic</td>
<td>.63</td>
<td>.56</td>
<td>1.28</td>
<td>1.88</td>
<td>.63 - 5.59</td>
</tr>
<tr>
<td>Disability</td>
<td>.36</td>
<td>.51</td>
<td>.50</td>
<td>1.44</td>
<td>.52 - 3.94</td>
</tr>
<tr>
<td>Addiction</td>
<td>-1.21*</td>
<td>.43</td>
<td>7.94</td>
<td>.30</td>
<td>.13 - .69</td>
</tr>
<tr>
<td>Anger</td>
<td>.62*</td>
<td>.30</td>
<td>4.41</td>
<td>1.86</td>
<td>1.04 - 3.33</td>
</tr>
<tr>
<td>Guilt</td>
<td>.71*</td>
<td>.27</td>
<td>7.04</td>
<td>2.03</td>
<td>1.20 - 3.41</td>
</tr>
<tr>
<td>Stressors</td>
<td>.03</td>
<td>.31</td>
<td>.01</td>
<td>1.03</td>
<td>.56 - 1.90</td>
</tr>
<tr>
<td>Complicated Grief</td>
<td>-.04</td>
<td>.27</td>
<td>.02</td>
<td>.96</td>
<td>.57 - 1.63</td>
</tr>
<tr>
<td>Spiritual Distress</td>
<td>.32</td>
<td>.33</td>
<td>.98</td>
<td>1.38</td>
<td>.73 - 2.62</td>
</tr>
<tr>
<td>Mother's Age</td>
<td>.02</td>
<td>.02</td>
<td>1.53</td>
<td>1.02</td>
<td>.99 - 1.06</td>
</tr>
<tr>
<td>G Age (weeks)</td>
<td>-.02</td>
<td>.01</td>
<td>2.12</td>
<td>.98</td>
<td>.96 - 1.01</td>
</tr>
<tr>
<td>Constant</td>
<td>-2.85</td>
<td>.59</td>
<td>23.52</td>
<td>.06</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Degrees of freedom = 1 for all predictors.

** <.001; * <.05.
CHAPTER FIVE: DISCUSSION

This research study was conducted to better understand a perinatal bereavement treatment program and how it impacts bereaved parents healing after miscarriage and infant loss. Specifically, the researcher focused on whether there was a relationship between pre-bereavement risk factors, assigned risk levels for PMADS, engagement in therapy, and PMAD scores on the Edinburgh Postnatal Depression Scale that assesses for perinatal depression. Ultimately, the researcher aims to promote standardization of care for perinatal parents to ensure no mother, father, or caregiver falls through the cracks of accessing trauma-informed, quality support and therapeutic services after a miscarriage or infant loss.

Interpretations

The BEFSP provided a bereavement family support program to 1,098 mothers who experienced infant loss from 2015 – 2023 in the Southeast Region of the United States. For over 1,000 mothers to have experienced miscarriage or infant loss in one rural hospital in West Tennessee in the span of just eight years is shocking. The researcher chose this research topic because of the vast numbers of perinatal loss that are not widely known about because mothers may not be openly talking about their losses, others are not aware unless someone close to them has experienced a perinatal loss, and unless trained or working in the perinatal field, many people do not realize how frequently infant loss is occurring. Twenty-five percent of pregnancies end in loss (American Pregnancy Association, 2019).

Despite miscarriage and infant loss being highly impactful and potentially traumatic, society does not offer enough support to perinatal bereaved parents (Weir, 2018). Some miscarriages occur prior to parents telling others they are pregnant, and even when people do know, loved ones may fail to recognize how significant a loss a miscarriage can be on a parent
(Weir, 2018). The stigma around mental health, infertility, miscarriage, and infant loss silences these mothers and families and inhibits them from getting the proper support and treatment that could help them. Stigma contributes to the silence, but perinatal loss is also incredibly vulnerable and layered. With loved ones potentially not having met the infant, the loss may be invisible to those directly around the parents (Weir, 2018).

Despite perinatal loss being one of the most common pregnancy complications, healthcare providers are often not trained on how to deliver this news to parents, and how a parent is told can contribute to mental health anguish and further add to a parent’s distress (Brann et al., 2020). Even though one-fourth of pregnancies may end in a loss (American Pregnancy Association, 2019), some families are left with no diagnosis or explanation as to why their baby died. Mothers may even experience multiple miscarriages before doctors will agree that medical testing and interventions are warranted.

Like many losses, community may show up initially, but after the initial days and weeks, the funeral over, others have gone back to work and their own lives, while these families are left with empty arms and feeling alone in their grief. Parental leave looks different now, if even taken. Older siblings are left confused, and parents are having hard conversations about death that they may not have had to have before or only had to do about a dead pet fish. Due to these evident needs of the whole family, the BEFSP added support components to the program for fathers, grandparents, and siblings.

Of the 1,098 mothers who the BEFSP had cared for, the mean age of the mothers was 28, but ages ranged from 14 – 44 years old. Postpartum Support International (2023) trains that perinatal mental health concerns impact mothers of all ages, races, and ethnicities, which is shown in the BEFSP data as well. The mothers’ races and ethnicities in the BEFSP program
included, 61% White, 35% African American or Black, 3% Hispanic or Latino, 0.1% Chinese, and 1% self-identified as other race or ethnicity. The city of Jackson, Tennessee where the main hospital (642 beds) the BEFSP serves has a racial make-up of 46% White, 46% Black or African American, 4.3% Hispanic or Latino, 1.3% Asian, 0.1% American Indian and Alaska Native, 0.1% Native Hawaiian and Other Pacific Islander, and 3.4% two or more races (United States Census Bureau, 2022). The hospital serves residents from 17 surrounding rural counties.

For the BEFSP there were 53 miscarriages (5%), 875 fetal deaths (81%), 114 neonatal deaths (10%), 18 SIDS deaths (2%), 21 hospice deaths (2%), and three listed as other. The average gestational age was 19 weeks with the maximum gestational age 42 weeks. Nationally, most miscarriages (80%) occur before 12 weeks, one to five percent occur between week 13 – 19, and after 20 weeks an infant loss is called a still birth (March of Dimes, 2023). Stillbirth risks increase after 32 weeks, and half occur at 40 weeks (Rosenstein et al., 2013). For the numbers available in the BEFSP fetal deaths make up the majority of the deaths represented (81%). This percentage may be so high because mothers may not be seeking out hospital treatment and/or grief support for early miscarriages and may be experiencing these losses at home. Thus, the miscarriages number in West Tennessee may be underrepresented due to mothers not seeking out, accessing, or receiving this type of support. With the hospital serving 17 rural counties, mothers may experience pregnancy complications but may still live a significant distance from accessible healthcare interventions.

For the BEFSP the mean infant age at death was 15 weeks old, the minimum age in weeks was 1 week post birth, and the maximum age was 156 weeks. Globally, one million newborns died within the first 24 hours of life in 2019 (WHO, 2022). Most neonatal deaths occurred within one week of birth (75%), and globally 2.4 million infants died within the first
month of life in 2020, which meant infants made up 47% of deaths for ages zero to five years old (WHO, 2022). This is up 40% from 1990, as the under-five years old mortality rate is declining faster than neonatal mortality rates (WHO, 2022). More research, education, and advocacy for supporting perinatal parents and their medical and mental health is needed.

Having trauma informed care and support from healthcare providers before, during, immediately after, and for the first year during pregnancy, postpartum, and after a loss this significant can be life changing. Research shows that parents remember the words healthcare providers use during this time for years after their child’s death. Words matter. Actions matter. Healthcare providers are often the first person to communicate to the parent that the loss is happening, and the provider’s approach and words may be the difference between a mother being able to start a healthy grieving process or not being able to function after leaving the hospital or doctor’s office (Rastegari, 2018). Training medical staff on grief support and connecting families with resources, like the BEFSP is doing, can make a difference in entire families’ lives for years after a loss.

In order to screen and timely support bereaved mothers, the BEFSP collected the EPDS one month after the loss. The mean score of the EPDS at one month post loss was 14.64. Question 10 on the EPDS asks: “The thought of harming myself has occurred to me” (Cox et al., 1987). For participants who did not indicate a zero (Never), and selected a 1 (Hardly ever), 2 (Sometimes), or 3 (Yes, quite often) on question 10 of the EPDS administration indicated varying severity of experiencing suicidal thoughts, and 33 out of 40 participated in therapy. In total, there were 168 mothers (15%) of the 1,098 who participated in therapy after their miscarriage or infant loss. For the therapy session totals that were available (as in bills were received from the therapists that the sessions had taken place and reimbursement from the
BEFSP foundation was provided), there were an average of three sessions per participant, ranging from one – six sessions (paid for by the BEFSP foundation).

Risk levels explained 13% of the variance in EPDS scores and risk levels were a statistically significant predictor of the EPDS score with a medium effect. Thus, the BEFSP team is doing an accurate job of identifying appropriate risk level that aligned with PMAD symptoms, informed follow up care timelines, and determined if a participant was referred to free therapy sessions provided by the foundation. Given that there is no standardized risk level assessment protocol for perinatal bereavement, this study was the first to examine if this type of protocol needs to be expanded to all hospitals and healthcare providers who treat bereaved parents of infant loss. Providing referrals and offering therapy with no charge to these mothers helped decrease the logistical and financial barrier of finding and paying for their own therapist that may be present and especially difficult during this time. Medical providers giving these referrals as part of wraparound, inclusive healthcare services may also help with the stigma of parents asking for help for their distress, poor functioning, and struggle with PMADs after losing their infant.

Studying participants’ pre-bereavement risk factors relationship with EPDS scores expands on the analysis of risk level and EPDS score. Risk factors make up the identified risk levels. The researcher studied the following available risk factors, depression, anxiety, panic, disability, addiction, anger, guilt, stressors, complicated grief, and spiritual distress for the BEFSP participants. In the presence of the other risk factors there was a significant relationship for depression and EPDS scores, anger and EPDS scores, and guilt and EPDS scores at one month post loss. Depression, anger, and guilt persisted and predicted EPDS scores at the one-month mark post loss.
Of the identified high risk factors the BEFSP collected (depression, anxiety, panic, disability, addiction, anger, and guilt), panic and disability were not significant predictors of high EPDS scores at the one-month mark post loss. The moderate (stressors) and low (complicated grief and spiritual distress) risk level determined factors were also not significant predictors of high EPDS scores, meaning the BEFSP team did a good job overall of identifying who needed to be considered high risk for timely follow up and therapy referrals. Panic attacks are a symptom of anxiety, but along with disability, were the least experienced of all of the risk factors for the BEFSP participants, with spiritual distress being the next least indicated. The BEFSP team may consider removing panic and disability as identified high risk factors for the participants, and instead label them as moderate or low risk level factors. The weighted linear regression showed that these pre-bereavement risk factors the BEFSP identified made up approximately 23% of the variance in EPDS scores one-month post perinatal loss, which means that pre-bereavement stressors contribute to or determine almost a quarter of the perinatal mood and anxiety symptoms that a mother may be experiencing one month after losing her infant. Thus, healthcare providers need to standardize screening for risk factors to identify how bereaved parents may be functioning and their mental health impacted after miscarriage and infant loss to provide adequate and timely support.

The BEFSP gathered data in real time so they could implement needed interventions for the mothers and families who were in the most need, which could help better protect them from complicated and prolonged grieving. This is the first study that has examined risk level and risk factors determinates with participation in therapy for perinatal bereaved parents. In this study, of all the initial risk factors collected by the hospital, depression was the strongest predictor both of future EPDS score and of entering into therapy. This suggests that depression is a major issue
after perinatal loss. Thus, screening for depression symptoms needs to be a focus for healthcare providers to have resources available to provide for this population of parents, as this is clearly a need and form of treatment that is readily desired and would be utilized.

In the current study, those that have depression were four times more likely to participate in therapy than those who were not depressed. If a participant did not have depression, then they were less likely to engage in therapy for their loss. Those who were experiencing guilt about the infant loss were twice as likely to participate in therapy. Those with anxiety were also twice as likely to get therapy. Those with anger symptoms were also almost twice (1.86) as likely to get therapy. Overall, sensitivity was low (44.0%), and specificity was high (94.6%) for this sample. Low sensitivity and high specificity shows the ability of a test to correctly identify those who will (sensitivity) or will not (specificity) participate in treatment, in this case, therapy. Thus, those who did not have depression, anxiety, anger, or guilt were less likely to participate in therapy. In the general population, about 6% of adults were diagnosed with major depression and of those about 66% of adults received treatment for depression in the past 12 months (National Institute of Health, 2021). The National Center for Health Statistics conducted the National Health Interview Survey in 2020 and found that women were more likely to have received mental health treatment than men and that 25.6% of women had taken part in either medication or counseling for their mental health in the past year.

For anxiety, the National Comorbidity Study Replication (Harvard Medical School, 2007) found that 19.1% of adults in the U.S. were diagnosed with anxiety, with females more likely to experience diagnosable anxiety symptoms (23.4%) than males (14.3%), and 31.1% of adults will have an anxiety disorder during their lifetime. Anger issues that interfere with relationships, work, or school impacts one in 13 adults in the U.S. (Okuda et al., 2016). Anger is
well-known to be one of the five common stages of grief originating from the Kübler-Ross Model (1969) from her book: On Death and Dying. Anger may occur once parents are expected to live in normal reality again after their loss, or when trying to understand how this could happen to them (psycom, 2022). While there may be societal pressure to control the display of anger, researchers and mental health professionals agree that anger is a necessary and healthy stage of grief (psycom, 2022).

These results suggested that one month after miscarriage or infant loss, depression, anxiety, anger, and guilt symptoms were still very present for these bereaved mothers, and these symptoms could indicate more of a desire, willingness, and/or need to get professional help for these symptoms. The results suggested that some of the other risk factors, for example, panic, may go down between the loss and the one-month mark. For parents who get pregnant again after their loss, depression and anxiety symptoms may get triggered or still be present for subsequent pregnancy and postpartum periods after perinatal loss (Blackmore et al., 2018), whereas some of the other PMAD symptoms may improve or have improved. As research continues to come out regarding parents’ prolonged mental health symptoms after loss, despite subsequent pregnancies, the BEFSP may want to continue to screen all parents with the EPDS for the full 13 months, regardless of referral source category or subsequent pregnancy, even if no longer wishing to get active grief education or phone follow up check-ins about their grief.

In contrast from the other risk factors, participants with addiction were three times less likely to get therapy, thus addiction seemed to be a barrier to engage in therapy for bereaved perinatal parents. Participants who did not have an addiction were more likely to participate in therapy. While there is no prior research as to why this may be the case after perinatal loss, contributing reasons could be the stigma of accessing addiction treatment, or active addiction
(including self-medicating to cope with the grief) being a barrier for engaging in treatment. The Substance Abuse and Mental Health Services Administration, known commonly as SAMHSA, put out an Advisory notice in 2021 that addressed the presence of and barrier that stigma still creates for those seeking treatment for their addictions (Baillieu & Wise, 2021). Stigma from family members, peers, society, and even health care providers, whether perceived or founded, leads those suffering from addiction to feel labeled, not valued or included by society as a whole and can lead to early discontinuation of treatment, delayed recovery, and an increase in dangerous behaviors (Baillieu & Wise, 2021). Talking with the BEFSP team leader, she hypothesized the barrier in starting treatment may be because the mothers who suffered from addiction or a history of addiction seemed to be living in more chaotic and crisis states, whether homeless, having less support, or unemployed. Not having stable housing or income could make it more difficult to participate in therapy or treatment, even if telehealth is offered, because of a lack of stable and accessible technology, as well as privacy issues.

Additionally, it has been known for some time that prenatal drug use and addiction, including tobacco, alcohol, THC, cocaine, heroin, and methamphetamine, can have negative health effects on a pregnant mother and the unborn infant that can impact medical outcomes (Rose et al., 2013). Guilt and shame may also play a factor in preventing mothers from getting mental health or addiction treatment after perinatal loss. Medical providers and addiction treatment centers should increase psychoeducation about potential risks and complications of drug abuse with negative maternal and fetal outcomes prior to parents conceiving (Rose et al., 2013) in order to better set parents up for success for planned and unplanned pregnancies.

Overall, mothers who have suffered from miscarriage or infant loss were found to have a statistically significant relationship (large effect size) between specific risk factors, including
depression, anger, and guilt, and PMAD symptoms on the Edinburgh Postnatal Depression Scale (EPDS) at one month after their loss. Participants who had a moderate/high risk level were found to have a statistically significant relationship (medium effect size) with higher EPDS scores. Lastly, those who were indicated to have depression, anxiety, and guilt risk factors were more likely to engage in therapy services, while those with addiction were less likely to engage in therapeutic support for their grief and PMAD symptoms.

**Limitations**

The research study includes the following limitations. First, this study examined secondary, self-reported data obtained from EPDS surveys completed by women who were patients at Jackson-Madison County General Hospital. This researcher is limited by the assumption that the data provided was accurate and that the questionnaires were administered correctly. There are known limitations with self-reported data, including a susceptibility to bias, including the potential for exaggerated responses, or not answering openly because of social desirability or mental health stigma contributing to the downplaying of admitting to how participants are truly feeling.

Furthermore, some data was missing regarding the number of therapy sessions for mothers who were engaged in therapy or who were referred to therapy post loss. This lack of data has been more of a focus of the BEFSP team since 2020, and consequently more consistent reporting of EPDS scores will lead to future opportunities to analyze this data as it becomes available. Prior to January 2020, only seven EPDS administrations were completed from 2017 – 2019. As a result it is possible that in the future more comparisons will be possible so that additional insight can be gained to support bereaved perinatal parents. Miscarriage and infant loss have continued to impact a high proportion (i.e., 25%) of parents of all ages, and as a society
there needs to be a much higher emphasis to support these parents through perinatal leave from work, grief and trauma informed trained healthcare providers, and greater empathy for bereaved individuals as a whole.

Additionally, due to the research design being nonexperimental, no conclusions about causality are feasible. It would not have been ethical to deny any mother any of the support measures and so none of the mothers were randomly assigned to experimental conditions and there was not a control group. Any missing variables that were not a focus in the study could provide alternate explanations for the findings in the study (Trochim et al., 2016). Since it is not possible to make alternative explanations for the results, internal validity may be limited (Rohrer, 2018) and may contribute to biased effect sizes (Kashner et al., 2020). Since direct observation of the collection of variables in the study is not possible, validity is contingent on the participants’ willingness to answer honestly (Jackson, 2015). If substantial deviations in the data existed from what was reported by the participants, including mental illness symptoms, addiction behaviors, or stressors, or a history of these symptoms or behaviors, this may limit the reliability of the EPDS scores, as well as the collection of risk factors, and contribute to biased results (Prior, 2009). Biased results can impact the validity of the reported findings (Prior, 2009).

The research study did not include a sampling procedure and was non-probabilistic. After giving voluntary consent, the mothers were automatic participants due to being perinatal patients who experienced infant loss and received medical services in the region of the trained BEFSP team. It is possible that the voluntary sample obtained was not representative of the bereaved perinatal population, which could pose a threat to external validity and generalizability of the results found in the study (Jackson, 2015). The participants were voluntary and offered services only after giving consent, and thus inclusion in the study was based on self-selection. Self-
selection can lead to nonresponse bias and may impact internal validity (Rohrer, 2018; Trochim et al., 2016). The data in this study is from a perinatal bereavement program that supports one region in the Southeastern part of the U.S. and participants are primarily obtaining care from one hospital which may contribute to the inability to generalize results to care provided in other facilities in other regions of the United States.

**Implications**

Participants with certain risk factors indicated whether a mother who has experienced a miscarriage or infant loss is more or less likely to get therapy. It is unknown how much time plays a factor in healing for the women in this study, but research has shown that a parent’s grief impact after infant loss can take years, even close to a decade to feel some relief (Kreicbergs et al., 2004; Lannen et al., 2008). This study demonstrates that supportive, timely measures being taken by the BEFSP model may help to speed up the healing process for these parents within the first year following their child’s death. This has implications for how other facilities could serve these women by ensuring they are screening and providing care from the moment a loss is expected to occur, while they are still at the healthcare facility, and informing timelines for appropriate follow up procedures for bereaved parents. Ultimately, these findings hope to contribute to a standard of care that supports all perinatal bereaved parents, regardless of what type of setting the parent is being treated in, how far along the pregnancy is at the time of the loss, any circumstances around the loss, or whether or not there is a diagnosis at the time of the infant’s death.

**Recommendations for Practice**

As perinatal researchers, advocates, and healthcare providers work to educate and spread awareness about perinatal mental health, including supporting bereaved parents of miscarriage
and infant loss, the researcher hopes that more parents in the BEFSP will decide to engage in therapy, and that this type of integrated behavioral health program will spread to all hospitals, Obstetrics and Gynecology offices, and to other healthcare professionals medically treating families after infant loss. As the hospital collects more participant data, practitioners and researchers can conduct more analyses regarding how these mothers are functioning over the first year after their loss that may further inform universal standard of care needed practices and other programs, including how to support bereaved parents’ posttraumatic growth and building resilience. The BEFSP team and other hospitals implementing perinatal bereavement programs may consider giving a baseline EPDS administration while the mother is still at the hospital or receiving healthcare services as part of hospital or discharge paperwork in order to be able to compare these scores to the EPDS scores one month after loss.

Due to the particularly difficult nature of these participants’ grief, it was not appropriate to be more assertive with the current data collection efforts. The BEFSP team currently offered behavioral health and grief support services three times and if the family still declines a service they do not ask again. The team also tries different staff members approaching the family about the services and at varying times during their hospital stay to try to decrease any barriers regarding misunderstanding or personality conflicts. This practice seemed appropriate given the sensitive and unexpected nature of what the families are going through. When perinatal families arrived at the point that the BEFSP team was now involved, they had already experienced hearing what could be some of the worst news of their lives. The BEFSP team worked hard to train all hospital workers and community perinatal providers that come in contact with these families on grief and loss education and how to provide trauma informed, integrated behavioral health care.
Through following a similar model to the BEFSP, perinatal bereavement family support programs can better set parents up for healing and recovery after the significant loss of an infant. Providing trauma-informed bereavement care, using evidence-based screening tools like the EPDS for perinatal depression, identifying risk factors for mental illness and complicated grief symptoms, and connecting parents with therapy early on after their loss can have a significant impact on functioning and healing for entire families. Not all parents have access to a best-practices program as part of a universal standard of care, like the BEFSP, in their area. For bereaved parents who do fall through the cracks and are not screened or offered mental health support during the perinatal period, it is still important for medical and mental health care providers to ask about a history of losses and ensure any needed follow up care, due to the profound and long-term impact the loss of an infant can have on a parent’s life (Weir, 2018).

Due to this research showing that mothers suffering from addiction, or a history of addiction are less likely to participate in mental health treatment offered to them after perinatal losses, providers need to place a greater emphasis on how to better support this group of parents. If parents do not have stable housing, income, or support an increase of social work or case management services may need to be offered first. Better addiction and addiction treatment education on negative maternal and fetal outcomes needs to occur in all healthcare settings to better set parents and their children up for success.

**Recommendations for Future Research**

Future research could study interaction effects between some of the variables studied in this research study and other related variables in perinatal hospice and bereavement programs or practices. A limitation in this study was sample size for some of the available variables. If more data is collected, then PMAD symptoms over time can be studied in greater detail over a longer
time frame. This could help further inform best practices for bereavement programs. For example, it would be interesting to see in future studies if the predictive relationships between determined risk levels and EPDS scores persisted past the one-month mark for participants in the BEFSP and other perinatal bereavement programs. Future research could also compare results with other perinatal bereavement programs.

Additionally, future research can focus on partners, grandparents, and siblings’ functioning and mental health. The BEFSP has supported fathers and provided sibling bags with support items since 2022. Data was currently being gathered on bereaved fathers’ mental health, since 2022. Support rooms and time was given to extended family members to be a part of the memory making process. More data can be gathered to look at other family member’s risk factors, mental health functioning, and support needs so that whole families can be supported during perinatal loss grieving. Providing wraparound care for families in turn better supports bereaved parents and anyone impacted by the loss. The results from this study could also be compared to future studies in other regions or areas of the country, as well as looking at differences between groups, such as referral source categories, or with other facilities or organizations that may be collecting similar data. Future studies could also delve deeper into mental health symptom differences between the BEFSP groups, such as mothers’ ages, races, whether a first-time parent, or having other children in the home.

**Conclusions**

Overall, the goal and mission of this research is to spread awareness, education, and advocacy for the mental health needs of perinatal bereaved parents and all parents, with or without living children. The results of this study may inform improvements and increased efforts in data collection to validate current efforts in integrated behavioral health care of bereaved
parents and support the standardization of these effective protocols as a universal standard of care for hospitals to provide trauma informed grief care to parents of infant loss. The researcher hopes this study is the first of many to support the mental health care of perinatal parents who have had to endure the heartbreak of losing a child, and to bring attention to and encourage compassion from healthcare providers, colleagues, insurance providers, and communities on the significant impact of infant loss.
References


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https://doi.org/10.1016/j.ajog.2009.09.007


https://www.marchofdimes.org/complications/miscarriage.aspx#


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https://doi.org/10.17226/12565


Parliamentary Committee on Palliative & Compassionate Care. (2011). *Not to be forgotten. Care of vulnerable Canadians.*


www.postpartum.net


Appendix A

Jackson Madison County General Hospital IRB Waiver

Jackson Madison County General Hospital IRB Waiver

October 06, 2022

TO: Lee Ann Sutton, BSW, CPLC
    Family Support Team Leader

From: IRB Office

RE: Butterfly’s Embrace Perinatal Bereavement Program

EXPEDITED REVIEW

The JMCGH IRB Chairman has reviewed this submission and determined it does not qualify as “human subject research.” The IRB has determined that the waiver, in whole or in part, of authorization satisfies the following criteria:

A. The use or disclosure of protected health information involves no more than a minimal risk to the privacy of individuals based on, at least, the presence of the following elements:

   i. An adequate plan to protect the identifiers from improper use and disclosure.
   ii. An adequate plan to destroy the identifiers at the earliest opportunity
   iii. Adequate written assurances that the identifiable protected health information will not be reused or disclosed to any other person or entity, except as required by law.

B. The research could not practicably be conducted without the waiver; and
C. The research could not practicably be conducted without access to and use of the protected health information.

This submission is approved and no follow-up is required.

Lee Ann Sutton, BSW, CPLC has agreed to be the contact person should any questions arise in the future regarding this research.

Please note: Any changes to this proposal that may alter it’s “non-human status: should be presented to the IRB for review prior to implementation of the change.

[Signature]
James T. Craig, Jr., M.D.
IRB Chairman

10/06/2022
Appendix B

University of Memphis IRB Waiver

Institutional Review Board  
Division of Research and Innovation  
Office of Research Compliance  
University of Memphis  
315 Admin Bldg  
Memphis, TN 38152-3370  
April 14, 2023  
PI Name: Mary Neal  
Co-Investigators: Pamela Cogdal, Eraina Schauss, Eli Jones  
Advisor and/or Co-PI: Melanie Burgess  
Submission Type: Admin Withdrawal  
Title: A Quantitative Study of a Parent Bereavement Treatment Program for Infant Loss: Risk Factors, Length of Treatment, and Healing  
IRB ID: PRO-FY2023-372

From the information provided on your determination review request for “A Quantitative Study of a Parent Bereavement Treatment Program for Infant Loss: Risk Factors, Length of Treatment, and Healing”, the IRB has determined that your activity does not meet the Office of Human Subjects Research Protections definition of human subjects research and 45 CFR part 46 does not apply. This determination applies only to the activities described in the submission noted above and does not apply to any changes to this project. Please submit a new request to the IRB for a determination if any changes are made which lead to any questions about whether the activities are research involving human subjects.

This study does not require IRB approval nor review. Your determination will be administratively withdrawn from Cayuse IRB and you will receive an email similar to this correspondence from irb@memphis.edu. This submission will be archived in Cayuse IRB.

Thanks,  
IRB Administrator  
Division of Research and Innovation  
Office of Research Compliance  
315 Administration Building  
Memphis, TN 38152-3370  
P: 901.678.2705  
F: 901.678.4409
# Appendix C

## Bereavement Contact Record

### Risk Factors

<table>
<thead>
<tr>
<th>Health-Mental Illness</th>
<th>Pre-BV</th>
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**Red** - High Risk (F/U within 72hrs & continued F/U weekly until risk decreases) 
**Blue** - Moderate Risk (F/U within 2 weeks)  
**Green** - Low Risk (F/U per Bereavement Contact Guidelines)
### Butterfly’s Embrace Bereavement Contact Record

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<td>Baby’s Date of Death</td>
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**Month: 7**
- Welcome Letter, “Understanding Grief”, & EB Group Letter
- “Strong Emotions” & “Going Back to Work”
- “Coping”
- Additional Resources
- “You Must Get Over It”
- “When Friends Are Not There”
- “Sleep”
- “Your Rights As You Grieve”
- “Four Tasks of Grief”
- “4 Things About Grief That Never Change”
- “Special Days”
- “Moving Forward”

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Joined Butterfly’s Embrace Online Support Page: Yes □ No □
Joined Heaven’s Cradle Online Support Page: Yes □ No □
# Appendix D

## Bereavement Contact Record Emergency Department (ED)

### RISK FACTORS

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Red = High Risk (F/U within 72hrs & continued f/u weekly until risk decreases)  □
Blue = Moderate Risk (F/U within 2 weeks) □
Green= Low Risk (F/U per Bereavement Contact Guidelines) □
### Butterfly's Embrace Bereavement Contact Record

Mother's Name:  
Address:  

Phone:  
Email:  

Baby's Date of Death:  
Gestational Age:  

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<td>Month 4: &quot;You Must Get Over It&quot; &amp; &quot;When Friends Are Not There&quot;</td>
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<td>Month 5: &quot;Four Tasks of Grief&quot;</td>
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Joined Butterfly's Embrace Online Support Page:  
Yes ☐ No ☐

Joined Heaven's Candle Online Support Page:  
Yes ☐ No ☐
Appendix E

Bereavement Contact Record West Tennessee Surgery Center (WTSC)

RISK FACTORS

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<th>Health-Mental Illness</th>
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Coping-Addiction Issues:
- Drug
- Alcohol
- SaX

Coping-Seesed Ideations:
- Conditioned
- Self-Expressed Plan
- Prior attempts

Coping-Heightened Emotional status:
- Anger
- Guilt
- Disorganized

Red= High Risk (F/U within 72hrs & continued f/u weekly until risk decreases)
Blue= Moderate Risk (F/U within 2 weeks)
Green= Low Risk (F/U per Bereavement Contact Guidelines)
Butterfly’s Embrace Bereavement Contact Record

Mother’s Name: ___________________________ Address: ___________________________

Phone: ___________________________ Email: ___________________________

Baby’s Date of Death: ___________ Gestational Age: ___________

Mailout: ___________________________ Date: ___________________________

Month 1: Welcome Letter, “Understanding Grief,” FB Group Letter
Month 2: “Strong Emotions” & “Sleep”
Month 3: “Coping” & “4 Things About Grief That Never Change”
Month 4: “You Must Get Over It” & “When Friends Are Not There”
Month 5: “Four Tasks of Grief”
Month 6: “Moving Forward”

Before Month 1: Intro Text
Before Month 1: Intro Phone Call
Month 1: Home Visit
Month 1: EPDS Score
Month 5: Phone Call

Joined Butterfly’s Embrace Online Support Page: Yes ☐ No ☐
Joined Heaven’s Candle Online Support Page: Yes ☐ No ☐
Appendix F

Edinburgh Postnatal Depression Scale (EPDS)

Edinburgh Postnatal Depression Scale\(^1\) (EPDS)

Name: ___________________________ Address: ___________________________

Your Date of Birth: ___________________________ Phone: ___________________________

Baby’s Date of Birth: ___________________________

As you are pregnant or have recently had a baby, we would like to know how you are feeling. Please check the answer that comes closest to how you have felt IN THE PAST 7 DAYS, not just how you feel today.

Here is an example, already completed.

I have felt happy:

☐ Yes, all the time
☐ Yes, most of the time This would mean: “I have felt happy most of the time” during the past week.
☐ No, not very often Please complete the other questions in the same way.
☐ No, not at all

In the past 7 days:

1. I have been able to laugh and see the funny side of things
   ☐ As much as I always could
   ☐ Not quite so much now
   ☐ Definitely not so much now
   ☐ Not at all

2. I have looked forward with enjoyment to things
   ☐ As much as I ever did
   ☐ Rather less than I used to
   ☐ Definitely less than I used to
   ☐ Hardly at all

3. I have blamed myself unnecessarily when things went wrong
   ☐ Yes, most of the time
   ☐ Yes, some of the time
   ☐ Not very often
   ☐ No, never

4. I have been anxious or worried for no good reason
   ☐ No, not at all
   ☐ Hardly ever
   ☐ Yes, sometimes
   ☐ Yes, very often

5. I have felt scared or panicly for no very good reason
   ☐ Yes, quite a lot
   ☐ Yes, sometimes
   ☐ No, not much
   ☐ No, not at all

6. Things have been getting on top of me
   ☐ Yes, most of the time I haven’t been able to cope at all
   ☐ Yes, sometimes I haven’t been coping as well as usual
   ☐ No, most of the time I have coped quite well
   ☐ No, I have been coping as well as ever

7. I have been so unhappy that I have had difficulty sleeping
   ☐ Yes, most of the time
   ☐ Yes, sometimes
   ☐ Not very often
   ☐ No, not at all

8. I have felt sad or miserable
   ☐ Yes, most of the time
   ☐ Yes, quite often
   ☐ Not very often
   ☐ No, not at all

9. I have been so unhappy that I have been crying
   ☐ Yes, most of the time
   ☐ Yes, quite often
   ☐ Only occasionally
   ☐ No, never

10. The thought of harming myself has occurred to me
    ☐ Yes, quite often
    ☐ Sometimes
    ☐ Hardly ever
    ☐ Never

Administered/Reviewed by ___________________________ Date ___________________________


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Edinburgh Postnatal Depression Scale\(^1\) (EPDS)

Postpartum depression is the most common complication of childbirth.\(^2\) The 10-question Edinburgh Postnatal Depression Scale (EPDS) is a valuable and efficient way of identifying patients at risk for "perinatal" depression. The EPDS is easy to administer and has proven to be an effective screening tool.

Mothers who score above 13 are likely to be suffering from a depressive illness of varying severity. The EPDS score should not override clinical judgment. A careful clinical assessment should be carried out to confirm the diagnosis. The scale indicates how the mother has felt \textit{during the previous week}. In doubtful cases it may be useful to repeat the tool after 2 weeks. The scale will not detect mothers with anxiety neuroses, phobias or personality disorders.

Women with postpartum depression need not feel alone. They may find useful information on the web sites of the National Women's Health Information Center \(<\text{www.nwhc.gov}\>) and from groups such as Postpartum Support International \(<\text{www.postpartumhelp.org}\>) and Depression after Delivery \(<\text{www.depressionafterdelivery.com}\>)

### SCORING

**QUESTIONS 1, 2, & 4 (without an *)**
Are scored 0, 1, 2 or 3 with top box scored as 0 and the bottom box scored as 3.

**QUESTIONS 3, 5-10 (marked with an *)**
Are reverse scored, with the top box scored as a 3 and the bottom box scored as 0.

Maximum score: 30  
Possible Depression: 10 or greater  
Always look at item 10 (suicidal thoughts)

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### Instructions for using the Edinburgh Postnatal Depression Scale:

1. The mother is asked to check the response that comes closest to how she has been feeling in the previous 7 days.
2. All the items must be completed.
3. Care should be taken to avoid the possibility of the mother discussing her answers with others. (Answers come from the mother or pregnant woman.)
4. The mother should complete the scale herself, unless she has limited English or has difficulty with reading.

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