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# EXPLORING THE LIVED EXPERIENCES OF DYSPHORIC MILK EJECTION REFLEX DURING POSTPARTUM BREASTFEEDING: A PHENOMENOLOGICAL STUDY

A Dissertation

Submitted to the School of Nursing

Duquesne University

In partial fulfillment of the requirements for

the degree of Doctor of Philosophy

By

Stephanie L Herr

August 2023

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Stephanie L Herr

# EXPLORING THE LIVED EXPERIENCES OF DYSPHORIC MILK EJECTION REFLEX DURING POSTPARTUM BREASTFEEDING: A PHENOMENOLOGICAL STUDY

By

Stephanie L Herr

Approved June 9, 2023

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#### ABSTRACT

# EXPLORING THE LIVED EXPERIENCES OF DYSPHORIC MILK EJECTION REFLEX DURING POSTPARTUM BREASTFEEDING: A PHENOMENOLOGICAL STUDY

By

Stephanie L Herr August 2023

Dissertation supervised by Dr. Jessica Devido

This study sought to explore the lived experiences of Dysphoric Milk Ejection Reflex (D-MER) during postpartum breastfeeding. A phenomenological method based on Giorgi's phenomenological underpinnings was used. The setting for this study was virtual interviews in a secure online platform. The sample consisted of 13 participants, selfidentifying as experiencing D-MER. Semi-structured interviews, with thematic analysis of transcription were conducted. Four major themes were identified: 1) *Breastfeeding concessions and toleration; 2) Something does not feel "normal"; 3) I remember a feeling like this before 4) This is real, and recognition is validating.* Conclusions were that women of this study value the importance of providing breastmilk, as the optimal nutritional source, to their infants, seek validation, support, and understanding related to

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the phenomenon they are experiencing, and feel a strong need for enhanced education and awareness within the healthcare provider population and prenatal education. Implications for nursing education include enhanced content related to the assessment and care of a woman experiencing D-MER, greater support strategies for these women, and more research, both qualitative and quantitative, due to the limited literature that currently exists. Future research recommendations include prevalence rates, impacts on maternal-newborn bonding, and impacts on the breastfeeding relationship. This research is a priority, for greater knowledge attainment regarding emotional sensations during lactation is strongly associated with positive breastfeeding outcomes related to bonding, duration, and psychological well-being.

#### DEDICATION

This manuscript is dedicated to my extremely supportive husband, who has been my sounding board throughout the past four years and who has picked up many daddy playground dates with my kids to give me time to write and research. To my 2 children, Adalyn and Macklin. Adalyn: Thank you to my sweet 5-year-old that grew up knowing that mommy needed "computer time" and sometimes had to play Barbies<sup>©</sup> by herself. I promise we have a lot more Barbie<sup>©</sup> play days ahead. My Macklin Jay, you gave me a whole new perspective on research when you were medevac'd at 7 days old and on a ventilator. If it wasn't for cutting edge research and dedicated doctoral professionals, we may not have you here today. To say I am a researcher, now makes me feel even more honored and privileged to have the potential to change lives through research. I hope one day you pursue the dreams you never thought could be accomplished. I love you so very much and look to support you in all your future endeavors. And lastly, to my mom and dad: thank you for always supporting me and allowing me to follow my dreams. My wonderful mother retired recently after over 20 years of being a public-school educator, and you are the reason I am here today, following my dreams. From living paycheck to paycheck with no heat in the winter, to now being a doctoral candidate: Like you always told me: "This is Varsity, not JV, put your game face on." I love you more than words can describe. Thank you.

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## LIST OF ABBREVIATIONS

| D-MER           | Dysphoric Milk Ejection Reflex                      |
|-----------------|---|
| PI              | PRIMARY INVESTIGATOR                                |
| PPD             | POSTPARTUM DEPRESSION                               |
| IBCLC           | INTERNATIONAL BOARD-CERTIFIED LACTATION CONSULTANT  |
| IRB             | INSTITUTIONAL REVIEW BOARD                          |
| ADHD            | ATTENTION DEFICIT HYPERACTIVE DISORDER              |
| MDMA: "ECSTASY" | 3,4 METHYLENEDIOXYMETHAMPHETAMINE                   |
| OCD             | OBSESSIVE COMPULSIVE DISORDER                       |
| PRISMA          | PREFERRED REPORTING ITEMS FOR SYSTEMATIC REVIEW AND |
|                 | Meta-Analyses                                       |

Chapter One

**Dissertation Proposal** 

#### **Specific Aims**

In the United States, more than 8 in 10 mothers initiate breastfeeding directly after birth ("Breastfeeding Data and Statistics," 2021). Breastfeeding is often associated with positive thoughts and emotional experiences; however, there can be difficulties and negative experiences that have psychologic implications for lactating women. While the American Academy of Pediatrics recommends that infants be exclusively breastfed for the first six months of life, only 56.7% of infants meet this benchmark in the United States ("Breastfeeding Data and Statistics," 2021).

Although there can be a variety of reasons breastfeeding may cease, a dysregulation of emotions during lactation is an important concern to address; specifically, a phenomenon called Dysphoric Milk Ejection Reflex (D-MER). D-MER occurs during milk letdown as breastfeeding is initiated. Because an exclusively breastfed newborn breastfeeds on average eight to twelve times per day and there are often multiple let-downs during a breastfeeding session, breastfeeding parents experience D-MER as a recurring negative stimuli (Hartmann et al., 2003; Heise & Wiessinger, 2011; Truchet & Honvo-Houéto, 2017). The breastfeeding mother experiencing D-MER may have feelings of hopelessness, sadness, and overall depression during the letdown phase of milk production (Heise & Wiessinger, 2011) . One study of D-MER estimated prevalence of 9.1% of all breastfeeding women (Ureño et al., 2019). Although gendered language will be used in this proposal, this topic applies to anyone who can become pregnant, including cisgender women as well as trans men and gender non-binary individuals.

The current literature includes descriptive studies that explore breastfeeding experiences through postpartum depression, aversion, and anxiety, but does not explore any lived experiences of breastfeeding with D-MER. For example, Watkinson et al. (2016) have explored mothers' experiences of embodied emotional sensations including depression, anxiety, and aversion during breastfeeding and how those feelings influenced the family unit, but it is important to note that breastfeeding aversion and postpartum depression are not correlated to D-MER in the current literature.

A mini-study was conducted to **describe**, **understand**, **and interpret the meaning of** D-MER in the breastfeeding mother, and five lived meaning units emerged: harboring emotional sensations during milk letdown, granting community belonging and provider knowledge, fostering past identical emotional sensations, enduring an assistive device delivery, and conceptualizing a traumatic birthing experience. Due to the findings of the mini-study further research is needed including a full-scale phenomenology.

The lack of conceptualization of D-MER, related to the breastfeeding experience, highlights the need for additional research. The voices and lived experiences of these individuals are essential to understand their unique challenges, aid in identifying the mothers' capacity for continuation of breastfeeding and enhance the ability to form a secure bond with their baby, which may have a strong impact on the emotional wellbeing of all family members (Heise & Wiessinger, 2011; Watkinson et al., 2016).

The dissertation study proposed uses Giorgi's descriptive phenomenological methodology to explore the lived experiences of postpartum breastfeeding women who selfidentify as having experienced D-MER. The proposed study will investigate their emotional sensations during lactation and further explore living with D-MER as a postpartum lactating

woman. The specific aim of this study is to 1) Explore the feelings, attitudes, and beliefs of postpartum breastfeeding women who have experienced D-MER. The research question for this study is: What are the lived experiences of postpartum breastfeeding women who self-identify as having experienced D-MER?

Findings from this study may help clinicians to better understand and support breastfeeding women experiencing D-MER. Currently, many nurses and obstetrical providers are unaware of D-MER and how to better support their patients experiencing it (Heise & Wiessinger, 2011). This knowledge may increase supportive care for mothers experiencing D-MER and influence lactation support services and improve breastfeeding continuation rates.

#### Significance

#### **Dysphoric Milk Ejection Reflex**

Most often, the term breastfeeding is described as an act of happiness, positive bonding, and an overall joyous experience between a mother and infant; The phenomenon of negative emotional sensations during milk letdown, D-MER, was self- identified by an International Board-Certified Lactation Consultant (IBCLC) Alia Macrina Heise in 2007. Heise's initial published research on D-MER was published in 2010. Since then, studies have been undertaken to explore D-MER related to psychological distress, emotional wellbeing, and the effects on the maternal-infant dyad. There has been one prevalence study of D-MER, conducted by retrospective chart review over a 12-month period, which estimated prevalence of about 9.1% of all breastfeeding women in the United States (Ureño et al., 2019).

There are only five published studies related to D-MER: one case series (Ureno et al., 2018), two case reports (Cox, 2010; Heise & Wiessinger, 2011), one descriptive prevalence study (Ureño et al., 2019), and one neurobiological literature review (Deif et al., 2021). Current

literature explores women's breastfeeding experiences through postpartum depression, aversion, and anxiety but does not make reference to, or explore, lived experiences of breastfeeding related to D-MER.

#### **Emotions During Dysphoric Milk Ejection Reflex**

Many hormones are involved in the act of breastfeeding and milk production, including oxytocin, prolactin, and dopamine (Truchet & Honvo-Houéto, 2017). These hormones can cause emotional instability during the postpartum period, especially if the hormones are dysregulated in some manner, which is seen in women with D-MER (Heise & Wiessinger, 2011; Ureño et al., 2018). Current literature looks to explore lactation and symptomology related to psychological distress, emotional wellbeing, and the effects on the maternal-infant dyad. The primary investigator (PI) conducted a literature review to synthesize, analyze, and evaluate the scope of literature on D-MER. Four themes from the current literature include Breastfeeding Self Efficacy and Maternal Role Attainment, Harboring Emotional Sensations and Distress, Granting Community Belonging, and Maternal Newborn Dyad of Feeding Methodology and Cessation.

## Self-Efficacy and Maternal Role Attainment while Breastfeeding

Self-efficacy relates to the idea that women have their own beliefs regarding their breastfeeding experiences and address's goal setting and goal fulfilment perceived by the individual woman. Role attainment in breastfeeding mothers is referring to the woman's competency to breastfeed her child (Cooke et al., 2007; Ritchie-Ewing et al., 2019).

Emotionally distressing symptoms during lactation may hinder women's breastfeeding self-efficacy and decrease their confidence (Cooke et al., 2007; Hegney et al., 2008; Morns et al., 2021; Ritchie-Ewing et al., 2019). A common motivator related to breastfeeding is the expectation that the woman perceives herself as a "good mother." These emotions can cause

women to feel guilt and isolative feelings, feelings of shame, and inadequacy related to motherhood and the lactation experience. It can also spark an "internal conflict" related to wanting to breastfeed but having feelings of anguish and low self-worth during the process (Cooke et al., 2007; Hegney et al., 2008; Morns et al., 2021; Shakespeare et al., 2004; Watkinson et al., 2016). A sense of disappointment and the terms "failure" and "inadequacy" are common terms lactating women use to describe themselves when feeling negative emotions during lactation (Cooke et al., 2007; Hegney et al., 2008; Ritchie-Ewing et al., 2019; Watkinson et al., 2016; Yate, 2017). Women can view their emotional reactions and perceived inability to succeed as flaws inherent in themselves and share a feeling of self-doubt in their maternal roles. Women speak to breastfeeding as a fundamental aspect of maternal identity and worth, equating failing at breastfeeding to failing at motherhood (Ritchie-Ewing et al., 2019; Yate, 2017).

Thus, evidence suggestions that there is an association between a mother seeing her motherhood and parenting experience as being a positive one if she is successful at breastfeeding. If a woman ceases to feed her infant breastmilk, available evidence suggests that she then may have a sense of failure and a decrease in confidence as a mother (Cooke et al., 2007; Ritchie-Ewing et al., 2019). According to Heise and Wiessinger (2011), D-MER can result in unwanted cessation of breastfeeding, which can affect a woman's view of her self-efficacy and maternal role attainment.

#### **Emotional Sensations and Distress while Breastfeeding**

There are many emotions felt during the breastfeeding experience that can affect the lactating mother. The neurotransmitters and hormonal transfers during the act of milk expression are vast, and it has been noted that these transfers are causing negative or distressing emotional feelings during milk letdown (Ureño et al., 2018). According to Heise and Wiessinger (2011),

the act of milk letdown, which is directly triggered by oxytocin release, also includes an abrupt drop in dopamine. This dopamine deficit is thought to be the cause of a negative, self-loathing feeling in D-MER women (Heise & Wiessinger, 2011).

Women express that their breastfeeding expectations are disillusioned after experiencing negative emotional sensations and distressing feelings during lactation, as breastfeeding is commonly noted to be a "simple, joyful, and natural task" that can be managed from birth throughout infancy (Hegney et al., 2008; Shakespeare et al., 2004). Women who experienced negative emotional sensations during lactation expressed many different emotional states during the lactation period. It is important to note that in D-MER, the negative connotations only occur during the milk letdown phase of lactation, and that these emotions do not last during the entire breastfeeding duration. Multiparous women reported feeling these distressing emotions with subsequent lactation periods with future children (Cox, 2010; Heise & Wiessinger, 2011; Stacey, 2020; Ureño et al., 2019; Ureño et al., 2018). During D-MER, a multitude of emotionally draining and distressing feelings have been reported including a "homesick, pit in stomach" feeling. Women also express feeling anxious, irritable, panicky, and agitated. (Cox, 2010; Heise & Wiessinger, 2011; Morns et al., 2021; Ureño et al., 2019; Ureño et al., 2018).

There are other conditions termed in breastfeeding literature that include negative emotions such as breastfeeding aversion, postpartum depression, and postpartum anxiety. The defining difference between these other conditions and D-MER is that D-MER symptomology is solely during milk letdown. Once milk letdown has occurred, the emotional changes and potentially distressing feelings cease.

Currently, there is minimal research noting feelings of D-MER concurrently with other named psychological conditions during the postpartum and lactation period. It is known,

however, that D-MER is a separate condition. D-MER and postpartum depression may occur concurrently, but it is the negative emotional wave at milk letdown that sets D-MER apart (Heise & Wiessinger, 2011).

Therefore, seeing the vast negative emotional sensations and feelings, it is a concerning phenomenon to be experiencing during the postpartum lactating period. Although there are variations in how individuals experience and manage negative emotions with D-MER, it is important to note that, in the current literature, all are distressing in some manner and have the ability to impede the act of breastfeeding and impair bonding between mother and baby (Hegney et al., 2008; Heise & Wiessinger, 2011; Ureño et al., 2018).

#### The Need for Community Belonging and Management of D-MER

Women who experience D-MER symptomology and negative emotional sensations during their lactation sessions frequently speak about the need for support in the community and within their family unit, incorporating healthcare providers and lactating women (Cox, 2010; Stacey, 2020). Awareness, education, and support groups have been reported by women to minimize the distress that D-MER can cause (Ureño et al., 2019).

Support from peers, specifically another person who could relate to their experiences (support groups), was valued and sought after by lactating women with emotional distress during lactation (Hegney et al., 2008). Having a trusting health professional to confide in and provide familiarity with their experiences increased an individual's confidence about the advice they received. Women felt reassured and supported in their breastfeeding experience (Hegney et al., 2008). According to Hegney et al. (2008), participants were frequently disappointed with professionals' lack of knowledge about embodied emotional sensations during breastfeeding. Current findings identify positive connotations related to peer support groups; speaking to

alleviation of guilt, normalization of symptoms, and making sense of experiences in a safe, shared space (Hegney et al., 2008; Heise & Wiessinger, 2011; Shakespeare et al., 2004; Stacey, 2020; Ureño et al., 2018; Uvnas-Moberg & Kendall-Tackett, 2018; Watkinson et al., 2016).

Thus, an improved educational understanding and increase in knowledge among support people and clinical practitioners may help to alleviate some of the anxieties and feelings women have when they experience and self-identifying with D-MER.

#### Feeding Methods and Breastfeeding Cessation related to D-MER

There are many ways to feed an infant, whether it be from the breast directly, breastmilk from a bottle or other devices, or formula in a bottle or other devices. Breastfeeding requires the act of milk removal from the body; therefore, if a woman chooses to breastfeed, her milk letdown is occurring regardless of how she is physically extracting her milk.

Women frequently cited the desire to stop breastfeeding or to decrease the frequency of breastfeeding sessions and supplement due to the emotional distress experienced during lactation (Cooke et al., 2007; Hegney et al., 2008; Morns et al., 2021; Ritchie-Ewing et al., 2019; Shakespeare et al., 2004; Ureño et al., 2019; Ureño et al., 2018; Uvnas-Moberg & Kendall-Tackett, 2018; Watkinson et al., 2016). The presence of depressive symptoms and anxiety impedes breastfeeding and positive breastfeeding behaviors, such as bonding and duration of feeding (Ritchie-Ewing et al., 2019). Conflicting feelings between the negative emotions and the expected benefit of breastmilk and the breastfeeding bonding experience are compared in these women. Many women report a desire to breastfeed, with the intention to provide closeness and nurturing to their child, despite feeling distressed during lactation (Morns et al., 2021). It is also important to annotate those participants who continued breastfeeding, despite these negative

emotions, reported a feeling of proudness, perseverance, optimism, and resiliency (Hegney et al., 2008; Morns et al., 2021).

Therefore, the negative feelings that arise with the phenomenon known as D-MER has the ability to cause women to cease the breastfeeding experience in total or decrease the amount of milk removals daily. Although these feelings are occurring during milk letdown, the phenomenon will occur regardless of how the woman is extracting her breastmilk and can have the ability to impede the bonding and breastfeeding experience in total.

#### **Study Design Rationale**

By utilizing a phenomenological methodology, the PI can explore and understand the lived experiences of breastfeeding women who self-identify as experiencing D-MER. The most appropriate method to uncover patterns and similarities of the human experience of lactation and psychological underpinnings is descriptive phenomenology (Giorgi, 2009). By doing this, it will help researchers better understanding the representation, knowledge, and perception surrounding D-MER.

Descriptive phenomenology is a philosophical method of inquiry that explores the human experience through open communication between the investigator and the participant and resolves to uncover the principles of the phenomenon studied (Giorgi, 2009). Using the phenomenology design of Edmund Husserl, the structures of the conscience experience as experienced from the first-person point of view is explored, along with relevant conditions of the experiences being investigated (Husserl, 1970). Active listening and critical reflection are done to remain receptive to the participants' experiences.

Most recently, the lead author completed a mini-phenomenological study related to D-MER and the number of participants, verbal encouragement, and necessity of this research

identified by women experiencing D-MER solidified the need to continue this research. With future research relating to D-MER, we can better understand and support breastfeeding women living with these emotional sensations and feelings. In addition, this research can aid in the knowledge and understanding of D-MER in healthcare providers and the obstetrical staff population by providing healthcare staff a glimpse into the lived experience of D-MER. Many providers are unaware of this phenomenon and how to better support their patients experiencing D-MER. This can ultimately increase breastfeeding success rates, maternal lactation support, and improve the overall nutritional status of the newborn.

#### **Implications to Nursing Research and Healthcare**

Knowledge gained from this study has the potential to inform and improve nursing care of patients and families experiencing the negative symptomology of D-MER. Future research is needed to integrate knowledge to develop clinical support strategies surrounding D-MER among the lactating population. Based on the few themes presented in the current literature, more research is needed, including qualitative, quantitative, and mixed method studies, because the existing evidence is limited. Greater knowledge regarding prevalence rates, impacts on maternalnewborn bonding, and impacts on the breastfeeding relationship are necessary to determine and promote effective interventions to support women experiencing D-MER. This research is a priority, for greater knowledge attainment regarding emotional sensations during lactation is strongly associated with positive breastfeeding outcomes related to bonding, duration, and psychological well-being (Heise & Wiessinger, 2011; Morns et al., 2021; Watkinson et al., 2016).

To encourage and support women experiencing D-MER and their breastfeeding process, it is suggested that educational support groups and breastfeeding classes incorporate discussion

about D-MER to support and help women understand they are not alone, and their emotional sensations are valid. Nurses and healthcare providers can also play a lead role in symptomology support and prevalence awareness through public health initiatives and education, such as D-MER support campaigns (Heise & Wiessinger, 2011; Ureño et al., 2019).

The paucity of research related to D-MER shows the gap in literature and the need for further exploration of this experience. Implementation of awareness and support groups is a high priority, but also a more generalized understanding of the management of symptomology, awareness, and better recognizing of the phenomenon. Although beyond the scope of this study, a basic understanding and potential physiological treatment for this condition would be extremely beneficial and would assist in increasing maternal newborn bonding and limit the cessation of breastfeeding due to the negative symptomology.

#### Innovation

Research to date on postpartum mood/psychological disturbance has focused on postpartum depression, anxiety, and breastfeeding aversion (Cooke et al., 2007; Darbyshire, 1989; Shakespeare et al., 2004). Current D-MER literature is sparse and has focused on prevalence rates in the United States and case reports with discussions of symptomology during D-MER. Current gaps in literature include, but are not limited to, the impact of D-MER on maternal-newborn bonding, breastfeeding duration, and supportive care needs of the lactating mother. This proposed study takes the viewpoint that D-MER is affecting more than just a woman's emotions for a few seconds during milk letdown, specifically having a high potential to hinder the maternal newborn bonding that accompanies the breastfeeding experience, which can affect the larger family unit. This study demonstrates innovation in three ways.

First, this study will explore the perceptions and experiences of women experiencing D-MER through a unique phenomenological lens, taking the experiences of the breastfeeding woman and studying the structures of their specific experiences. This study will generate new nursing knowledge regarding the phenomenological underpinnings related to feelings, attitudes, and beliefs of postpartum breastfeeding women experiencing D-MER (Giorgi, 2009). This study will elicit rich descriptive data, looking into the phenomenological lens of D-MER. The current literature includes descriptive studies that explore breastfeeding experiences through postpartum depression, aversion, and anxiety, but does not explore any lived experiences of breastfeeding with D-MER.

Second, this study will focus on postpartum breastfeeding women experiencing dysphoria and emotional sensations solely during the milk letdown phase of lactation. While reviewing current literature concerning breastfeeding women and emotional sensations during milk letdown, only five studies were found related to D-MER, including a case series, case reports, a descriptive prevalence study, and a neurobiological literature review. D-MER is often combined or termed in the literature with other postpartum emotional states, such as postpartum depression, breastfeeding aversion, and postpartum anxiety, but it is important to note that these phenomena are different than D-MER. This research study solely focuses on D-MER and the breastfeeding mother, which is a different approach from the other studies examining postpartum emotional states.

Third, this study will aid in the advancement of nursing science by eliciting new data about the supportive needs that mothers experiencing D-MER may need. Breastfeeding outcomes are routinely reported in the literature and significant foci include the support from lactation counselors, consultants, and additional support persons (family, friends, spouse) but

limited literature exists regarding support systems for D-MER. These support persons have been reported to provide barriers and success to the lactating individual and overarching family unit (Keim et al., 2021; Neifert & Bunik, 2013; Patel & Patel, 2016). By understanding the supportive care needs of the postpartum breastfeeding woman, there is great potential to provide support physically, mentally, and emotionally to the family unit. In summary, this research has the potential to elicit novel, meaningful information that can be translated to nursing research, practice, and education while supporting the family unit as a whole; aiding in bonding, initiation, and duration of lactation while experiencing D-MER (Keim et al., 2021; Neifert & Bunik, 2013; Patel & Patel, 2016).

#### Approach

#### **Preliminary Work**

A phenomenological mini-study informed this proposed study. The PI conducted the phenomenological mini-study to explore and understand the experiences of postpartum breastfeeding women who have identified as experiencing D-MER, and to evaluate the efficacy of a larger scale study in the future. The research question for the mini-study was: "What are the lived experiences of breastfeeding women who have identified as having experienced Dysphoric Milk Ejection Reflex (D-MER)?" Using Giorgi's phenomenological methodology, the PI collected data through observations and virtual semi structured interviews with postpartum breastfeeding women (Giorgi, 2009). Five postpartum breastfeeding mothers were recruited from a self-reported D-MER support group on social media and participated in the study. Data collected were transcribed verbatim and transferred into NVivo 12, a qualitative data manager. Analysis of data using Giorgi's five phases of analysis resulted in identification of 19 meaning

units and five lived meaning units. Due to the mini-study nature of this research, saturation of data was not reached.

All participants were interviewed via a virtual Zoom meeting in October of 2020, on a first come-first served basis. All women were breastfeeding their infant for at least 6 months postpartum. Demographic information was collected and included participants ages between 29-36 years old. Four women identified as non-Hispanic white, and one identified as other, specifying race as Anglo (Australian). Four women classified as "married", and one "living with partner." All five participants completed a different highest degree: one high school diploma, one associate degree, one bachelor's degree, one master's degree, and one doctoral degree. Two participants were employed for wages, one self-employed, one homemaker, and one student. Three women reported experiencing a vaginal birth, while one had a cesarean, and one had an assistive vacuum vaginal delivery. Two participants identified as breastfeeding their infant almost exclusively, while one exclusively breastfed, one minimally breastfed, and one gave expressed milk in addition to breastfeeding directly.

When analyzing the phenomenological data, five lived meaning units emerged within the interviews and were termed as: harboring emotional sensations during milk letdown, granting community belonging and provider knowledge, fostering past identical emotional sensations, enduring an assistive device delivery, and conceptualization of a traumatic birthing experience. The lived meaning elements embodied the essence of the mothers' thoughts and feelings connected to her breastfeeding experiences.

The harboring of emotional sensations during milk letdown speaks to the participants expression of negative, dysphoric feelings happening only during milk letdown, and subsiding after. Participants also expressed the lack of understanding of D-MER in their healthcare staff

and provider population. These women found that support groups and provider support aided in their acceptance and suppression of the dysphoria. Participants also spoke regarding their history of previous trauma and/or depression and anxiety, either before, during, or after pregnancy and commonly reported feeling this dysphoria in their lives previously. Identifying these emotions in prior traumatic events in their lives fostered past similar emotional sensations. Participants also spoke to experiencing assistive device deliveries, meaning their health care provider used a vacuum or forceps type of manual extraction during birth. Lastly, participants spoke to their birthing experience as being "traumatic." Participants used this term to describe their labor and/or birth and elaborated on their definition of birth trauma.

These findings show a lack of perceived community and provider knowledge, and demonstrate the feelings and attitudes related to experiencing D-MER. Future research may include increasing sample size, correlation related to symptomology, and increasing the community's knowledge surrounding the phenomenon.

#### Feasibility of a Full-Scale Study

Several lessons were learned from the completed mini-study regarding the feasibility of conducting a maxi-study. First, recruitment of participants was higher than anticipated. In the D-MER social media support page, over sixty women over a 5-day timeframe identified as wanting to participate in the study. For the proposed study, the PI will recruit from this social media support group, as membership has grown since the completion of the mini-study. Additionally, differing time zones were a barrier in the interview process, as many participants were not in the same time zone as the PI, which posed some meeting time challenges. The PI will accommodate flexibility of scheduling to assure the participants schedules are prioritized and respected.

Second, three of the five mini-study interviews were either shorter or longer than the onehour meeting range of time due to the participants actively caring for their infants during the virtual interviews. This multitasking posed a challenge, as some women intermittently needed to pause the interview to care for their children. As a result, the PI will offer flexibility in terms of rescheduling or allowing a small break to allow the participant to care for their infant then return to the call. Several sessions of data collection can also be accessible to accommodate the needs of the participants.

Third, during the mini-study interviewing process, probing questions were asked based on the responses of the participants. Some of these probing questions provided rich information about the participants lived experiences relating to D-MER, including the term "homesick" and the phrase "pit in stomach feeling." This will prompt the PI to include some of those terms and phrases in the formal interview guide questions for the proposed maxi-study to establish convergence.

The mini-study was conducted to describe, understand, and interpret the meaning of D-MER in the breastfeeding mother. With the participant pool limited to five participants, data saturation did not occur. However, this mini-study informed the PI on the feasibility and necessity of a maxi study to be completed. Therefore, further analysis and understanding of D-MER surrounding the lactation period and the support needed during this phenomenon is warranted, specifically in a larger pool of participants, to assure saturation of data is obtained and full phenomenological underpinnings are described and understood.

#### **Research Design**

The proposed qualitative study will be guided by Giorgi's Phenomenological Methodology (Giorgi, 2009). The most appropriate method to uncover patterns and similarities

of the human experience of lactation and psychological underpinnings is descriptive phenomenology. Descriptive phenomenology is a philosophical method of inquiry that intends to explore the human experience through open communication between the investigator and the participant and resolves to uncover the principles of the phenomenon studied (Giorgi, 2009; Wojnar & Swanson, 2007).

Guided by Giorgi's methodology, the PI will collect data via fieldnotes and observations within a secure Zoom Online Room for individual interviews. The raw data collected, in which the investigator assumes a human scientific phenomenological reduction (setting aside affirmation or negation and using description), is the participants' experiences of the specific phenomenon (Pratt, 2017). The research question of interest is: What are the lived experiences of recently delivered postpartum breastfeeding women who self-identify as having experienced Dysphoric Milk Ejection Reflex (D-MER)?

#### **Setting and Sample**

Participant recruitment is aimed at a Facebook group geared to provide support to women who self-report symptomology of D-MER and to further understand D-MER in research, education, and professional settings. This group is composed of over 5,400 members from across the world. A gatekeeper associated with a Facebook group who moderates membership will be included to assist with the promotion of the proposed study. The PI may also seek recruitment through additional social media support groups and through a local hospital's lactation services. The population of interest is postpartum breastfeeding women who self-identify as experiencing D-MER.

The inclusion criteria include: 1. Participants who are of childbearing age and English speaking. 2. All participants will have self-reported that they have previously experienced D-

MER based on their personal and lived experiences. 3. Gave birth to a living newborn, no longer than 36 months prior to the data collection date, and breastfed the same infant, for any length of time during their postpartum period. 4. Participant needs to have internet access, computer, and/or smartphone access for interview purposes.

Breastfeeding duration is not specified for this research due to the PI wanting a purposeful sampling for a variety of stages postpartum. By interviewing women in different stages of their breastfeeding journey, the PI can extract additional information and understanding, based on postpartum length and breastfeeding duration. However, it is important to note that the participant does not have to be exclusively breastfeeding at the time of interview. Exclusion criteria include: 1. Any woman who is not English speaking. The PI is not fluent in any other languages; therefore participants need to be English speaking.

This study is not limited in reference to the setting or location of the participants, as participation is open to women globally. Approximately 12 to 15 postpartum women will be recruited or until saturation of data occurs (Saunders et al., 2018). The continuation of participant interviews will occur if data saturation does not occur at 15 participants, but due to time constraints, the PI will interview no more than 20 women. Women who participated in the ministudy will be considered participants and their data will be incorporated in the full study.

#### **Recruitment and Consent**

The PI will inform the Facebook D-MER group's gatekeeper of the study's purpose and will develop a recruitment flyer to post on the Facebook page. The flyer, which will be approved by the Duquesne University Institutional Review Board (IRB), will include a brief description of the proposal, participant inclusion criteria, and contact information for the PI. Interested participants will contact the PI by email, phone, or text to discuss the details of the study and to

determine eligibility. The PI will screen for eligible participants during the initial contact and obtain their contact information. The PI will also utilize a snowball sampling method to gather participants via social media. Snowball sampling uses a small pool of initial participants to nominate, through their social networks, other participants who meet the eligibility criteria and could potentially contribute to a specific study. If they know someone who is interested, they will share the PI's contact information to participate.

The research will be conducted in a manner that maintains the respect, confidentiality, and privacy of all participants. Participants will be treated with respect according to the ethical guidelines for the conduct of research. The PI will explain the procedure and purpose for the research to each potential participant. Voluntary informed consent will be obtained before beginning the study, and participants will have the right to withdraw from the study at any time without fear of retribution. If a participant notifies the principal investigator of the desire to withdraw, all data from the participant will be destroyed.

Consent for this study will be obtained before collecting participant information such as demographic and interview data. Risks, benefits, and compensation will be shared with participants during the informed consent procedure of the research study. There are minimal risks associated with participating in this study, but some emotional distress can occur from past trauma or emotions experienced. Although it is not anticipated that the interview will cause undue distress for the participants, if participants become distressed during the interview, the interview will be stopped, and the individual will be referred to emotional support services.

A signed copy of the informed consent will be provided to each participant virtually for their records. The informed consent will be read to individuals who are unable to read. Informed consents will be signed and collected electronically via Qualtrics, an online key metrics survey

platform, and stored on a password protected computer for three years. There will be a subject ID # on the study survey to allow the investigator to label that person's interviews with their subject ID from the survey. Full procedure and data related to protection of research participants can be found in Appendix A.

### **Data Collection**

Participants will be asked at the start of data collection to complete a socio-demographic form, delivered via a Qualtrics link, developed by the PI to collect information on the participant's social and economic backgrounds, including pertinent information related to duration of their breastfeeding journey. All data will be secured on a password protected computer. Participants will then engage with the PI in semi-structured interviews that will take place in the participants' environment of choice via a virtual Zoom platform. Visual capture of the participant is requested via web camera but can be turned off at the discretion of the participant. It is estimated that completion of the demographic form and interview may last between 30-120 minutes.

The PI will set up a convenient time based on the schedule of the participant, for their first meeting via Zoom. The PI will explain the procedure and purpose for the research to each potential participant. Once the participant's questions are answered and the individual agrees to participate through verbal assent of understanding of the research process, the consent form will be signed using the informed consent form from Qualtrics. Participants will then be sent a new Qualtrics link with the demographic form. Supplementary field data may be collected in one to two additional interviews if completion of data is not accomplished in the initial interview. One to two additional interviews may also be requested by the PI if further fieldnotes or clarification is needed.

## **Demographic form**

Participants will complete an electronic PI-designed demographic data form capturing descriptive information relevant to the domain of inquiry (Appendix B). Data form and responses will be recorded in English. Factors include age in years, race, marital status, highest degree or level of school completed, employment status, household annual income, age of youngest infant, method of most recent birth, feeding methodology, and duration of breastfeeding if no longer breastfeeding at time of interview. Education level and household income are captured since they are identified as social determinants of health associated with lactation (Al-Nuaimi et al., 2017).

## Semi-structured interview guide

The PI will utilize a semi-structured PI-designed, interview guide with questions reflective of descriptive phenomenological underpinnings (Appendix C). The phenomenological researcher Giorgi (1997) stated that, "Questions are generally broad and open ended so that the subject has sufficient opportunity to express his or her viewpoint extensively," which reflected a generalist approach (p. 245). Giorgi does not specify as to how the interview should proceed other than via broad, open-ended questions. This emphasizes an important phenomenological concept of context, which is the lifeworld and experience of the participant, as being vital for the interview progression (Bevan, 2014).

To undertake the phenomenological reduction, a PI is required to abstain from the use of personal knowledge, theory, or beliefs. To abstain from the use of personal knowledge is what Husserl (1970) called "bracketing," which is a setting aside of what we already know about a given phenomenon. It is important to understand that total abstention is an unreasonable expectation of the PI. Bracketing, or abstention, requires a PI to become aware of his or her own natural attitude, immersion in their lifeworld, and how it is taken for granted (Bevan, 2014). To

allow successful bracketing, the PI will follow a semi-structured interview guide with openended questions. By being aware of the assumption that the PI might post leading questions into consciousness, semi-structured interviews can be arranged to steer and guide the interview.

#### Data Analysis/Analytic Plan

Descriptive data captured in the maternal demographic form will be considered in the context of the qualitative analysis. Descriptive statistics, such as frequencies, percentages, and ranges, will be used to describe demographic data. Analysis of maternal demographics in conjunction with qualitative data and fieldnotes will provide a more complete understanding of the phenomenon of interest (Schreiber & Asner-Self, 2011).

Giorgi's phenomenological methodology for qualitative research provides a systematic, six-step structured analysis method. First, interviews will be visually recorded, audio recorded and transcribed verbatim for analysis. Data management will be done via NVivo12 software. The PI will use visuals related to participants affect, expressions, background, and setting, audio, in relation to tone of voice and dialect during interview, and fieldnote journaling to examine data. Data analysis will be completed by the PI and will follow Giorgi's six steps of descriptive phenomenology data analysis. According to Giorgi (2009), "The results reflect a careful description of precisely the features of the experienced phenomenon as they present themselves to the consciousness of the PI" (pp. 130-131).

The PI will analyze data according to these six stages: 1) transcribe interviews verbatim using NVIVO12 software, 2) suspend one's personal beliefs or convictions about the phenomenon of interest prior to examination of data to minimize personal bias, 3) read and reread data to indirectly experience the phenomenon described by participants, 4) transform data into small sections to indicate participants change in flow of consciousness during the interview,

5) reread the small sections for transformation into shared components of the participants' lived experience, and 6) integrate components into the phenomenon's general meaning structure (Giorgi, 2009). By transforming descriptions into meaning units, the PI can form meaning units into meaning structure, and then will conclude with a synthesis of the phenomenon of interest. Data will be analyzed to include emergent theme analysis and descriptive phenomenological analysis.

#### **Study Limitations**

A limitation for this study includes restricting the language of study to English only. Further analysis of D-MER in postpartum participants who speak a language other than English may provide deeper insights from various cultural perspectives, as language and culture have a homologous relationship. Cultural perspectives could be a valuable lens to observe in this phenomenon and could provide a more holistic perspective of D-MER.

In addition to language, self- selection sampling may also be a limitation to this study. Self-selection sampling may give bias, as the individual is selecting themselves to be included in the research, thus resulting in sample that is not representative of an overall population or specified group.

Another limitation includes sampling and access to internet and the Zoom platform. Sampling for this study will be pulled through a support page on social media and may limit the pool of participants who may not have access to social media platforms. In addition, the need for internet access and a Zoom account for virtual meeting may pose limitations to the number and diversity of participants recruited.

## **Potential Barriers and Strategies**

Recruitment of postpartum breastfeeding participants can be a potential barrier to this study, as a mother who is actively caring for an infant does not have ample "free time" during their day to participate in an interview session and complete required documentation such as the demographic form and consent. Leach et al. (2017) states that the postpartum population is a hard-to-reach population due to the commitment of time tending to families. By recruiting women from a D-MER support group specifically, the participants are more likely to contribute to research on this topic, as many women in the group voice the desire for more research to be done surrounding D-MER and their willingness to participate in future research.

In addition, the PI will also send a reminder to the participant via email, or the communication method of their choice, to assure both parties can accommodate the meeting day and time. The interview day and time will be selected by the participant, and mutually agreed upon with the PI. By allowing the participant to select the day and time of the interview, the PI aims to decrease participation burden and support parents' care of their infant while home and/or respecting time at their place of employment. Leach et al. (2017) performed a feasibility study speaking to the recruitment of postpartum participants via online versus face-to-face interviewing and found that online recruitment and interviewing is low cost and highly efficient. It is also important to note that Leach et al. (2017) states that internet usage is high in this general population, which can increase feasibility to recruit and retain postpartum participants for research studies.

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#### Appendix A

#### **Protection of Research Participants**

The research will be conducted in a manner that maintains the respect, confidentiality, and privacy of all participants. IRB approval will be obtained at Duquesne University. Once the participant views the recruitment flyer and is interested in participating in the study, the participant will contact the PI from their contact information provided on the recruitment flyer. The PI will explain the procedure and purpose for the research to each potential participant.

Withdrawal procedures from this study will be shared with the participant at the informed consent action of the study. The participants are under no obligation to start or continue this study. Study participants can withdraw from the study at any time by not completing the online demographic form or by stopping the interview. Any data that is collected before withdrawal will be destroyed.

Participants will be treated with respect according to the ethical guidelines for the conduct of research. Voluntary informed consent will be obtained before beginning the study, and participants will have the right to withdraw from the study at any time without fear of retribution. If a participant notifies the principal investigator of the desire to withdraw, all data from the participant will be destroyed. While not anticipated, if participants become distressed during the interview, the interview will be stopped, and the individual will be referred to emotional support services. Although legal residence status of participants will not be asked as part of the interview process or on the demographic survey, the PI will not disclose any information about legal or illegal residency status if revealed by the participants.

# Appendix B

### Demographic Questionnaire

Participant ID #:

All information provided on this form will be kept strictly confidential and will only be used for the purposes of this research project.

- 1. What is your age (in years)?
- 2. What is your race?
  - a. American Indian or Alaska Native
  - b. Asian
  - c. Black or African American
  - d. Hispanic or Latino
  - e. Native Hawaiian or Other Pacific Islander
  - f. White
- 3. Which of the following best describes the gender you identify as?
  - a. Male
  - b. Female
  - c. Non-binary
  - d. Trans-gender
  - e. Prefer to self-describe below
    - 1. \_\_\_\_\_
- 4. Please select your current marital status.
  - a. Divorced
  - b. Living with partner
  - c. Married
  - d. Single, never married
  - e. Separated
  - f. Widowed
- 5. Please select your highest degree or level of education.
  - a. No schooling completed
  - b. Nursery school to 8th grade
  - c. Some high school, no diploma

- d. High school graduate, diploma or equivalent (for example: GED)
- e. Some college credit, no degree
- f. Trade/technical/vocational training
- g. Associate degree
- h. Bachelor's degree
- i. Master's degree
- j. Doctorate degree
- 6. Please select your type of employment.
  - a. Work for someone else full time
  - b. Temporarily unemployed
  - c. Self-employed
  - d. Works for someone else part-time
  - e. Retired, not employed
  - f. Student, disabled, etc., not employed
  - g. Full-time homemaker
- 7. Please report your current household annual income
  - a. Under \$30,000
  - b. \$30,000-\$60,000
  - c. \$60,000-\$90,000
  - d. \$90,000-\$120,000
  - e. Over \$120,000

8. How many children have you given birth to?

- 9. If this is not your first child, have you experienced D-MER emotional sensations with prior lactation?
  - a. Yes
  - b. No
  - c. N/A

10. How old is your youngest infant?

- 11. Please select the type of birth you had with your last delivery
  - a. Vaginal birth
  - b. Cesarean Delivery
- 12. With your last birth, did your birth provider use any devices to assist in delivery?
  - a. Assisted forceps vaginal birth
  - b. Assisted vacuum vaginal birth
  - c. No devices
  - d. Not sure
- 13. How do you describe the way in which you breastfed/breastfeed your youngest child from birth to current? \* *Please select the most appropriate response:* 
  - a. **Exclusive breastfeeding:** No other liquid or solid from any other source enters the infant's mouth.
  - b. Almost exclusive: Allows occasional tastes of other liquids, traditional foods, vitamins, or medicines.
  - c. **Full breast milk feeding:** The infant receives expressed breast milk in addition to breastfeeding.
  - d. Partial: Any feeding of expressed breast milk.
  - e. Token: Minimal, occasional breastfeeds for comfort.

If you no longer breastfeed your baby, how long after birth did you completely stop breastfeeding? Please be as specific as possible (in weeks).

*Note.* Adapted from Labbok, M. H. & Krasovec, K. (1990). Towards consistency in breastfeeding definitions. *Studies in Family Planning*, *21*(4), 226-230.

# Appendix C

### **Sample Interview Guide**

I am interested in learning from you about your experiences related to your breastfeeding journey and experience.

Before we talk about your experiences, can you tell me a bit more about yourself?

What about your family, who do you consider family?

I am interested in learning about your past experiences related to breastfeeding. Can you tell me about that?

To be part of the study you have identified that you had experienced Dysphoric Milk Ejection Reflex. Can you tell me about that experience?

How did you identify having D-MER? Did you speak to a Certified Lactation Consultant regarding your experience, talk to peers, or utilize the internet to identify?

Have your tried any types of treatment or remedies for the symptoms you have experienced?

Can you tell me about anything you may have experienced about D-MER and breastfeeding?

Thank you for the opportunity to share your experiences. Is there anything that you have forgotten or that you may remember now that you would like to share with me?

\*Probing questions can be asked to verify and gather additional detail regarding the participant's lived experience, if needed.

Chapter Two

Integrative Review

Dysphoric Milk Ejection Reflex in Human Lactation: An Integrative Literature Review

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#### Abstract

**Background:** Postpartum mothers may endure challenges during lactation that may have longterm psychological effects on their breastfeeding experience. Few studies explore the dysregulation of emotions during nursing sessions, known as Dysphoric Milk Ejection Reflex. During the letdown stage of milk production, the client may experience feelings of helplessness, melancholy, and general unhappiness. The symptoms subside after the mother's milk has let down, but return during subsequent letdowns.

Research Aim: To evaluate the scope of published literature on Dysphoric Milk Ejection Reflex.

**Method:** Whittemore and Knafl's methodology guided this integrative review. Five databases were searched for primary research, summaries, and editorials on Dysphoric Milk Ejection Reflex in lactating individuals. Literature searched also included websites, pamphlets, and conference proceedings found via Google and Google Scholar.

**Results:** A total of 11 articles, from five different countries, met inclusion criteria for review. Studies on Dysphoric Milk Ejection Reflex and negative emotional sensations during lactation were synthesized under five conceptual umbrellas: *Experiences and Sensations of Dysphoric Milk Ejection Reflex, Biological Underpinnings of Dysphoric Milk Ejection Reflex, Impact of Dysphoric Milk Ejection Reflex on Maternal Role and Breastfeeding Self-Efficacy, Support, Understanding, and Awareness, Reduction and Cessation of Breastfeeding.* 

**Conclusion:** D-MER is a neurobiological condition in breastfeeding women characterized by low mood and negative feelings during milk ejection. D-MER is linked to maternal psychological distress and breastfeeding discontinuation. Priority areas for future research on D- MER include biological origins and interventions aimed at prevention, symptom control, and greater awareness of the condition.

**Keywords:** Dysphoric Milk Ejection Reflex, milk letdown, breastfeeding, integrative review, emotional sensations, lactation, [Mesh terms: Breastfeeding, Lactation, Psychological Distress]

#### Background

Dysphoric milk ejection reflex, also known as D-MER, is an understudied phenomenon involving dysregulation of emotions during breastfeeding. D-MER occurs during the milk ejection reflex (i.e., "let-down") (Heise & Wiessinger, 2011). Women typically have multiple milk ejections in a single breastfeeding or milk expression/pumping session (Ureño et al., 2018), and D-MER can recur with each milk ejection (Ureño et al., 2018). Individuals with D-MER experience feelings of hopelessness, sadness, and feelings of dread with milk ejections, with symptoms subsiding relatively quickly--often within thirty seconds of onset (Cox, 2010; Heise & Wiessinger, 2011; Ureño et al., 2018). Currently, no medical diagnosis (ICD code) exists for this phenomenon, and it may go unrecognized by health professionals. D-MER is self-diagnosed by some women who self-identify with the symptomology of D-MER, while others may experience the symptoms, but are unaware that it is an established physiological condition (Cox, 2010; Heise & Wiessinger, 2011).

Current literature addresses negative breastfeeding sensations and symptomology mainly through the lens of postpartum depression, postpartum anxiety, and general breastfeeding aversion, but there is a paucity of research on D-MER. Breastfeeding aversion is considered negative emotions and feelings during the entire breastfeeding session, or negative emotional feelings towards the act of breastfeeding; this differs from negative feelings confined to the period after milk ejection, characteristic of D-MER (Morns et al., 2021). Morns et al. (2021) describes aversion as "feelings of disgust caused by the thought or sight of breastfeeding" and describes D-MER as "one such experience, which is characterized by feelings of dysphoria that last during the milk ejection reflex and then ceases" (pp. 128-135). Breastfeeding aversion and postpartum depression are not correlated with D-MER in the current literature.

A better understanding of D-MER, including its causes, trajectory, and sequelae can inform future interventions aimed at its prevention and management. The purpose of this integrative review was to systematically evaluate the scope of published literature on D-MER and to identify gaps for future research in this area. We use gendered language (e.g., mother, women) throughout this review to maintain consistency with language of included studies. However, in all of the included studies, it is unclear if or how gender identity was assessed.

#### Methods

#### Design

This integrative review was based on the Whittemore and Knafl (2005) review methodology that allows inclusion of both empirical and theoretical literature. We undertook an integrative review rather than a systematic review, because of the limited scope of empirical research on D-MER. The steps involved in Whittemore and Knafl's method include: identifying the problem and purpose, searching the literature, evaluating and analyzing the data, and synthesizing and presenting the findings.

#### Sample

We coordinated our work using Covidence ("Covidence Systematic Review Software," 2023), an online system that enables completion of key review tasks including storing references, removing duplicate references, independently screening titles and abstracts for inclusion, storing and reviewing full text for exclusion, and resolving reviewer differences. The lead author (SH) was the primary reviewer for this integrative review, performing the literature searches and grading evidence; however, the other authors participated in review and offered feedback on the findings and interpretations. The search was limited to any published literature within the past 20 years (2003-2023) and published in English. Studies were excluded if they did not refer to the

term "D-MER," "dysphoric milk ejection reflex," or emotional or psychological distress occurring with milk ejection/let-down. The Preferred Reporting Items for Systematic Review and Meta-analyses (PRISMA) guidelines were used and can be seen in Figure 1.

### **Data Collection**

The literature search was conducted by the first author (SH) in collaboration with a health science librarian using the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, APA PsycInfo, Cochrane Database of Systematic Reviews, and Embase. Literature searched also included websites, pamphlets, and conference proceedings found via Google and Google Scholar. Search terms included: Dysphoric Milk Ejection Reflex OR D-MER OR Milk Let-down OR breastfeeding AND Psychological Distress OR Emotional Distress OR aversion OR agitation. The search strategy involved Medical Subject Heading terms and Boolean operators according to the guidelines for each database. The search strategy resulted in 11 articles, one quantitative and six qualitative studies, one perspective article, and three literature reviews with a combined total sample size in all studies of 1,895 maternal participants. Search results are available by request from the corresponding author. The search was limited to any published literature within the past 20 years (2003-2023), and the last date of literature searched was June 13<sup>th</sup>, 2023.

#### Measurement

The Preferred Reporting Items for Systematic Review and Meta-analyses (PRISMA) guidelines were used to guide data extraction and reporting. Analysis of the articles occurred through the development of a matrix table (Table 1 and Table 2) that included the author/title/journal, setting, publication date, study purpose, design, sample, findings extracted from each of the 11 studies and level of evidence and quality evaluation from the JBI-QARI

checklists. During data reduction, the articles were divided into subgroups based on the type of evidence (qualitative, descriptive studies, reviews) and examined sequentially.

#### **Data Analysis**

The data were then analyzed by repetitive comparison to identify common themes (Whittemore & Knafl, 2005). Several interrelated themes were identified across multiple studies; those having higher quality research scores were weighted more prominently in consolidating the themes reported here. The methodological quality of the studies was appraised by the primary author using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI): Checklist for Case Series, Checklist for Prevalence Studies, and Checklist for Qualitative Research. Three narrative review articles and one perspective article did not have corresponding checklists, and as such, their quality was not appraised.

Qualitative studies were appraised for congruency between the research method and philosophical perspective, research question, method of data collection, data analysis methods, and results interpretation. Qualitative studies were also appraised for inclusion of a discussion on the researcher's influence/positionality, representation of participants' voices through inclusion of direct quotes, evidence of ethical conduct, and conclusions that are grounded in the data analysis. The single quantitative study (a descriptive prevalence design) was evaluated based on the following elements: sample recruitment, sample size, and inclusion criteria; hypotheses and findings were linked to a theoretical framework; the tools used to evaluate outcome(s) had reported reliability and validity evidence; appropriate statistical analysis; and if findings were generalizable.

Each article could receive a summative score based on numerous criteria on the respective checklist (each criteria scored 0=no, 1=yes). A cut score of 60% of the total possible

checklist score was predefined as the minimum requirement to consider the study of sufficiently high quality for inclusion in the review, as suggested by the Joanna Briggs Institute (Porritt et al., 2014) (Table 2). None of the selected studies were excluded based on their quality.

#### Results

The initial database searches resulted in a total of 280 articles: 159 articles from PubMed, 30 articles from APA PsycInfo, 34 articles from CINHAL, and 57 articles from Embase. The search flow diagram is displayed in Figure 1 using the Covidence Systematic Review software. A total of 25 articles underwent full text screening, of which 14 were excluded. The articles were deemed ineligible due to the following reasons: did not address D-MER, were not human participants, and publication year. Eleven studies were eligible and reviewed: one quantitative and six qualitative studies, one perspective article, and three literature reviews.

The quantitative study assessed the prevalence of D-MER among 164 women in the U.S. at a 6-8 week postpartum visit via retrospective chart review, then surveyed an additional 115 women who were experiencing D-MER about their symptoms (Ureño et al., 2019). Included qualitative studies addressed D-MER triggers, experiences, treatment and management approaches, and impacts including on maternal mental health. The qualitative literature was comprised of samples between one subject in a case report (Cox, 2010; Heise & Wiessinger, 2011) to a meta-ethnographic review comprised of 1,791 total participants (Morns et al., 2021). Among all studies, participants were recruited via local hospitals, social media, paper and electronic flyers, and local parenting community groups.

Countries of origin, for both qualitative and quantitative studies, included Australia, India, Iran, United Kingdom, and the United States. The ages of study participants ranged from 16 (Morns et al., 2021) to 55 years old (Yate, 2017). In three studies that reported on participant

race, 50-95% of participants in each study's sample were white (Ureño et al., 2019; Watkinson et al., 2016; Yate, 2017). Out of 16 participants across four studies whose parity was assessed, primiparous women accounted for 25% (n=4/16) of the total sample (Cox, 2010; Heise & Wiessinger, 2011; Ureño et al., 2018; Watkinson et al., 2016).

Out of the 11 articles reviewed, nine used the phrase D-MER (Cox, 2010; Deif et al., 2021; Frawley & McGuinness, 2023; Heise & Wiessinger, 2011; Morns et al., 2021; Stacey, 2020; Ureño et al., 2019; Ureño et al., 2018; Uvnas-Moberg & Kendall-Tackett, 2018). Two articles referred to breastfeeding aversion but were included due to likely overlap with D-MER according to descriptions provided (Morns et al., 2021; Yate, 2017). One article referred to "embodied emotional sensations during breastfeeding" and cited multiple breastfeeding conditions, such as D-MER and aversion (Watkinson et al., 2016).

In analyzing the quality of seven articles whose designs mapped to available JBI-QARI checklists, the minimum score rating was a 70% (Ureño et al., 2018), and the maximum score was 100% (Cox, 2010; Heise & Wiessinger, 2011; Morns et al., 2021; Watkinson et al., 2016; Yate, 2017). Quality scores are included in Table 2.

#### Synthesis and Content Analysis

Five summarizing themes were identified based on the synthesis and analysis of data across reviewed articles: 1. *Experiences and Sensations of D-MER 2. Biological Underpinnings* of *D-MER 3. Impact of D-MER on Maternal Role Outcomes and Breastfeeding Self-Efficacy* 4. *Support, Understanding, and Awareness,* and 5. *Reduction and Cessation of Breastfeeding. Experiences and Sensations of D-MER and Symptom Management* 

There were four studies (Morns et al., 2021; Ureño et al., 2019; Watkinson et al., 2016; Yate, 2017) including a case study, descriptive study, a meta-ethnographic review, and qualitative study, with 1,895 total participants that addressed negative feelings and emotions during D-MER. Participants endorsing D-MER or D-MER like symptomatology reported the negative feelings occurred within one to five minutes after starting to breastfeed (Ureño et al., 2019) and resolved roughly two to three minutes after their initial milk letdown, and recured with subsequent milk let downs in the same breastfeeding session (Ureño et al., 2019). Multiparous women reported feeling these distressing emotions with subsequent lactation periods with future children (Cox, 2010; Heise & Wiessinger, 2011; Stacey, 2020; Ureño et al., 2019; Ureño et al., 2018).

Participants reported feeling a multitude of distressing experiences, including a "homesick, pit in stomach" feeling, anxious, dysphoric, irritable, panicky, agitated, and emotionally drained (Cox, 2010; Deif et al., 2021; Frawley & McGuinness, 2023; Heise & Wiessinger, 2011; Morns et al., 2021; Ureño et al., 2019; Ureño et al., 2018; Uvnas-Moberg & Kendall-Tackett, 2018). There was variation in that some participants reported a single dominant negative feeling during let-down, while others experienced a range of negative emotions during let-down. Heise and Wiessinger (2011) speculate from their case report on D-MER that there is likely a spectrum of three major D-MER symptom categories: depression, anxiety, and anger. The intensity of these feelings and emotions varies between individuals and may be classified as mild, moderate, or severe (Heise & Wiessinger, 2011).

In a case study by Cox (2010), D-MER symptoms occurred within the first month of lactation initiation, and continued throughout the lactation period, until weaning at 20 months postpartum. Ureño et al. (2018) found in their case series that three participants experiencing D-MER felt negative emotions begin around week two postpartum. In all included studies reporting on D-MER timing, symptom severity decreased over time (Cox, 2010; Deif et al., 2021; Frawley

& McGuinness, 2023; Heise & Wiessinger, 2011; Morns et al., 2021; Stacey, 2020; Ureño et al., 2019; Ureño et al., 2018).

D-MER symptom management was measured and/or discussed in seven included articles (Cox, 2010; Deif et al., 2021; Frawley & McGuinness, 2023; Heise & Wiessinger, 2011; Morns et al., 2021; Ureño et al., 2019; Ureño et al., 2018). In these studies, participants found that their D-MER symptoms/emotions became more manageable after learning about the condition as a physiological phenomenon. Awareness, education, and support groups enabled participants to minimize the distress that D-MER caused (Cox, 2010; Heise & Wiessinger, 2011; Ureño et al., 2019; Watkinson et al., 2016). Ureño et al. (2019) explored symptom management in their descriptive study, with 44% of participants reporting that distraction improved symptoms. Lack of sleep (54%) and stress (46%) were reported to be the most common factors to worsen symptomology.

#### **Biological Underpinnings of D-MER**

All reviewed articles discussed potential etiologies of D-MER. In a case report by Heise and Wiessinger (2011), the authors noted the probable role of oxytocin and dopamine in D-MER. In particular, dopamine's rise and fall during breastfeeding being more abrupt than other neurotransmitters mirrors the rapid onset and fall of D-MER symptoms (Heise & Wiessinger, 2011). In seven articles, dopamine was noted as the probable key neurotransmitter causing D-MER symptoms (Cox, 2010; Deif et al., 2021; Frawley & McGuinness, 2023; Heise & Wiessinger, 2011; Stacey, 2020; Ureño et al., 2018; Uvnas-Moberg & Kendall-Tackett, 2018). As dopamine is released from the hypothalamus and falls in response to the release of prolactin, the extreme drop at the time of initial milk release is suggested to cause the negative emotional

sensations (Heise & Wiessinger, 2011; Stacey, 2020). An experimental study done in 1982 (Plotsky & Neill, 1982) reported a "momentary but profound" decrease in dopamine secretion in response to mammary stimulation, cited by Heise and Wiessinger (2011).

In a literature review/update by Deif et al. (2021), the authors explored the potential psychoneurobiology of D-MER, specifically the intracerebral release of oxytocin, increased expression of oxytocin, and inhibition of dopamine. According to Deif et al. (2021), "During breastfeeding, there is an increase in intracerebral release of oxytocin and the expression of oxytocin receptors in specific brain locations" (p. 4) . This produces higher circulating oxytocin levels, which correlate to the mesocortiolimbic reward activation (Deif et al., 2021). Because of this pathophysiology, reduction in circulating oxytocin may be implicated in the dysphoric experiences in D-MER (Deif et al., 2021). Dopamine is also a stimulant to release oxytocin, but neurotransmitter patterns are hard to determine, since the brain is not as easily penetrated as the blood. Therefore, the true pathophysiologic underpinnings are hard to determine (Deif et al., 2021). In a case study by Cox (2010), a participant's medical provider ordered thyroid function tests in an attempt to determine the cause of her negative emotions during breastfeeding. Her results were normal, and the participant also spoke with lactation consultants and breastfeeding counselors who were unable to give any insight on the etiology of the problem (Cox, 2010).

### Impact of D-MER on Maternal Role and Breastfeeding Self-Efficacy

In six studies with 1,803 participants who were surveyed or interviewed while actively or having previously breastfed, there was a relationship between distressing symptoms during lactation and breastfeeding self-efficacy and maternal self-confidence (Cox, 2010; Heise & Wiessinger, 2011; Morns et al., 2021; Ureño et al., 2018; Watkinson et al., 2016; Yate, 2017). Study participants referred to their feelings of guilt, shame, and distress during lactation and a

negative impact on their breastfeeding confidence and self-confidence as a mother (Cox, 2010; Heise & Wiessinger, 2011; Morns et al., 2021; Ureño et al., 2018; Yate, 2017). Four articles referenced D-MER specifically (distressing emotions only during milk letdown) (Cox, 2010; Heise & Wiessinger, 2011; Ureño et al., 2019; Ureño et al., 2018) while three articles referenced D-MER and/or breastfeeding aversion (distress at any point during the lactation experience) (Morns et al., 2021; Watkinson et al., 2016; Yate, 2017)

The emotions experienced during D-MER and breastfeeding aversion led to guilt and isolation, feelings of shame, and inadequacy related to motherhood and the lactation experience (Morns et al., 2021; Watkinson et al., 2016). Women experienced "internal conflict" related to their desire to breastfeed while simultaneously having feelings of anguish and "low self-worth," during the process (Heise & Wiessinger, 2011; Yate, 2017). Participants viewed their negative emotional reactions as flaws inherent in themselves as mothers. Breastfeeding was identified as a fundamental aspect of maternal identity and worth, with women equating failing at breastfeeding to failing at motherhood (Frawley & McGuinness, 2023; Morns et al., 2021; Yate, 2017).

#### Support, Understanding, and Awareness

Five qualitative and one quantitative study, including 809 participants, addressed women's interactions and experiences with peers, health professionals, and partners/family regarding D-MER (Cox, 2010; Heise & Wiessinger, 2011; Ureño et al., 2019; Ureño et al., 2018; Watkinson et al., 2016; Yate, 2017). Participants identified that social support for D-MER was important, including the need for understanding and being heard with regard to their symptom experience and emotional response to symptoms (Cox, 2010; Frawley & McGuinness, 2023; Heise & Wiessinger, 2011; Morns et al., 2021; Stacey, 2020; Ureño et al., 2018; Uvnas-Moberg & Kendall-Tackett, 2018). Women noted that distraction, music, and aromatherapy may be

avenues to explore for healthcare providers and others supporting women experiencing D-MER (Heise & Wiessinger, 2011).

Participants experiencing D-MER and negative emotional sensations during breastfeeding indicated a need for both increased peer lactation support and incorporation of healthcare providers into support groups to promote D-MER understanding and awareness (Cox, 2010; Ureño et al., 2019; Ureño et al., 2018). Participants noted that peer support groups had the potential to alleviate guilt, normalize symptoms, and help them to make sense of their experiences in a safe, shared space (Heise & Wiessinger, 2011; Stacey, 2020; Ureño et al., 2018; Uvnas-Moberg & Kendall-Tackett, 2018)

Having a trusted health care professional that was familiar with D-MER increased women's confidence about the advice they were receiving about D-MER and helped them to feel reassured and supported in their breastfeeding experiences (Heise & Wiessinger, 2011; Ureño et al., 2019). Participants in a case series by Ureño et al. (2018) expressed disappointment with professionals' lack of knowledge about embodied emotional sensations during breastfeeding. In a perspective article by Frawley and McGuinness (2023), it was noted that mental health nurses are important in identifying D-MER and supporting women experiencing it. The authors suggest steps that mental health professionals can take to provide emotional and practical support to a postpartum woman experiencing D-MER, including creation of an open discussion with the breastfeeding mother regarding the symptoms being experienced and creating a mindful approach to manage symptoms (Frawley & McGuinness, 2023).

#### **Reduction and Cessation of Breastfeeding**

Four studies addressed reduction or cessation of breastfeeding as a method used to alleviate D-MER symptomatology (Cox, 2010; Heise & Wiessinger, 2011; Ureño et al., 2019;

Ureño et al., 2018) and two studies addressed breastfeeding reduction or cessation in the context of breastfeeding aversion (Morns et al., 2021; Yate, 2017). Participants in qualitative studies (case series, case report, meta-ethnography) and quantitative studies (descriptive prevalence) studies who experienced D-MER indicated a desire to stop breastfeeding or to decrease the frequency of breastfeeding sessions and supplement with infant formula due to the emotional distress during lactation (Deif et al., 2021; Frawley & McGuinness, 2023; Morns et al., 2021; Ureño et al., 2019; Ureño et al., 2018; Uvnas-Moberg & Kendall-Tackett, 2018). Two participants in a case series by Ureño et al. (2018) indicated stopping or reducing breastfeeding due to D-MER symptomology specifically, whereas another participant continued to breastfeed past 12 months, but noted that if the negative feelings had persisted more than the 30 second milk letdown, she would have weaned her child sooner (Ureño et al., 2018). In a metaethnographic review by Morns et al. (2021), the authors report, "Although women wanted to breastfeed several were not able to continue as a result of feeling an aversion during breastfeeding" (p. 132). These women described conflicted feelings after they stopped breastfeeding—relief alongside sadness, the latter stemming from the loss of a bonding experience and the infant health benefits of breastfeeding (Morns et al., 2021). Participants who continued breastfeeding, despite these negative emotions, reported a feeling of proudness, perseverance, optimism, and resiliency (Morns et al., 2021; Ureño et al., 2018).

#### Discussion

This integrative review synthesized the current literature on D-MER's etiology, symptomology, management, and impacts across a wide variety of settings and sociocultural contexts. Despite a relatively high observed prevalence of D-MER as reported in one study, in the United States, 9.1 % (Ureño et al., 2019), we found few published articles characterizing D-

MER or its impacts on lactating women and their families. The five summarizing themes generated from this synthesis indicate that D-MER has a probable link with postpartum dopamine perturbation, and the typical presentation involves variable and transient feelings of hopelessness, anxiety, and a feeling of depression and anxiety. While some individuals experiencing D-MER are able to manage this negative stimuli via mindfulness-based techniques and/or support and recognition of the condition by the healthcare community, D-MER is a risk factor for undesired breastfeeding cessation.

Three articles included in this review addressed breastfeeding aversion and negative feelings during breastfeeding and not D-MER specifically (Morns et al., 2021; Watkinson et al., 2016; Yate, 2017). However, they were included because descriptions of findings within the article could be interpreted to overlap with D-MER. Morns et al. (2021) and others (Watkinson et al., 2016; Yate, 2017) have highlighted several important differences between D-MER and breastfeeding aversion, including aversion being a general dislike of breastfeeding and the negative feelings occurring at times other than milk ejection. These have significant implications for development of prevention and management strategies for both conditions moving forward.

Current research has suggested some plausible physiological causes of D-MER related to dopamine. It is known that dopamine, oxytocin, and prolactin are all prominent in the breastfeeding mother, but current literature is limited in the knowledge and understanding of how neurotransmitters affect the body and cause these negative emotional sensations. Future research is needed to explore how other medical conditions, substances and medications, environmental factors/epigenetics, or experiences may influence D-MER's occurrence or course.

Participants in the included studies who experienced D-MER highlighted the need for support from peers also experiencing D-MER, healthcare providers, and within their family unit

(Cox, 2010; Frawley & McGuinness, 2023; Stacey, 2020; Ureño et al., 2019). According to Ureño et al. (2018), support groups can help to minimize the distress that these dysphoric feelings may cause (Ureño et al., 2018). Ureño et al. (2019) stated, "Support Groups have previously been found to minimize the distress that D-MER can cause. In this study, only 6.1% of respondents reported that counseling/therapy made symptoms better; however, we did not collect data on the number of respondents who sought out counseling and/or therapy (p. 672). Social and clinical support is recognized as a critical component of other breastfeeding support interventions (Quality, 2015; Services, 2013) The U.S. Department of Health and Human Services includes nine strategic goals to support women who are breastfeeding. Specifically, strategy three and four speak to support services: access to professional support and peer support groups (Quality, 2015). According to the CDC, these early intervention support programs, including lactation consultants, physicians, and nursing staff allow a barrier to be broken down for the mother and baby. Women's experiences early on in their breastfeeding journey influence whether or not they breastfeed, and for how long (Quality, 2015). Moon and Woo (2021) explored and synthesized the current evidence of mothers' experiences of online breastfeeding peer support by integrative review. The authors describe the positive aspects of online breastfeeding support groups and the potential to change breastfeeding outcomes and perceptions (Moon & Woo, 2021), Sayres and Visentin (2018), in a literature review, discuss family centered breastfeeding and the importance of even distribution of responsibility in the mother's household. Also included is the strength of the woman's support system and how to involve the family unit in the breastfeeding experience. This author also reviewed peer support groups, and state that "In addition to help from the family, recent studies have examined different types of peer sup-port groups, including 'support coaches', 'visiting family support workers', and 'drop-

in centers' (e.g., Baby Cafes) with the aim of promoting a supportive method for nursing mothers" (Sayres & Visentin, 2018, p. 593)

In some included studies, distraction and mindfulness-based exercises were noted as potentially effective approaches to reduce D-MER symptoms (Stacey, 2020; Ureño et al., 2018; Uvnas-Moberg & Kendall-Tackett, 2018). Uvnas-Moberg and Kendall-Tackett (2018) spoke to mindfulness and its proven efficacy in many health conditions. This technique, combined with cognitive therapy, has a potential to lessen the flood of negative emotions and symptoms associated with D-MER (Uvnas-Moberg & Kendall-Tackett, 2018). By focusing on breathing and being present in the moment, it reminds the breastfeeding woman that they are experiencing "thoughts", not facts. The authors conclude by stating that "mindfulness is a powerful mechanism for downregulating the stress response" (Uvnas-Moberg & Kendall-Tackett, 2018, p. 28). A randomized control trial by Lucas et al. (2019) explored breastfeeding self-management interventions in 60 breastfeeding women. The author spoke to self-management strategies of distraction, cognitive reframing, breathing, and relaxation, and their effectiveness at reducing pain perception and anxiety (Lucas et al., 2019).

#### Limitations

The depth and scope of this review was limited by the lack of primary research published on D-MER. In addition, the appraisal of available evidence was completed by a single reviewer, in consultation with a group of researchers. The search strategy used in this review may have failed to retrieve all applicable research and excluded grey literature. Most included studies were also conducted in high-income countries with nuclear family structures. Research that includes different cultures and regions is needed.

### Conclusion

There is an overall lack of research on D-MER. Available research indicates that D-MER is not rare, follows a relatively predictable pattern in terms of symptom onset and resolution, has a likely physiologic rather than psychologic basis, and has negative impacts on maternal psyche and breastfeeding outcomes. Most existing literature on the condition encompasses clinical opinion, case studies/case reports, and reviews and is conducted in high-income countries, like the United States. Epidemiologic research including diverse populations is indicated to understand D-MER's etiology, risk factors, and impacts. Future research should also address the development and integration of prevention and management strategies.

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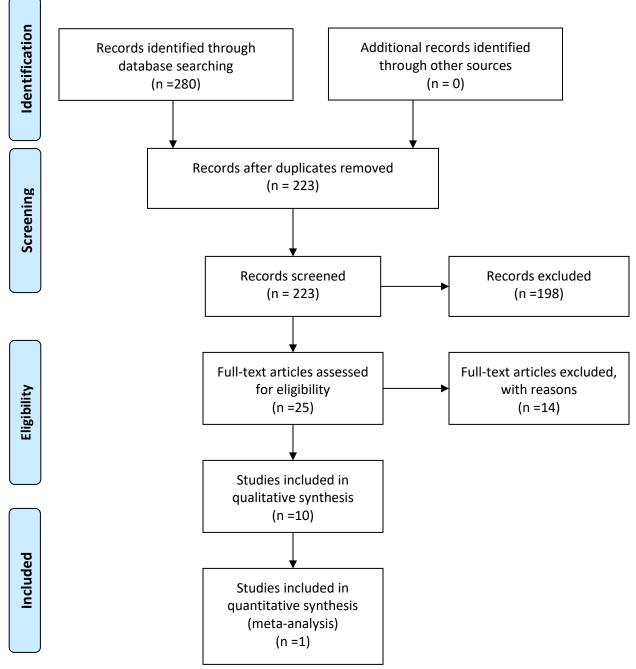
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# Appendix A

## Figure 1

### PRISMA Flow Chart



Note. PRISMA flow chart: Covidence Software

Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1271/journal.pmed1000

doi:10.1371/journal.pmed1000

# Appendix B

# Table 1

*Characteristics of Included Studies (N=11)* 

| First author, year, title, setting(s)  | Design/Method    | Aim/Purpose  | Sample (N)  |
|--|------------------|--|---|
|  |                  |  |   |
| Cox (2010)<br>A case of dysphoric milk ejection<br>reflex (D-MER)  | Case study       | To describe a mother's<br>experience with D-MER with<br>her fourth child                               | N=1,<br>One patient case study;<br>participant had 4 children,<br>previously breastfed other                                |
| Australia  |                  |  | children for a combined 81 months.  |
| Deif et al. (2021)<br>Dysphoric Milk Ejection Reflex:<br>The Psychoneurobiology of the<br>Breastfeeding Experience | Narrative review | To provide background on D-<br>MER incorporating both<br>neurobiological and<br>psychological theories | N=10<br>Research articles and online<br>sources cited involving<br>neurotransmitter and hormonal<br>activity in D-MER       |
| Egypt  |                  |  |   |
| Heise and Wiessinger (2011)<br>Dysphoric milk ejection reflex: A<br>case report                                    | Case report      | To describe course of D-MER<br>in one mother, including<br>management of symptoms                      | N=1,<br>One mother with 3 children,<br>reported lactation experience<br>with third child (10+ months<br>lactation duration) |
| United States  |                  |  |   |

| First author, year, title, setting(s)  | Design/Method  | Aim/Purpose  | Sample (N)   |
|--|--|--|--|
|  | -  |  |  |
| Frawley & McGuiness (2023)<br>Dysphoric milk ejection reflex (D-<br>MER) and its implications for<br>mental health nursing   | Perspective Article  | To describe relationship<br>between D-MER and mental<br>health, provide practice<br>implications for D-MER in<br>mental health nursing | N/A  |
| Europe   |  |  |  |
| Morns et al. (2021)<br>Women who experience feelings<br>of aversion while breastfeeding:<br>A meta-ethnographic review<br>Canada, Australia, and United<br>Kingdom | Meta ethnographic<br>qualitative synthesis –<br>MEDLINE, CINAHL,<br>PsycINFO, Maternity and<br>Infant Care databases-<br>literature published<br>between 2000 to 2019. | To synthesize the literature on<br>breastfeeding aversion  | Five qualitative studies-<br>sample size 1,791 total<br>participants:<br>Study 1:n= 191<br>Study 2: n=889<br>Study 3: n=11<br>Study 4: n=6<br>Study 5: n=694 |
|  |  |  |  |
| Stacey (2020)<br>Dysphoric milk ejection reflex  | Narrative<br>review/commentary   | To review current research,<br>limitations, and areas of further<br>research related to D-MER  | N=3,   |

| First author, year, title, setting(s)  | Design/Method   | Aim/Purpose   | Sample (N)  |
|--|---|---|---|
| United States and Australia  |   |   | 3 published studies (case<br>series: 3 participants),<br>narrative review (N/A<br>participants), and case report:<br>1 participant) |
| Ureño et al. (2018)<br>Dysphoric Milk Ejection Reflex:<br>A Case Series                | Case series   | To explore experiences of<br>women with D-MER   | N=3,<br>Three participants, with 2-4<br>children  |
| Large Army Hospital in United<br>States  |   |   |   |
| Ureño et al. (2019)<br>Dysphoric Milk Ejection Reflex:<br>A Descriptive Study          | Prevalence study-<br>retrospective chart review<br>and cross-sectional survey | To examine the prevalence of<br>D-MER among breastfeeding<br>women and to describe the<br>experience of symptoms<br>associated with D-MER | N=99 survey, N=164 chart<br>review<br>Anonymous cross-sectional,<br>online survey   |
| Large Military Center in<br>Southeastern United States<br>(Womack Army Medical Center) |   |   | 99 recruited survey responses<br>related to self-identification of<br>D-MER   |
|  |   |   | A separate 164 retrospective<br>postpartum chart reviews were<br>performed for prevalence rate                                      |

| First author, year, title, setting(s)   | Design/Method                        | Aim/Purpose   | Sample (N)  |
|---|--------------------------------------|---|---|
| Uvnas-Moberg and Kendall-<br>Tackett (2018)<br>The Mystery of D-MER: What<br>Can Hormonal Research Tell Us<br>About Dysphoric Milk-Ejection<br>Reflex?  | Narrative review                     | To examine the phenomenon of<br>D-MER in relation to hormonal<br>case report research, provide<br>hypotheses on the potential<br>cause of D-MER, and suggest<br>possible strategies mothers can<br>use cope with symptoms | N/A   |
| Watkinson et al. (2016)<br>Maternal experiences of<br>embodied emotional sensations<br>during breast feeding: An<br>Interpretative Phenomenological<br>Analysis<br>Europe, America, and Australia | Interpretive<br>phenomenology        | To explore mothers'<br>experiences of embodied<br>emotional sensations during<br>breastfeeding, and impacts on<br>self-concept and relationships  | N=11,<br>11 mothers who reported<br>experiencing or having<br>experienced negative<br>embodied emotional<br>sensations associated with<br>breastfeeding in the past five<br>years |
| Yate (2017)<br>A Qualitative Study on Negative<br>Emotions Triggered by   | Qualitative interpretive description | To explore experiences of<br>breastfeeding aversion and<br>agitation  | N=694,<br>694 random women who<br>completed an anonymous  |

| First author, year, title, setting(s)   | Design/Method | Aim/Purpose | Sample (N)                     |
|---|---------------|-------------|--------------------------------|
| Breastfeeding; Describing the   |               |             | online survey on their         |
| Phenomenon of<br>Breastfeeding/Nursing Aversion<br>and Agitation in Breastfeeding |               |             | experiences with breastfeeding |
| Mothers<br>International Survey: Europe,  |               |             |                                |
| India, Iran, and America  |               |             |                                |

Note. Adapted from Health Sciences Literature Review Made Easy: The Matrix Method by Judith Garrard

D-MER: Dysphoric Milk Ejection Reflex

## Table 2

# Assessment of D-MER Measurement within the Sample (N=11), Data Summary Table, including Variables and Reliability

| Authors, title, journal  | Variable(s)  | Instrument             | Findings/Results   | JBI Appraisal          |
|--|--|------------------------|--|------------------------|
|  |  |                        |  | (60% cut off<br>score) |
| Cox (2010)<br>A case of dysphoric<br>milk ejection reflex (D-<br>MER)<br>Breastfeeding Review                            | <ul> <li>Breastfeeding</li> <li>Postpartum</li> <li>Negative Emotions</li> <li>Milk Ejection</li> </ul>  | Case Report- Interview | <ul> <li>Feelings of sadness,<br/>panic, dread during milk<br/>letdown, even when not<br/>breastfeeding (random<br/>letdown)</li> <li>Providers (doctor,<br/>psychologist, lactation<br/>consultant, and Child<br/>Health Nurse) unaware of<br/>D-MER etiology and all<br/>interested in wanting to<br/>support patient</li> <li>Did not want to wean;<br/>persevered by being<br/>aware of D-MER,<br/>provider support</li> </ul> | 8/8- 100%<br>Reliable  |
| Deif et al. (2021)<br>Dysphoric Milk<br>Ejection Reflex: The<br>Psychoneurobiology of<br>the Breastfeeding<br>Experience | <ul> <li>Breastfeeding</li> <li>Postpartum</li> <li>Negative Emotions</li> <li>Milk Ejection</li> <li>Dopamine</li> <li>Oxytocin</li> <li>Prolactin</li> </ul> | Literature Review      | <ul> <li>D-MER not commonly<br/>researched</li> <li>Potential hormonal,<br/>neurobiological, and<br/>psychological etiology</li> <li>Low, transient levels of<br/>dopamine during milk</li> </ul>  | N/A (not<br>research)  |

| Authors, title, journal  | Variable(s)  | Instrument                        | Findings/Results   | JBI Appraisal          |
|--|--|-----------------------------------|--|------------------------|
|  |  |                                   |  | (60% cut off<br>score) |
| Frontiers in Global<br>Women's Health  |  |                                   | ejection may play key<br>role  |                        |
| Heise and Wiessinger<br>(2011)<br>Dysphoric milk ejection<br>reflex: A case report<br>International<br>Breastfeeding Journal | <ul> <li>Breastfeeding</li> <li>Postpartum</li> <li>Negative Emotions</li> <li>Milk Ejection</li> <li>Dopamine</li> <li>Reassurance</li> </ul> | Case Report- Interview            | <ul> <li>Dysphoria only during<br/>milk ejection and<br/>uninfluenced by<br/>participant's birth and<br/>lived postpartum<br/>experiences</li> <li>Symptoms increased<br/>under certain<br/>circumstances (e.g.,<br/>alcohol use, smoking,<br/>caffeine, acute stress) that<br/>commonly influence<br/>dopamine levels (increase<br/>in smoking, alcohol,<br/>caffeine, and decrease in<br/>stress).</li> <li>Awareness of D-MER's<br/>existence was key in<br/>coming to terms with<br/>symptoms</li> </ul> | 8/8- 100%<br>Reliable  |
| Frawley & McGuiness<br>(2023)  | <ul> <li>Breastfeeding</li> <li>Postpartum</li> <li>Negative Emotions</li> <li>Milk Ejection</li> </ul>  | Perspective- Literature<br>Review | • Difficulties with<br>breastfeeding exacerbates<br>postnatal mental health<br>issues  | N/A (not<br>research)  |

D-MER and the Breastfeeding Mother

| Authors, title, journal   | Variable(s)  | Instrument                            | Findings/Results  | JBI Appraisal           |
|---|--|---------------------------------------|---|-------------------------|
|   |  |                                       |   | (60% cut off<br>score)  |
| Dysphoric milk ejection<br>reflex (D-MER) and its<br>implications for mental<br>health nursing<br>International Journal of<br>Mental Health Nursing | Mental Health     Nursing  |                                       | <ul> <li>Different origins and<br/>clinical presentation of<br/>breastfeeding aversion vs<br/>D-MER</li> <li>Mental health nurses<br/>need more education on<br/>breastfeeding and D-<br/>MER to provide adequate<br/>support</li> </ul>  |                         |
| Morns et al. (2021)<br>Women who experience<br>feelings of aversion<br>while breastfeeding: A<br>meta-ethnographic<br>review<br>Women and Birth     | <ul> <li>Breastfeeding</li> <li>Postpartum</li> <li>Negative Emotions</li> <li>Aversion</li> <li>Inadequacy</li> </ul> | Meta-Ethnography-Literature<br>Review | <ul> <li>Strong embodied<br/>emotional sensations,<br/>overwhelming/ negative<br/>feelings, guilt, shame,<br/>sense of failure</li> <li>Further negative<br/>implications such as<br/>breastfeeding<br/>discontinuation</li> <li>Differentiation of<br/>aversion and D-MER</li> </ul> | 10/10- 100%<br>Reliable |

| Authors, title, journal  | Variable(s)   | Instrument                          | Findings/Results  | JBI Appraisal          |
|--|---|-------------------------------------|---|------------------------|
|  |   |                                     |   | (60% cut off<br>score) |
| Stacey (2020)<br>Dysphoric milk ejection<br>reflex<br>Breastfeeding Review                           | <ul> <li>Breastfeeding</li> <li>Postpartum</li> <li>Negative Emotions</li> <li>Milk Ejection</li> <li>Dopamine</li> <li>Knowing</li> <li>Distraction</li> </ul>   | Commentary- Review of<br>Literature | <ul> <li>D-MER characterized by<br/>negative emotions such<br/>as homesickness, self-<br/>loathing, anger, anxiety,<br/>dread, and suicidal<br/>thoughts</li> <li>Use of certain herbal<br/>supplements and<br/>medications, dietary<br/>changes (caffeine intake),<br/>and lack of sleep/stress<br/>worsened D-MER<br/>symptoms</li> <li>60-80% of women with<br/>D-MER reported<br/>previous mental health<br/>conditions<br/>(anxiety/depression)</li> </ul> | N/A (not<br>research)  |
| Ureño et al. (2018)<br>Dysphoric Milk<br>Ejection Reflex: A Case<br>Series<br>Breastfeeding Medicine | <ul> <li>Breastfeeding</li> <li>Postpartum</li> <li>Negative Emotions</li> <li>Dysphoria</li> <li>Milk Ejection</li> <li>Dopamine</li> <li>Prolactin</li> <li>Knowledge</li> <li>Distraction</li> </ul> | Case Series- Interviews             | <ul> <li>Sudden onset of negative<br/>feelings during let down<br/>of each breastfeeding<br/>session</li> <li>More intense feelings<br/>associated with longer<br/>lasting symptoms</li> <li>Increasing negative<br/>feelings after taking<br/>Metoclopramide</li> </ul>  | 7/10- 70%<br>Reliable  |

| Authors, title, journal   | Variable(s)   | Instrument                                | Findings/Results   | JBI Appraisal          |
|---|---|---|--|------------------------|
|   |   |   |  | (60% cut off<br>score) |
|   |   |   | <ul> <li>Rhodiola rosea, root<br/>supplement, small<br/>improvement in<br/>symptoms</li> <li>Symptoms decreased<br/>over period of months</li> </ul>   |                        |
| Ureño et al. (2019)<br>Dysphoric Milk<br>Ejection Reflex: A<br>Descriptive Study<br>Breastfeeding Medicine  | <ul> <li>Breastfeeding</li> <li>Postpartum</li> <li>Negative Emotions</li> <li>Dysphoria</li> <li>Milk Ejection</li> <li>Prevalence</li> </ul>                  | Survey<br>Retrospective Chart Review      | <ul> <li>15 women out of 164<br/>postpartum chart reviews,<br/>self-identified as having a<br/>negative emotional<br/>response, for a<br/>prevalence rate of 9.1%</li> <li>Relief upon finding that<br/>D-MER was an existing<br/>phenomenon</li> <li>Awareness, education,<br/>and support groups<br/>helped with D-MER<br/>distress</li> </ul> | 8/9- 89%<br>Reliable   |
| Uvnas-Moberg and<br>Kendall-Tackett (2018)<br>The Mystery of D-MER:<br>What Can Hormonal<br>Research Tell Us About<br>Dysphoric Milk-<br>Ejection Reflex?<br>Clinical Lactation | <ul> <li>Breastfeeding</li> <li>Postpartum</li> <li>Negative Emotions</li> <li>Dysphoria</li> <li>Milk Ejection</li> <li>Oxytocin</li> <li>Prolactin</li> </ul> | Review of Literature-<br>Narrative Review | <ul> <li>Women report D-MER<br/>type feelings appearing<br/>upon let down and<br/>subsiding up to 10<br/>minutes after</li> <li>Symptoms include<br/>negative feelings,<br/>dizziness, overwhelming<br/>sadness, anger, panic</li> </ul>   | N/A (not<br>research)  |

D-MER and the Breastfeeding Mother

| Authors, title, journal  | Variable(s)  | Instrument   | Findings/Results   | JBI Appraisal           |
|--|--|--|--|-------------------------|
|  |  |  |  | (60% cut off<br>score)  |
|  |  |  | <ul> <li>Severe symptoms<br/>prompts weaning in some<br/>cases</li> <li>Can co-occur with<br/>postpartum depression<br/>and/or anxiety.</li> <li>Dopamine, oxytocin,<br/>self-care, skin to skin,<br/>and environment factors<br/>may influence D-MER<br/>and comfort/coping<br/>during symptoms</li> </ul>  |                         |
| Watkinson et al. (2016)<br>Maternal experiences of<br>embodied emotional<br>sensations during<br>breast feeding: An<br>Interpretative<br>Phenomenological<br>Analysis<br>Midwifery | <ul> <li>Breastfeeding</li> <li>Postpartum</li> <li>Negative Emotions</li> <li>Aversion</li> <li>Embodied<br/>Emotions</li> <li>Inadequacy</li> <li>Frustration</li> </ul> | Interview- Interpretive<br>Phenomenological Analysis | <ul> <li>Intense "gut wrenching"<br/>feelings during<br/>breastfeeding</li> <li>"Proof of being a good<br/>mother" is equated with<br/>successful breastfeeding.<br/>Women noting self-<br/>doubt, and support<br/>seeking behaviors as<br/>being inadequate and<br/>failing as a mother.</li> <li>Others' and self<br/>understanding of D-MER<br/>helps to manage negative<br/>emotions and feelings;<br/>healthcare providers</li> </ul> | 10/10- 100%<br>Reliable |

| Authors, title, journal  | Variable(s)  | Instrument | Findings/Results   | JBI Appraisal<br>(60% cut off<br>score) |
|--|--|------------|--|---|
|  |  |            | generally unaware of D-<br>MER   |   |
| Yate (2017)<br>A Qualitative Study on<br>Negative Emotions<br>Triggered by<br>Breastfeeding;<br>Describing the<br>Phenomenon of<br>Breastfeeding/Nursing<br>Aversion and Agitation<br>in Breastfeeding<br>Mothers<br>Iranian Journal of<br>Nursing and Midwifery<br>Research | <ul> <li>Breastfeeding</li> <li>Postpartum</li> <li>Negative Emotions</li> <li>Aversion</li> <li>Challenges</li> <li>Guilt</li> <li>Shame</li> <li>Emotional Distress</li> </ul> | Survey     | <ul> <li>Etiology unclear</li> <li>Feelings of wanting to<br/>unlatch, anger, rage, and<br/>internal conflict</li> <li>Pain and other triggers<br/>possible</li> <li>Desire to understand<br/>phenomenon more and<br/>bring awareness</li> </ul> | 10/10- 100%<br>Reliable                 |

Note. Adapted from Health Sciences Literature Review Made Easy: The Matrix Method by Judith Garrard

JBI: Joanna Briggs Institute

### Chapter Three

**Results Manuscript** 

# Exploring the Lived Experiences of Dysphoric Milk Ejection Reflex During Postpartum Breastfeeding: A Phenomenological Study

#### Abstract

**Background:** Dysphoric Milk Ejection Reflex (D-MER) is defined as an undesirable feeling in which women experience within seconds of milk letdown. This dysphoria is an understudied phenomenon involving dysregulation of emotions during milk ejection. Current literature explores women's breastfeeding experiences through postpartum depression and aversion, but does not explore the lived experiences of breastfeeding related to D-MER.

**Research Aim:** To explore the lived experiences of recently delivered postpartum breastfeeding women who self-identify as having experienced Dysphoric Milk Ejection Reflex.

**Methods:** A prospective, cross-sectional, phenomenological study was carried out through indepth interviews with 13 recently delivered postpartum women who self-identified as experiencing D-MER. Purposive sampling was used. The data were analyzed using Giorgi's Descriptive Phenomenological method of analysis.

**Results:** The analysis revealed a common experience of frustration, unawareness, and validation between the mothers' breastfeeding experiences. Their journey was characterized by four distinct themes described as the following: 1) *Breastfeeding concessions and toleration; 2) Something* 

does not feel "normal"; 3) I remember a feeling like this before 4) This is real, and recognition is validating.

**Conclusion:** The women in this study described unique challenges and experiences with the phenomenon of D-MER. They expressed experiences its physiological and psychological implications. However, once women were able to discover the term, they felt a sense of validation and urge to spread awareness of this limitedly known phenomenon.

## **Keywords:**

dysphoric milk ejection reflex, lactation, human milk, milk letdown, negative feelings, phenomenology

## Background

Breastfeeding is often thought of as a positive experience, with positive emotional experiences; however, there can be difficulties and unpleasant experiences that have psychological inferences for lactating women. The dysregulation of emotions during breastfeeding sessions is an important area that is under-researched, specifically a phenomenon called Dysphoric Milk Ejection Reflex, also known as D-MER. This experience happens during a mother's milk let-down as she begins to breastfeed, happening roughly eight to twelve times daily. The mother may have feelings of hopelessness, sadness, and overall depression during the let-down phase of milk production. Once the mother's milk has "let-down", the symptoms quickly subside and usually last no longer than about thirty seconds, or the duration of the milk let-down (Cox, 2010; Heise & Wiessinger, 2011; Ureño et al., 2018). Currently, no medical diagnosis exists for this phenomenon and may even be unrecognized by some Certified Lactation Consultants. D-MER is recognized by some women who self-identify with the symptomology of D-MER, while others may experience the symptoms but be unaware that it is an established physiological problem.

It has been directly observed, that during D-MER, neurotransmitters in the brain are affected, either by depletion or a dysregulated reuptake of dopamine and/or prolactin levels (Heise & Wiessinger, 2011). According to Bosquet Enlow et al. (2014), "[Maternal] physiological stress regulatory systems (e.g., hypothalamic– pituitary–adrenal [HPA], autonomic nervous system, central nervous system) become organized during the first months through caregiver–infant transactions, with sensitive caregiving promoting effective stress regulation" (pp. 41-42).

Current literature explores women's breastfeeding experiences related to postpartum depression and anxiety but does not suggest or explore any experiences of breastfeeding mothers related to D-MER. As a result of this gap in literature, this study aimed to understand the lived experiences of recently delivered postpartum breastfeeding women who self-identify as having experienced Dysphoric Milk Ejection Reflex.

#### Method

### **Research Design**

This descriptive phenomenological qualitative research study was conducted to explore the breastfeeding experiences of women who self-identify as experiencing D-MER. The most appropriate method to uncover patterns and similarities of the human experience of lactation and psychological underpinnings is descriptive phenomenology.

Using the phenomenology design of Edmund Husserl, the structures of the conscience experience as experienced from the first-person point of view was explored, along with relevant conditions of the experiences being investigated.

## Setting

This study was not limited in reference to the setting or location of the participants, as participation was open to women globally. The language used for research was English, but one participant was multilingual. Breastfeeding duration is not specified for this research due to the PI wanting a purposeful sampling for a variety of stages postpartum. The average duration of breastfeeding in participants was three months, with the longest duration of 14 months.

#### Sample

A purposeful sample of 13 women who self-report symptomology of D-MER via the social media platform titled "D-MER Support Group" were selected for this study. This group is

composed of over 5,400 members from across the world. A gatekeeper associated with a Facebook group who moderates membership was included to assist with recruitment and promotion of this study.

The inclusion criteria included: 1. Participants who are of childbearing age and English speaking. 2. All participants self-reported that they have previously experienced D-MER based on their personal and lived experiences. 3. Gave birth to a living newborn, no longer than 36 months prior to the data collection date, and breastfed the same infant, for any length of time during their postpartum period. 4. Participant needed to have internet access, computer, and/or smartphone access for interview purposes. Exclusion criteria included any woman who is not English speaking.

By interviewing women in different stages of their breastfeeding journey, the PI can extract additional information and understanding, based on postpartum length and breastfeeding duration. However, it is important to note that the participant did not have to be exclusively breastfeeding at the time of interview.

## **Data Collection**

Recruitment of participants occurred in January of 2023, with data collection occurring between February 2023 and March 2023. Women received notification of the study by a recruitment flyer posted on a "D-MER Support Group" social media page. Women who were interested in participating in the study were encouraged to contact the PI with any questions. If there were no questions, a link to the consent form was provided on the recruitment flyer and consent was obtained via Qualtrics. Before the interview, sociodemographic characteristics were collected through a Qualtrics online link. These were self-identified age, race, gender identification, marital status, education level, type of employment, and annual household income.

Additionally, information about breastfeeding was collected, such as children, children age, delivery type, and breastfeeding exclusivity (**Exclusive breastfeeding:** No other liquid or solid from any other source enters the infant's mouth. **Almost exclusive:** Allows occasional tastes of other liquids, traditional foods, vitamins, or medicines. **Full breast milk feeding:** The infant receives expressed breast milk in addition to breastfeeding. **Partial:** Any feeding of expressed breast milk. **Token:** Minimal, occasional breastfeeds for comfort.)

Interviews were arranged by the participant and PI, based on a mutually agreed upon day and time. Interviews were conducted in a secure Zoom Online Room, video and audio recorded, and transcribed verbatim for coding and analysis by the PI. A semi-structured interview guide was utilized to elicit data about participants' breastfeeding experience (Appendix A). This interview guide was somewhat open-ended in structure to allow participants to ultimately guide data collection (i.e., concepts/new ideas brought up by the participants will be investigated). Fieldnotes were taken during interviews in a notebook, contained by the PI and securely locked after each interview. On average the individual interviews lasted approximately 50 min. Pseudonyms are used to preserve confidentiality and anonymity.

### **Data Analysis**

To analyze demographic data, Qualtrics data was extracted, and summary statistics were calculated. Data management was done by the PI, with oversight by secondary researchers, with the assistance of Nvivo12 software. Data analysis occurred concurrently with data collection and was completed by the PI following Giorgi's six steps of descriptive phenomenology data analysis. According to Giorgi, "The results reflect a careful description of precisely the features of the experienced phenomenon as they present themselves to the consciousness of the researcher" (Giorgi, 2009, pp. 130–131). These six steps include: 1) transcribe interviews

verbatim, 2) suspend one's personal beliefs or convictions about the phenomenon of interest prior to examination of data, 3) read and re-read data to indirectly experience the phenomenon described by participants, 4) transform data into small sections to indicate participants change in flow of consciousness during the interview, 5) reread the small sections for transformation into shared components of the participants' lived experience, and 6) integrate components into the phenomenon's general meaning structure. For this study the general meaning structures were articulated as themes. Data was analyzed in a manner to include emergent themes as part of the descriptive phenomenological analysis. Active listening and critical reflection were done to remain receptive to the participants' experiences (Giorgi, 1997).

The final level of analysis resulted in themes and reveal what it was like to be breastfeeding while experiencing D-MER. Trustworthiness was ensured through bracketing and auditability, by observation field notes, questionnaires, and during data collection via in-depth interviews. These muti-methods enable the contextualization of the participants' meanings through their lived experiences.

#### Results

### **Characteristics of the Sample**

The sociodemographic characteristics are presented in Appendix B, Table 2. Thirteen women whose infants were less than 36 months old participated in this study. Over 200 women signed consent forms to participate in this study. The PI selected participants based on a first come, first served basis. The PI then closed the loop of communication with the unselected, remaining participants informing them that data saturation had been reached and they were not selected to participate.

Of the 13 completed demographic survey responses, all 13 participants (100%) selfidentified as female. All participants were over the age of 18, and 92% identified as white. When looking at geographical location, 9 participants (69%) live in the United States, 2 participants (15%) in the United Kingdom, 1 participant (8%) in Senegal, and 1 participant (8%) in Australia. In 69% of the sample, a bachelor's degree was the highest educational level and 92% reported their marital status as married. Of birthing types, 77% had vaginal deliveries and 54% reported being first time mothers. Of the mothers that were not primipara, 100% reported feeling D-MER symptoms in their previous lactation experience.

## Themes

The themes identified from data collection and analysis describe a common story of the unpleasant feelings, frustration of the breastfeeding journey, and finally, validation of their experiences and feelings during the postpartum period. As women started to breastfeed their infants and noticed an abnormal feeling during their milk ejection, they further explored the phenomenon being felt. Consistent with Giorgi's phenomenology, the findings are present with 19 meaning units, which were used to form 4 structural themes, seen in Appendix B, Table 3. These themes included: 1) *Breastfeeding concessions and toleration; 2) Something does not feel "normal"; 3) I remember a feeling like this before 4) This is real, and recognition is validating.* 

## **Breastfeeding Concessions and Toleration**

The essential theme, *breastfeeding concessions and toleration*, describes the women's intentions, goal setting regarding her breastfeeding journey, and troubles during the latch process. All women had planned to breastfeed and expressed their belief that breastmilk is the desired intake of choice for their infants. They were all well informed that breastfeeding is the optimal way of feeding their infant and contributed to enhanced early development and growth.

This is illustrated by Loise who stated, "Everything says that breast milk is the healthiest. So, I want to obviously do what's best for the kids."

Upon feeling the symptoms of D-MER, women immediately felt a sense of disconnect and hinderance on their breastfeeding experience. Once Loise experienced the symptoms of D-MER, her feelings surrounding breastfeeding and the experience of lactation changed. Breastfeeding was very important to Loise, and her mourning the loss of this experience can be felt in the statement below:

I knew formula was expensive, but I was just going crazy, and I like cried and cried, and then, like wrote this huge, long letter to my husband one day when he was at work, and he came home, and I gave it to him, and like, went in my room and sobbed and he's like, "You can switch to a formula, it's fine," and I was like, "No, it's not. I'm gonna make us go bankrupt." But like suddenly it was like all these, like small things, were some of these huge obstacles around me. I feel like going through that experience once every 3 h for 2 months, 3 months. Yeah, it definitely like messes with you and makes everything seem worse than it is.

Loise breastfed exclusively for 10 weeks before switching to formula and expressed breast milk.

All the women in the study had a duration goal set in their minds related to their breastfeeding journey; most even before giving birth. Women also spoke about the feelings of wanting to cease breastfeeding once feeling these negative emotions. All 13 mothers spoke about their individual goals and how D-MER impacted their specific goals and breastfeeding outcomes. Isabelle reached her initial breastfeeding "duration" goal, but was not enjoying her experience, and therefore settled and adjusted her breastfeeding goals upon stopping her breastfeeding journey: My goal at first is, I want to make it like 3 months. Initially, I wanted to make it a year, and then I was like, "Wait, let's see if I can make it 6 months, because this sucks," and I just didn't like it, you know, and that made me feel sad because I was like, I wish that I enjoyed this experience. I'm just counting down the days to where I think she's like healthy enough that I can wean her. And that was discouraging.

Isabelle breastfed for 6 months before switching to formula. Becky expressed very similar feelings speaking to goal attainment and the determination to reach that goal:

I just knew [my breastfeeding journey was ending]. You know when you have a goal in mind, and I'd already exceeded it. But because I had such a definitive stop. I was just like, "I just have to get through it." I see that when you know when you can predict, when you can see a finish line, you can tolerate something a lot more than when you don't.

Becky noted her breastfeeding experience ended at 12 weeks. Women expressed their knowledge surrounding breastmilk and it being the optimum nutritional intake for their infants. As demonstrated in the following statement, formula was not an option for some women, such as Carol, even while experiencing D-MER:

*I, personally, would have continued [and did continue for 16 months]. I have very, very, very strong feelings about just health in general, and the benefits of breastmilk. So, like for that reason, I don't think there is anything that could have stopped me from breastfeeding.* 

The desire to breastfeed was a commonality among women and their overriding concern for the welfare of their children. All women expressed the feeling of pressure in relation to societal beliefs that formula is shameful and felt a "maternal guilt" when deciding to wean their children, for reasons due to D-MER and other breastfeeding difficulties experienced. Eleven of

the 13 women also mentioned breastfeeding difficulties related to latch and physical discomfort and eight women had infants with diagnosed tongue tie. Carol, who had five children, mentioned that her first two children did not experience tongue tie, and she did not recall experiencing the D-MER feelings and symptomology with them; however, with her three children thereafter, all had diagnosed tongue ties, had much difficulty with latching, and experienced D-MER:

So, when my third son, the one that I had a really bad D-MER with when he was born, he had a lip and tongue tie. I never experienced that with my other two kids, and the first eight days were like excruciating. And these two also have lip and tongue ties and nursing them at the beginning was really painful. It is possible that that is one of the things that contributed to me having D-MER with these three, and not my first two. My first two, there was no anxiety, like anxiety related to pain at the beginning of nursing. I wonder if that might have like been one of the reasons, just because it was so painful and sure a lot of anxiety thinking about latching. I know I've never even thought about that connection before, but that is one thing that related to these three.

Thus, it was important for all women to reach their lactation journey goal, which was individualized and personal to each woman. Once women started breastfeeding, their goals and personal viewpoints related to breastfeeding varied based on their early lactation experiences, education, support, and societal attributes.

#### Something Does Not Feel "Normal"

The theme, *something does not feel "normal,"* describes the experiences of feelings and symptomology women experienced during their initial latch while breastfeeding their infants. These experiences and feelings solidified the necessity to further explore what they were feeling and the abnormality of their symptomology. Women spoke to these negative emotional

sensations only occurring during milk letdown and subsiding soon after milk ejection. All women in the study noted that they did not need to be actively feeding their infant to feel these sensations. These sensations were felt during every milk letdown, including spontaneous letdowns (i.e.: grocery store, park, work, etc.). Twelve of the 13 women experienced worsening feeling during pumping, rather than direct breastfeeding. Women spoke about being unaware that these feelings were not "normal," however, they knew that they were not enjoyable. When speaking to friends and family, many women did not find that other breastfeeding women experienced the same feelings. A participant in the previously conducted D-MER mini-study explained that her friend described the feeling of breastfeeding and hormonal release as "loving something so much." She used this analogy: "When I start breastfeeding, I could be thinking about yoga. But when my milk letdown occurs, I don't just like yoga, I love it so much. I want to do yoga all the time because it is amazing." The study participant noted how different she felt than her friend. The profound abnormality in emotional sensations during breastfeeding was spoken by Kim, stated below,

It wasn't until the colostrum wasn't there. Because I remember it happening and I was saying to the midwives while still in the process of something, "It's not right. Something's not right." And they're going, "Oh", and I was crying when I'm feeding her and just like in an absolute panic.

Loise mentioned a very similar experience of the unknown symptomology being felt:

I don't feel right, like something's really wrong... and [my husband] is like, "What's wrong?" I'm like I do not feel well at all like I don't know if I'm about to pass out or barf or die like something. Something is not right.

In addition, when describing the abnormal feelings further, Loise also explained:

The first thing I would think is like a sinking feeling like, okay. Like almost as if like, there was some vacuum inside just going like it just felt like the life drained out of me like I was go with falling down a hole. It's really hard to describe, but like that would be like the first. It's like there's literally a physical sensation to it. It just, it suddenly was like something is wrong with my body. Something is wrong with your body, and like, because I thought I was dying.

All women in the study explained that these abnormal feelings were heightened during the evening hours, and mentioned a feeling of impending doom, dread, and debilitation. Each women's experience with D-MER symptomology was unique yet had a similar essence. Women spoke to physical symptoms of nausea, body aches, and overall feeling of sickness, in addition to psychological symptoms of anxiety, panic, sadness, deep nostalgia; a longing for something that was non-existent. Carol described her feelings as, "*The worst type of anticipation you can possibly imagine, like that is what D-MER feels like to me.*"

A similarity between all 13 women interviewed was that these feelings were only during milk letdown, and potentially a few minutes after. As emphasized by Carol,

I started noticing that I was getting really really, really, anxious, particularly when my milk let down. And that was when I was noticing like, I mean, I felt like I was gonna like hyperventilate in my heart would start racing. I even just thinking about it right now. I can like feel myself extremely stressed out, and it would get to the point where, like, I just felt like I was like spiraling, and it was only for I mean, you know that, It's only for a couple of minutes.

Many women spoke to the fact of simply knowing a milk let down was coming, merely because of these psychological feelings that came just before milk ejection. Grace spoke to the feelings

she experienced and the noticeable correlation to only occurring during milk letdown and the continuation of feelings with every let down.

I described it to my husband like the clouds like covered the sun and then I would feel the prickle, and then it would, would go away. And it was like this. It was literally, it felt like grief. That was what it felt like, like everything that I cared about was gone, and I couldn't get it back. And then it went away, and it was really weird. And then that just consistently kept happening with every let down from then on.

Although symptomology reported was individualized between women, all women in the study expressed feelings of "a negative sensation and not a pleasant experience, mentally, physically, and emotionally."

## I Remember a Feeling Like This Before

The theme, *I remember a feeling like this before*, represents the women's experiences and descriptions of the D-MER feelings and correlating them to similar feelings in their lives, ranging from childhood to adulthood. Out of the 13 women, 12 recollected feeling this negative emotional feeling at another point in their lives, most noted in childhood and/or adolescence. The commonality among 11 out of the 13 women was the connection between these D-MER feelings and intimacy. Jennifer stated that "*Same thing would happen after orgasm, but to a lesser extent, because I just I didn't make the connection*." Frances stated, "*I definitely recognize having it after having an orgasm*. " Hannah and Isabelle, who did not experience these feelings, both spoke to their experiences and intimacy. Hannah has never experienced an orgasm, and Isabelle spoke to nipple sensitivity but not the specific feelings felt during D-MER. When asked if there was any experience of these feelings during intimacy, Hannah mentioned to the PI, "*I don't think* 

so. I have like, I've never orgasmed. So, if it comes after organism, then it's not something I would have experienced." Isabelle speaks to her differing intimacy feelings below:

I can't think of another time that I felt that in like sexual intimacy. I don't think I did like, I said, I've always had like nipple sensitivity like I don't like having, I don't like being touched by anyone, you know, so like to have a baby on them. I was already a little like this is going to be weird for me, but the emotional aspect, like I had never experienced that sensation before.

Women shared that these feelings would occur upon any type of nipple stimulation, and/or post orgasm, attributing these feelings to a hormonal imbalance. Hannah explained how something as simple as activities of daily living would stimulate her nipples and cause the feelings associated with D-MER:

I definitely can say with my husband being intimate. And even just like, sometimes, if I was getting out the shower and the towel. Like anything that kind of stimulate it I was

*like, sometimes it would happen it, whether I was breastfeeding or not, I don't know.* Becky stated how she recognized these feelings in her life during intimacy and describes having these feelings for the same brief amount of time, 5 minutes or so, as similarly during breastfeeding:

Post coital, It's the only time but it was not as strong, but throughout my whole life, and not every time. But I'd be like, why is it after sex? I feel this sadness, this like, what is life? That level of like sinking low, and it would go away and like it never lasts more than 5 min. Whether it's post coital or D-MER. It only lasted about 5 min.

In addition to these similar feelings during intimacy, women also spoke about the deep nostalgia feelings that they described and remembering having these feelings early on in their

lives, and through adolescence. Grace spoke about these feelings while growing up, "It's something that I have felt at other time, but not like any specific like situation. But I remember growing up like having like occasional homesickness, and that nostalgia."

Isabelle also correlated her feelings with D-MER to other life experiences.

But I remember as a child feeling this feeling sometimes like, okay, oh, not exactly, but it was like a longing like a weird longing, but I couldn't put my finger on like I need something. It was like I'm hungry, or I'm thirsty, but like it's not one of those it's like that's why I say like kind of like nostalgia. It was like. I'm like aching for something, and I'm sick about it. But like I can't put my finger on it like. What is it that I need right now, and I kind of remember feeling that a couple of times when I was younger. And then, like, Yeah, I like I remember them like when I was a little older.

Upon interviewing Jennifer, she quickly remembered D-MER type feelings in her past while experimenting with recreation drugs, specifically ecstasy, also known as "Mollie." Appreciating her honesty and experience, the PI went back to the previous 9 women and asked if anyone had experience with this specific behavioral feelings and recreational drugs. Two additional women, Becky and Diana, had remembered experimenting with drugs and feeling these feelings. Becky had mentioned these feelings with cocaine use, and Diana with Delta 8 THC. Jennifer spoke in depth about her experience with ecstasy and the importance of looking into the physiological hormonal and neurotransmitter actions in the brain because of these similar feelings:

I'm really trying to wrap my brains to think of things from my past, like any sort of like medical drug experience or anything that would be relevant to this study. Like definitely looking into ecstasy, and the way that the brain works because they're very similar

feelings and maybe try to find, like other moms that have experimented with those drugs, because they, the feeling, is very similar. I don't know why but once you once, you peak, that's when, like everything like it's like a, it's like a big orgasm, like everything is awesome, and like everything is great. And then, like you're not dropping anymore, and the feeling is like magnified. Imagine the D-MER feeling but more intense. But I definitely would look into MDMA. The components of that drug. What it does to your brain, and why it could have a sort of correlation.

All women in the study expressed a type of past or present mental and/or behavioral tendency, such as anxiety, depression, OCD, and more specifically ADHD before, during, and/or after breastfeeding. Some women expressed having past experiences with anxiety and depression, while others noted their diagnosis came during their postpartum period. One woman, Grace, spoke to the physiological aspects of attention deficit hyperactivity disorder (ADHD) and the role of dopamine, in relation to the understanding that D-MER is also from a dopamine imbalance:

Last year I did get an ADHD diagnosis which I've been very curious about, because I know, my understanding, is the dysphoric milk feeling is, I think, related to the drop in dopamine before, I believe it's correct, and is released. And so, I wonder because dopamine is one of the key factors in ADHD.

Jennifer felt that it was very important to note that her experiences with postpartum depression was very different than the experiences of D-MER. She wanted to make it very known that while she experienced both, they were very separate issues:

I had a pretty traumatic Caesarean section experience. So, I do think that contributed my postpartum depression. But that I am very clear about that being an aside, you know, like

the whole D-MER thing, and like the postpartum depression thing. Like they can live in the same world, but I knew that I had both, because I had D-MER, like I was like this is nothing to do with the Caesarean. This has nothing to do with like the blues. This shit is different like I know this feeling. I was very sure I was like this is not it. Did [having postpartum depression] help? No, it didn't help, it sucked. But I just want to point out that I knew that it was very separate issues. Being able to create like just the knowing, is what helped me the most like being able to separate the PPD. Like the post-partum depression and the blues, from like knowing that this was a separate issue helps me a lot.

These emotional feelings were not unfamiliar to many women, as many women have expressed feeling a similar negative feeling during intimacy, recreational drug use, as a child (homesickness), and upon experiencing grief in their personal lives. Women also expressed having a previous diagnosis or undiagnosed condition such as obsessive-compulsive disorder (OCD), ADHD, and depression/anxiety previously, as well as after pregnancy.

## This is Real, and Recognition is Validating.

The theme, *this is real, and recognition is validating.*, discusses the importance of women's desire for understanding in the healthcare field about D-MER and how distraction was a commonality of all women to help endure the negative feelings. Once women discovered that D-MER is experienced by many other women, they felt a sense of validation and "relief", knowing that their feelings were real. Also, many women who reported these feelings to their provider were misdiagnosed as having postpartum depression and were prescribed a selective serotonin reuptake inhibitor (SSRI), typically Zoloft.

Loise mentioned, specifically, that her healthcare provider felt that an SSRI would help her feelings, stating "*My OB gave me like a prescription of Zoloft, and I took it. I didn't really notice any difference with anything.*"

Abigail mentioned even feeling frightened to speak to her healthcare team about the feelings she was experiencing stating, "*I reported it to my health visitor*. *D-MER is not really something that, it's not a big thing in the UK. And people I spoke to didn't have a clue. It made me not want to get help, because I was frightened of what would happen [related to custody and legal well-being of her child.]*" Abigail mentioned she was afraid her child would get taken away from her with these negative feelings occurring.

Many women spoke about the people around them not having an awareness of D-MER's existence or an understanding of how to support them in managing their symptoms. This included health providers, as well as family and friends. Dismissal was another term that many women spoke of when expressing their feelings to their healthcare provider and close family and friends. Kim made two separate statements regarding this dismissal she experienced:

I was very, very dismissed by a lot of people. So, I was very open with the doctor about that. I did feel like a lot of them still dismissed. "You're a first-time mom, it's [breastfeeding's] hard for everyone. You'll get over it."

After Kim realized that these feelings were not related to holding the baby or feelings of irregular bonding with her baby, she called her countries [Australia] breastfeeding help line. This was the first time where she felt as though someone was listening to her and expressed a sense of great relief that she was being heard and her feelings were real.

So, we were calling them at 8 0'clock that night because I'm thinking like this is a game changing now. I've just discovered something. And so, I was speaking to a lady on that

helpline. And she said to me, look, I think this is actually something that I don't know much about. I can tell you that what you're experiencing is real, but not many women experience it. I need to get my supervisor to call you back.

Kim also mentioned in this same situation, that once the supervisor of the breastfeeding help line called her back that she was very open to everyone around her regarding these feelings, specifically in the private hospital she delivered in, and there was *"zero, absolutely zero awareness"* when she felt these feelings right after her delivery, while still inpatient.

Validation was spoken about by all women in the study once they felt heard and understood, either by finding the term D-MER online, or by a healthcare provider, more often a lactation consultant, looking into the phenomenon closer for the women. Frustration was also mentioned concurrently with validation, because although the women were relieved to find that their feelings were of a specific phenomenon that does exist, many found this information by their own research, using a web browsing platform or seeing social media influencers speak about it. Loise mentioned hearing it from a social media influencer and expressed her frustration in hearing it from her and not from a nurse or healthcare provider when she was expressing her feelings to them directly.

She just goes by [name taken out for anonymity] and she had a baby in August of 2021. And she breastfed and had the same experience. I think one day she just posted in her stories like, does anybody else feel like this, and people responded. And then someone responded, saying, this is called D-MER, it's a literal thing and that's the first I had heard of it, and like I read up on it. I'm like holy shit, like I literally told the nurses multiple times about this, and no one said anything. The nurses didn't even say, "Let me get the lactation consultant."

Becky mentioned a similar experience with finding more information about D-MER from online research, although she mentioned a lactation consultant at her pediatrician's office who was aware of the phenomenon.

And then I googled it, and it was like a shot in the dark and I found it, and I was like what the-? this is a real thing. Midwives, my primary care doctor, didn't know what it was. And then I mentioned it at a pediatric visit, and they had a lactation consultant come in, who had, like a handout with information of the Facebook group, but the only reason that they knew to give me information is because I googled it and it was like D-MER.

Women also described experimenting with different remedies to combat their D-MER symptoms. These included drinking cold water during milk letdown, distraction by watching television, reading a book, or enjoying a pleasurable snack, and magnesium supplements. Although these remedies may "help", all women stated that nothing truly "cured" their symptoms. After discovering that there was a "term" for this phenomenon, many women expressed an overall feeling of relief in knowing. All participants expressed reassurance for the support they found in the D-MER Community Support Page on social media. Abigail stated, "*It was reassuring to know I wasn't the only one.*" Distraction was a technique that some participants used to manage their D-MER symptoms during milk letdown. Kim spoke to watching a favorite television show to help her connect to something else during the milk letdown. Carol spoke to Pavlovian conditioning, "So started experimenting with like the Pavilion *effect, and like, can I train myself to associate my milk let down with eating chocolate instead of like extreme anxiety and things like that. And actually, it was. It was really successful.*"

Mary spoke to distraction but felt that a simple distraction did not help. She felt that "mindless" distraction was not efficient enough to help her symptoms. She needed to be completed occupied and immersed in what she was doing for distraction to be successful for her:

I could not do, mindless because it was not enough distraction for me. I wound up doing like continuing education and like certifications, because I need to be like completely involved in whatever I was doing, like games on my phone was not enough. I had to do it for credit and that was probably what worked the best was being completely occupied in something else.

One thing that all women agreed on was that simply talking with their spouse or someone else in the room did not help their symptoms. All women stated that conversations needed to end while their milk was letting down and the feelings were being experienced. Once the feelings subsided, conversations could start up again. Kim called it a "*cognitive overload*." Diana mentioned her needing her husband to be silent while breastfeeding:

Yeah, I definitely I kind of feel like I don't really clench my fist, but I do like tense up, feel tense. I have to take some deep breaths. And then, like if [my husband] is talking to me about something brought up the other day. I started breastfeeding. He starts talking to me about money. I was like no wait until, like do not talk to me about stressful anything or anything in general while I'm breastfeeding.

Isabelle agreed that she could not converse with anyone and needed complete silence: *Pin drop silence. I need people not to talk to me, I needed like silence. Like if my husband was trying to have a conversation with me. Like, as I said, I would have to tell them like, hold on like, just hold on. and then I would like, get through the worst of it. And then I'm* 

*like, okay. You could talk to me now, but especially when I was pumping, I couldn't talk to anyone.* 

## Discussion

This study is the first of its kind to use a phenomenological approach to understand the emotion and lived experience of D-MER. Participation in the study provided a voice to women who have undergone these negative emotions and feelings during lactation. It highlights certain validation and maternal confidence gained from the experience and adds to the literature of D-MER that was not previously found.

## **Disappointment & Healthcare Unawareness**

Despite the women in this study being committed and open to a breastfeeding relationship, they found that breastfeeding with the experiences of D-MER lead to disappointment and frustration, rather than the natural and positive bonding experience they anticipated. It is important to highlight that every participant during her interview, mentioned the deep urge and importance of more education about this phenomenon. The PI specifically completed an IBCLC examination and noted that the education regarding D-MER to the lactation consultant population is few and far between. D-MER is mentioned, minimally, in Lactation Consultant preparatory textbooks, such as *The Breastfeeding Atlas and Counseling the Nursing Mother*, but the etiology of the phenomenon is not well understood and lacks understanding for healthcare providers to support these women experiencing D-MER. The participants stories paint a picture of health professionals' lack of knowledge about D-MER and the breastfeeding experience. In the clinical settings where the women in this study gave birth, there was no identification of D-MER when the women expressed their feelings to their healthcare providers.

#### Need for More Information: The Numbers Speak for Themselves

Findings from the PI's integrative review demonstrates the limited number of published research articles speaking about D-MER. In addition, the importance of further research is evident from the women interviewed and the 12,000 members of the D-MER Facebook support group. It is important to note that over 200 consent forms were signed in under 48 hours after posting a recruitment flier to the support page. These women are longing for answers and validation regarding the phenomenon of D-MER. In addition, investigation of the association between a woman's perceived psychological control and the level of severity of D-MER will promote the development of interventions and support services, including a potential treatment or symptom reduction, to help women overcome the negative symptomology of D-MER to improve the overall breastfeeding experience. The prevalence of D-MER is growing in practice, but more rigorous research related to prevalence, causation, and support is needed in the United States and globally.

#### **Roles and Reuptake of Dopamine**

Previous literature has mentioned the relationship between dopamine and the physiological underpinnings of D-MER (Deif et al., 2021; Heise & Wiessinger, 2011). Women in this study spoke to the relationships between the similar feelings of D-MER and ADHD, and D-MER and recreational drug use, specifically MDMA. Both ADHD and MDMA have an involvement with neurotransmitters, and more specifically, dopamine (Christoffel et al., 2021; Deif et al., 2021) When experiencing D-MER, dopamine drops rapidly, resulting in a short dopamine deficit (Deif et al., 2021) Like other amphetamines, MDMA enhances release of these neurotransmitters and/or blocks their reuptake, resulting in increased neurotransmitter levels within the synaptic cleft. With large amounts of neurotransmitters being released, such as

dopamine and oxytocin, the brain then becomes depleted, contributing to the negative psychological aftereffects. Similarly, women spoke to the similar feelings of D-MER and postintimacy, specifically after orgasm. Again, relating back to the role of dopamine, "Secretion of the hormone oxytocin leads to rhythmic muscle contraction and ejaculation. The larger the release of oxytocin, the more intense the orgasm. After that, the nucleus accumbens rewards us with a good portion of dopamine that we feel as relaxing pleasure" (Clark, 2020, para 15). In a woman with a dopamine reuptake problem--a potential etiology for D-MER, this dopamine would not be as high, resulting in the negative feelings, versus positive, relaxing pleasurable feelings.

## **Implications and Significance to Nursing**

The robust number of participants and verbal encouragement and necessity of this research from the public who are currently experiencing this phenomenon solidifies the need to perform and continue this research. With future research relating to D-MER, we can better understand and support breastfeeding women living with these unstable emotional sensations and feelings. This can ultimately increase breastfeeding success rates and improve the overall nutritional status of the newborn.

According to several studies, (Keim et al., 2021; Neifert & Bunik, 2013; Patel & Patel, 2016) research has the potential to yield novel, insightful data that can be interpreted into maternal and pediatric health practices and advance future nursing research, practice, and education while supporting the family as a whole. This research may help families cope with D-MER by promoting bonding and the beginning and continuation of lactation. Because there is little existing evidence for the highlighted themes discussed in this study, more qualitative and quantitative research is required.

As stated above, implications for future work may include exploring the lived experiences in women of color. The PI noted that 92% of the selected population identified as white. Further exploration of this phenomenon in women of color is extremely important to determine if these feelings are differentiated in women of different race.

Lastly, to let women understand they are not alone and that their feelings are supported and valid, education support groups and breastfeeding seminars should be made more widely available. This will allow encouragement and support along their nursing journey, Nurses and other healthcare workers can also promote and increase the incidence of symptomology through public health initiatives and education, such as D-MER support and awareness campaigns.

#### Limitations

Although this research was conducted with participants in 4 different countries, a future exploration of D-MER from participants speaking languages other than English may uncover different experiences. In addition, most of our sample identified as white, heterosexual, and described a heteronormative/nuclear family structure. The experiences of historically excluded groups should be included in future research efforts characterizing D-MER.

Another limitation included the necessity to access an electronic device, with reliable internet, to complete patient interviews. Concurrently with electronic device access, recruitment was done via a D-MER Facebook support group, which includes roughly 12,000 members. Many women who do not have access to social media were not able to view the flier, therefore, were excluded from participating.

Lastly, because women were recruited from a self-reported D-MER social media support group, these women identified their own, individual, symptoms and their symptoms were significant enough to be explored further, independently. There are varying degrees of intensity

of symptoms, and it is possible that the women selected in this study had some of the most severe symptoms experienced with D-MER, based on their identification that something was wrong, and their further exploration of the symptoms felt.

## Conclusion

This study provides a beginning understanding of the importance of education and knowledge surrounding the phenomenon of D-MER and validation of D-MER symptomology in the postpartum breastfeeding community. The women who experience D-MER have unique experiences and feelings, yet all women agree that their sensations are unpleasant and hindered their overall breastfeeding experience: past, present, and future.

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## Appendix A

## Sample Interview Guide

I am interested in learning from you about your experiences related to your breastfeeding journey and experience.

Before we talk about your experiences, can you tell me a bit more about yourself?

What about your family, who do you consider family?

I am interested in learning about your past experiences related to breastfeeding. Can you tell me about that?

To be part of the study you have identified that you had experienced Dysphoric Milk Ejection Reflex. Can you tell me about that experience?

How did you identify having D-MER? Did you speak to a Certified Lactation Consultant regarding your experience, talk to peers, or utilize the internet to identify?

Have your tried any types of treatment or remedies for the symptoms you have experienced?

Can you tell me about anything you may have experienced about D-MER and breastfeeding?

Thank you for the opportunity to share your experiences. Is there anything that you have forgotten or that you may remember now that you would like to share with me?

\*Probing questions can be asked to verify and gather additional detail regarding the participant's lived experience, if needed.

# Appendix B

# Table 2

Demographic Data

|                                       | N= | %   |
|---------------------------------------|----|-----|
| Race                                  |    |     |
| White                                 | 12 | 92% |
| Hispanic or Latino                    | 0  | 0   |
| Black or African<br>American          | 0  | 0   |
| Asian                                 | 1  | 8%  |
| Native Hawiian or<br>Pacific Islander | 0  | 0   |
| American Indian<br>or Alaska Native   | 0  | 0   |
| Other                                 | 0  | 0   |
| Marital Status                        |    |     |
| Divorced                              | 0  | 0   |
| Living with<br>Partner                | 1  | 8%  |
| Married                               | 12 | 92% |
| Single, Never<br>Married              | 0  | 0   |
| Separated                             | 0  | 0   |
| Widowed                               | 0  | 0   |
| Education                             |    |     |
| Below High School                     | 0  | 0   |

| High School<br>Diploma    | 0        | 0                    |
|---------------------------|----------|----------------------|
| Some College<br>Credit    | 1        | 8%                   |
| Trade School              | 1        | 8%                   |
| Associates                | 0        | 0                    |
| Bachelors                 | 8        | 61%                  |
| Masters                   | 2        | 15%                  |
| Doctorate                 | 1        | 8%                   |
|                           |          |                      |
| <b>Employment Status</b>  |          |                      |
| Full Time                 | 5        | 38%                  |
| Part Time                 | 4        | 31%                  |
| Self Employed             | 2        | 15%                  |
| Homemaker                 | 2        | 15%                  |
| Annual Household II       | ncome    |                      |
| Under 30k                 | 0        | 0                    |
| 30-60k                    | 1        | 8%                   |
| 60-90k                    | 3        | 23%                  |
| 90-120k                   | 4        | 30%                  |
| Over 120k                 | 5        | 38%                  |
|                           |          |                      |
| Type of Birth             | 1        | Γ                    |
| Vaginal                   | 9        | 69%                  |
| C/S                       | 4        | 31%                  |
|                           |          |                      |
| Assistive Birth           | 1        | 8%                   |
|                           | Mean     | Range                |
| Breastfeeding<br>Duration | 4 months | 8 weeks-16<br>months |
| -                         | Mean     | Range                |

| Age (in years) | 32 years | 26-39 years |
|----------------|----------|-------------|
|----------------|----------|-------------|

Note: This table shows demographic information collected from N=13 participants, including

age ranges and breastfeeding duration.

## Table 3

Meaning Units and Emerged Themes

| Meaning Units                           | Themes Emerged                           |  |
|---|--|--|
| 1a- Desire to Breastfeed                |  |  |
| 1b- Goal Setting & Expectations         | 1. Breastfeeding concessions and         |  |
| Ic- Tongue Tie                          | toleration                               |  |
| 2a- Sensory Overload                    |  |  |
| 2b- Pumping worse                       |  |  |
| 2c- Evening Hours heightened Feelings   | 2. Something does not feel "normal"      |  |
| 2d- Impending Doom Feeling              |  |  |
| 3a- Feelings during other times         |  |  |
| 3b- Feelings of Grief                   |  |  |
| 3c- Intimacy & Nipple Sensitivity       | <i>3. I remember a feeling like this</i> |  |
| 3d- Experiences with Recreational Drugs | before                                   |  |
| 3e- ADHD                                |  |  |
| <i>3f- Depression/Anxiety</i>           |  |  |
| 4a- Provider Dismissal                  |  |  |
| 4b- Google as a Diagnosis               |  |  |
| 4c- Reassurance in "knowing"            |  |  |
| 4d- Online Support Groups               | 4. This is real, and recognition is      |  |
| 4e- Drinking Ice Water during Let Down  | validating                               |  |
| 4 <i>f</i> -Distraction                 |  |  |

Note-This table shows the 19 meaning units with four emergent themes connected based on Giorgi's phenomenology.