January 2020

Dysphoric Milk Ejection Reflex: A Narrative Inquiry of Women's Experiences and Perceptions

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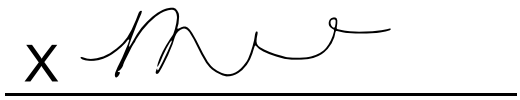

Date: 10/16/2020

DYSPHORIC MILK EJECTION REFLEX: A NARRATIVE INQUIRY OF WOMEN'S EXPERIENCES AND PERCEPTIONS

BY

BRANDI WINCHESTER

Submitted to the Faculty of the Graduate School of
Eastern Kentucky University
in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

2020

DEDICATION

For Linda

ACKNOWLEDGEMENTS

It is with the support and mentorship of Dr. MaryEllen Thompson that the significance of women's stories becomes a catalyst for relief. The research design reflects her genuine passion for qualitative inquiry and support for my desire to explore embodied experiences and their innate ability to make change, as we as human beings continuously make meaning.

Dr. Leslie Hardman and Dr. Jennifer Height's support of my desire to utilize family-centeredness to illustrate this unconventional topic brought the research relevance and illustrated the potential for a more diverse understanding of the topic.

Abstract

Background

Dysphoric milk ejection reflex is an idiopathic condition experienced by some breastfeeding women that is characterized by an abrupt experience of negative emotions or sensation prior to milk let-down. Many women struggle to make sense of the condition, and report barriers to communicating with others about their experiences and accessing support from healthcare providers. Dysphoric milk ejection reflex is often reported by women to impact self-efficacy and contribute to secondary psychological effects.

Research aim

Exploration of the experience of Dysphoric Milk Ejection Reflex. Investigation of the impact of diagnosis on the sense of wellness and self-efficacy of affected mothers.

Methods

A narrative research approach was utilized with data collected from a social media site in order to explore women's experiences of the condition, as well as how the virtual context was utilized to make sense of their experiences and seek support.

Results

Recurring themes and patterns emerged from the data coding process, including raw description of experiences, metaemotion, and the impact of diagnosis and validation.

Conclusions

Women reported experiencing a wide variety of negative emotions and sensations, with many reporting long lasting negative psychological effects associated with striving to understand their experiences. Some participants reported that understanding of the

condition reduced the long-term effects of striving to understand their experience. The rich narrative data can inform practice, highlights the effects of power imbalance in the client-provider relationship, and supports further research for education as a means of intervention.

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D-MER Introduction

Dysphoric milk ejection reflex [d-MER] is a condition experienced by some breastfeeding women that is characterized by an abrupt and brief experience of negative emotions prior to milk ejection (Heise & Wiessinger, 2011). The negative emotions experienced by women range from mild to severe, and tend to last only moments. The term dysphoria describes the range of negative feelings, with women having different experiences and describing the feeling using different words. Common descriptions of the experience are "hollow", "wave", "despair", "shame", "guilt", "self-disgust", "hopelessness", and "pit" (D-MER.org, 2019; Heise & Wiessinger, 2011). As a result of these feelings, many women that experience D-MER question their psychological wellbeing (Heise & Wiessinger, 2011).

Etiology

The majority of research available about d-MER explores the experience of dysphoria upon milk release. The body of current evidence is small and consists mostly of case studies, descriptive studies, or phenomenological analysis of the experience. The etiology of the condition is idiopathic as of present, though many women's health professionals believe that the condition is physiological. According to Uvnas-Moberg and Kendall-Tackett (2018), the condition is likely caused by an adverse reaction to the hormone oxytocin, causing a stress response. On the other hand, Heise and Wiessinger (2011) hypothesize that the condition results from an increase in the hormone prolactin and subsequent drop in dopamine. While the cause is unknown, the consensus among

most researchers at this time is that the condition is likely caused by the endocrine system. At present, Heise and Wiessinger's (2011), and Uvnas-Moberg and Kendall-Tackett's (2018) research are the only studies that primarily investigate the hormonal etiology.

Making Sense of the D-MER Experience

In their phenomenological analysis, Watkinson, Murray, and Simpson (2016) describe the wave of emotion as embodied emotional sensations. They define embodied emotional sensations as "marked or sudden emergence of the... distressing emotional and visceral experiences (e.g., sadness, anger or anxiety) specifically associated with milk-release or the breastfeeding act" (Watkinson et al., 2016, p. 54). In their research, they found that the intense and sudden "negative bodily response" of participants was challenging for women to understand and communicate with others (Watkinson et al., 2016). Women did not feel that they understood how to talk about it, struggled to make sense what was happening or why it was happening, and they did not feel that the emotional experience was authentic. They were cognizant of their authentic positive emotional responses to their children and feelings about their children, and aware that the negative emotions associated with milk ejection did not seem to reflect their genuinely positive emotions. This incongruence was a topic of concern for many participants.

For some women, secondary to the negative emotional experience with milk ejection were subsequent psychological effects that extended beyond ejection. Women attributed these lasting effects to their tendency to interpret the temporary negative experience. Reported self-interpretations include self-doubt, inadequacy as a mother,

and concerns about mental health status. In this way, the fleeting moments of the negative experience contributed to lasting effects on the remainder of women's days, effects that impacted the women's sense of self-efficacy (Watkinson et al., 2016).

Barriers to Obtaining Support

Participants in the Watkinson et al. (2016) study as well as other case studies reported several barriers to obtaining support. Primarily, many found it challenging to understand the phenomenon in order to discuss it, and had difficulty coming up with clear and detailed descriptions of their experiences, often using words or phrases. The Watkinson et al. 2016 participants also described negative experiences seeking care from their healthcare providers. Many reported having their symptoms misinterpreted as postnatal depression. In *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM–5*), postnatal depression is categorized as Major Depressive Disorder with peripartum onset (American Psychiatric Association, 2013). The diagnostic criteria for this condition include the persistence of symptoms for two consecutive weeks. As the primary negative experience lasts minutes at most, the condition is differentiated from Major Depressive Disorder with peripartum onset (Ureño, Berry-Cabán, Adams, Buchheit, & Hopkinson, 2019). Other participants reported fear of seeking healthcare that stemmed from the power imbalance between patient and provider, or distrust. One participant reported concern that her provider would report her to Child Protective Services if she revealed her "urge to throw her child", clarifying that she "never had the actual intention" and "would not act on it" (Watkinson et al., 2016, p. 57).

Self-Efficacy

The experience of D-MER and challenges that resulted from the "embodied emotional sensations" impacted mothers' sense of self worth, self-efficacy, and sense of meeting expectations of their roles (Watkinson et al., 2016, p. 57). There is a broad association between breastfeeding and maternal identity. Breastfeeding self-efficacy is a parent's belief in their ability to succeed in breastfeeding, and is "one of the strongest predictors" of "breastfeeding behaviors over time" (Tuthill, McGrath, Graber, Cusson, & Young, 2016). Poor breastfeeding self-efficacy impacted the Watkinson et al. (2016) participants' ability to meet their self-constructed role expectations of mothers. Some reported that breastfeeding their child positively contributed to their sense of self, with many choosing to continue breastfeeding despite the negative experience. Many mothers reported highly valuing breastfeeding for pragmatic and emotional connection reasons, and felt a sense of failure at mothering as a result of their poor breastfeeding self-efficacy. As a result of the primary sensations during breastfeeding as well as secondary emotions sourced from interpreting the primary effects, some women reported "being less immune to everyday challenges" of mothering and a sense of loss of control (Watkinson et al., 2016, p. 56). Despite these experiences, many of the participants persisted at breastfeeding in order to demonstrate commitment to being a "good mother", reflecting the prominent view among Watkinson et al.'s participants that breastfeeding contributes to performing the role of a "good mother".

Model of Human Occupation [MOHO] aims to "explain how occupation is motivated, patterned, and performed" (Kielhofner, as cited in MOHO Web, 2019). MOHO will be utilized to explore mothers' occupational motivation, patterns, and

performance in regard to breastfeeding while experiencing symptoms of D-MER. The model is an open system, comprised of parts that are hierarchical and dynamic, with the system representing the Human Being, and its interaction with its environment composing human occupation (Kielhofner & Burke, 1980). The three subsystems of MOHO include volition, habituation, and performance, with volition exerting influence over all subsystems, and habituation exerting influence over performance. According to MOHO motivation is strongly rooted in volition, a collective of "traits" called personal causation, interests, and values. In MOHO's infancy, an individual's traits were considered to be primary influences on behavior. Personal causation was defined by Kielhoner and Burke (1980) as "a person's belief in proven efficacy in some sphere of action" and deemed it necessary for "competent occupational behavior" (p. 576). Helfrich, Kielhofner, and Mattingly (1994) explained "traits are assumed to be the accumulation of experience - for example accrued successes summing to a feeling of efficacy" (p. 315). Through the lens of MOHO, the mothers' belief in their ability to effectively breastfeed, along with their interests and values, strongly influences how and if they will continue to perform the occupation of breastfeeding. This dynamic relationship is demonstrative of the inter-related nature of occupational motivation, patterns, and performance.

Breastfeeding Benefits

The health benefits of breastfeeding for both mother and child have been widely discussed in recent years. The Center for Disease Control and Prevention [CDC] (2019) dubbed breastfeeding as "the clinical gold standard for infant feeding and nutrition" and the World Health Organization [WHO] (2019) refers to breastfeeding as "the normal

way of providing young infants with the nutrients they need for healthy growth and development". Human breast milk is a live substance that contains antibodies to protect babies from disease, as well as a composition that specifically meets babies' nutritional needs (U.S. Department of Health and Human Services [HHS], 2011). According to WHO (2017), "breastfeeding is one of the most effective ways to ensure infant health and survival".

Benefits to babies include a decreased risk for "asthma, childhood leukemia, childhood obesity, ear infections, eczema, diarrhea and vomiting, lower respiratory infections, necrotizing enterocolitis, sudden infant death syndrome, and type 2 diabetes" (CDC, 2019). Multiple research sources indicate a positive relationship between breastfeeding and cognitive function, as demonstrated by scores on the Bayley Scales of Infant Development, Communicative Development Inventory, Ages and Stages Questionnaire, Revised Peabody Picture Vocabulary Test, and the Wechsler Intelligence Scale for Children (Krol & Grossmann, 2018). In their research, Krol and Grossmann (2018) specify that these studies controlled for maternal factors, including but not limited to, intelligence quotient, social class, psychopathology, attachment, infant birth weight, income, education, and employment.

Mothers who breastfeed experience a decreased risk for ovarian and breast cancer, type 2 diabetes, and post partum depression, as well as the benefits of weight loss and pregnancy prevention, with 98% effectiveness for women who exclusively breastfeed for up to six months (WHO, 2019). Typically, mothers whom breastfeed experience psychological benefits, including self-reported reduction in anxiety and negative mood (Krol & Grossmann, 2018). Physiological indicators of this phenomenon

support the self-reports. Physiological research shows that breastfeeding mothers experience "stronger vagal tone modulation, reduced blood pressure, and reduced heart rate reactivity", as well as a "reduced cortisol response when faced with social stress" (as cited in Krol & Grossmann, 2018, p. 981).

Barriers Experienced by Typical Breastfeeding Mothers

Despite the benefits, only 25% of United States mothers exclusively breastfed their babies through six months in 2015 (CDC, 2018). Numerous barriers exist that may be attributed to the statistic. The *Occupational Therapy Practice Framework: Domain and Process* (American Occupational Therapy Association [AOTA], 2014) describes occupational therapists' purview, referred to as the Domain, as a "dynamic interrelationship between occupations, client factors, performance skills, performance patterns, and context and environment", and AOTA describes the interrelationship as "of equal value, and together they interact to affect the client's occupational identity, health, well-being, and participation in life" (p. S4). Breastfeeding is a complex co-occupation, or occupation that cannot be performed by an individual alone, that is addressed by occupational therapists as an activity of daily living for infant feeding, or an instrumental activity of daily living for childrearing (AOTA, 2014). The barriers experienced by typical breastfeeding mothers will be discussed within the contexts and environments of which they occur, as defined by the *Framework*.

Personal contextual barriers include lack of education about breastfeeding, including benefits of breastfeeding and also breastfeeding skills. This is relevant to breastfeeding initiation and breastfeeding continuance. Another personal contextual barrier could be lack of paid parental leave, which may serve as a more significant

barrier to those of a lower socioeconomic status. Needing to return to work is an example of a temporal contextual barrier. According to *Breastfeeding Report Card* (CDC, 2018), in 2015 less than 50% of infants were exclusively breastfed until three months. Comparing this figure to the 25% of infants that were exclusively breastfed until six months shows that half of breastfeeding mothers cease exclusively breastfeeding within six months. Some attribute this pattern to the challenges associated with returning to the workplace, and CDC (2018) cites breastfeeding support for mothers from workplaces as "critical". Reasons mothers need to return to work are often cited as financial need, expectations of her role as an employee, as well as career goals. Duration of breastfeeding is another aspect of the temporal context. Some infants feed frequently, and this may interfere with a mother's ability to perform other activities. In this case, the mothers may feel a lack of balance between pleasurable, productive, and restorative occupations, or ability to satisfactorily balance engagement in meaningful occupations with those necessary for their roles as mothers (Pierce, 2001). Cultural contextual barriers exist, as breastfeeding is considered the norm within many cultural groups, while formula-feeding is considered the norm within others. U.S. Department of Health and Human Services [HHS] (2011) cites the cultural belief that bigger babies are better as a barrier to breastfeeding, as breastfed babies are at a lower risk for obesity.

Social environmental barriers are significant for many women. HHS (2011) cites several social factors that can interfere with breastfeeding initiation or the act of breastfeeding. Primarily, social norms influence women's choices to initiate breastfeeding, as formula-feeding is considered the norm in the United States. Reasons for the shift from breastfeeding to formula feeding being the norm have been attributed

to sexualization of women's breasts, workplace expectations, and effective advertising of formula, including distribution of formula to new mothers by healthcare providers (Swigart et al., 2017, Nelson, Li, & Perrine, 2015). Norms about where, when, and how babies should be breastfed in public influence women's choices to initiate and continue to breastfeed. Many women have experienced pressure to breastfeed in restrooms and other un-natural settings as a result of social norms. Social norms change over time, with formula feeding being the norm for only the last couple of generations. Grandmothers tend to offer support for new mothers, including both physical support and provision of advice. However, many current grandmothers belong to the generational cohort that accepts formula feeding as the norm, and may not be able to offer support to mothers, or approval. Another considerable social environmental barrier is the participation of fathers in parenting routines. Commonly, mothers cite a desire for fathers to participate in feeding, and express fear that breastfeeding will exclude them from the experience. As breastfeeding mothers tend to be more successful with the support of others, harnessing the support of grandmothers and fathers has become an aim of the *Surgeon General's Call to Action to Support Breastfeeding* (HHS, 2011).

Physical environmental barriers to breastfeeding include access to breastfeeding materials. Materials include a breast pump for return to work or to store excess milk, related bottles and sanitary equipment, and supportive devices such as nipple shields. Lack of private space for expression of breastmilk within the workplace or other spaces frequented by mothers, and private space if desired by mothers for nursing, excluding restrooms, is a commonly reported issue experienced by mothers (HHS, 2011). Physical distance is another barrier within the physical environment, including between the

mother and child for access to breastfeed, and physical access to breastfeeding-related healthcare services including transportation.

The virtual context is pivotal for breastfeeding mothers. It serves as a barrier, as anti-breastfeeding propaganda is frequently distributed on social media. Further, access to misinformation about breastfeeding is a threat to those seeking support. It is clear that a multitude of supportive educational materials are available to mothers who possess the ability to recognize reliable sources of health information. A trend subsequent to the emergence of social media is use of the internet as a tool to seek support from others (Wagg, Callanan, & Hassett, 2019). Therefor, lack of access to the virtual context serves as a barrier to breastfeeding.

Use of the Internet for Health Information, Self-Diagnosis, and Support

Typical breastfeeding mothers (referred to in this article as those who do not experience D-MER) experience a plethora of barriers and tend to subsequently seek support from online sources including social media, health information websites, message boards, and blogs. In this context, many mothers with D-MER have made sense of their conditions, sought support from others, and accessed information related to treatment and outcomes. Women who experience the effects of D-MER are also at risk for experiencing the barriers known to effect typical breastfeeding mothers, increasing the need for support for this population.

Online self-diagnosis has become a topic of controversy, with the potential for individuals to access poor quality of information or attempt to self-treat instead of seeking medical attention. However many women with D-MER experienced not receiving information about D-MER from their healthcare providers, with some

reporting their providers attributing the symptoms to postpartum depression. A hallmark of D-MER is desire for the women who experience it to understand "what is wrong with them". With few scholarly resources available to healthcare providers about D-MER, this question is left unanswered for many mothers, who often turn to the internet for understanding. A recent study highlights the potential for individuals with rare conditions to find a diagnosis. The article reveals that, "35% of all American adults have used the internet for diagnosis. Of these “online diagnosers,” 46% went to a physician with their findings and a surprising 41% of these got a confirmation of their diagnosis" (as cited in Svenstrup, Jørgensen, & Winther, 2015, p. e1083145-3).

Online communities for support have been a boon to individuals around the world who experience rare conditions. The experience of seeking and receiving support from others who experienced the same condition served as a "normalizing" function for Watkinson et al.'s participants (2016). Experiences of "profound relief", "alleviation of their sense of defectiveness and failure at motherhood" and recognition that they are not "crazy" or "bad mothers" were all reported by Watkinson et al.'s (2016) participants.

Relief

Most sources of research indicate that the diagnosis experience results in relief, or "making the condition more tolerable" (Heise & Wiessinger, 2011, p. 1). Watkinson et al. (2016) found that identification of the condition, as well as knowing that others shared the experience, was a source of relief for mothers. Along with feeling that they were "not crazy", or feeling psychologically validated, this collective understanding changed participants' perceptions of D-MER, and women felt it reduced the influence it had on them. The understanding that the negative feelings resulted from a physiological

process served a "non-blaming and de-shaming function" (Watkinson et al., 2016). The cessation of attempts to self-interpret or rationalize their experience decreased the secondary effects including questioning their mental health, self-doubt, and poor self-efficacy for breastfeeding as well as mothering. The D-MER phenomenon supports further understanding and need for decimation of information about the condition to mothers, as well as healthcare practitioners and professionals specializing in breastfeeding support.

II. Research

Background

Dysphoric milk ejection reflex [d-MER] is a condition experienced by some breastfeeding women that is characterized by an abrupt and brief experience of negative emotions prior to milk ejection (Heise & Wiessinger, 2011). The negative emotions experienced by women range from mild to severe, and tend to last only moments. The term dysphoria describes the range of negative feelings, with women having different experiences and describing the feeling using different words. Common descriptions of the experience are "hollow", "wave", "despair", "shame", "guilt", "self-disgust", "hopelessness", and "pit" (D-MER.org, 2019; Heise & Wiessinger, 2011). As a result of these feelings, many women that experience d-MER question their psychological wellbeing (Heise & Wiessinger, 2011).

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Aims

Review of the present body of research is indicative that insufficient communication with healthcare providers is a barrier for women who experience d-MER. Description of the experience is challenging for women, and the primary aim of this study is to explore the raw descriptive language used by women to support rapport between provider and patient. A phenomenon highlighted by review of literature is

understanding of the condition being a contributing factor to reduction of symptoms. In reflection, another aim of this research is to identify the relationship between diagnosis and sense of wellness experienced by participants. Women's health care and family practice providers possess pivotal opportunities as primary sources of patient education, and their positions to utilize therapeutic use of self in practice. This study is significant, as health care providers equipped with descriptive knowledge can support patients' sense of self-efficacy and wellness, with consideration of the power imbalance between patient and provider.

Methods

Design

Upon review of literature, it is evident that research about the condition is limited, comprised mainly of a few case studies. The data presented in the case studies does not reflect the tone of social media posts that were reviewed alongside the scholarly research. This incongruence demonstrated evidence of a need for narrative inquiry, for an analysis of women's stories about d-MER in their own words, which were much more raw than those presented in the existing research. Narrative inquiry offers exploration of the meaning of an experience and its impact on the construction of identity (Reissman, 2008). A wealth of d-MER data exists within the virtual context that offers a window to examine women's indiscrete stories. Removed from the context of the patient-provider relationship and without the influence of power imbalance that women cited as a barrier to seeking support, these stories are a primary resource to understand d-MER and inform practice.

An application for limited review was submitted the Eastern Kentucky University Internal Review Board. The application was granted exemption as a result of the possibility of no more than minimal risk to participants.

Setting and Relevant Context

Data was collected from previous posts and inquires on the social media platform Reddit, including responses and comments of anonymous users. Reddit, unlike other social media sites, does not require use and display of biographical information. As a result, usernames are often pseudonyms. The use of social media allowed the researcher to reach a very specific population of people, as it is unknown how many experience d-MER, but it is believed to be rare. Use of virtual context for the collection of research data is a new concept, but relevant for understanding how individuals make sense of conditions, as well as seek and share support. Secondary to anonymity and qualities of the research design, information about specific socio-economic, breastfeeding, geographic and socio-cultural contexts was not accessible.

Sample

Purposeful homogenous selection was utilized to bound the study in order to sample a group that supports illumination of the phenomenon of d-MER (DePoy & Gitlin, 2016). Individuals who elected to post content about their experiences of d-MER previously to the research protocol were identified as potential participants, with users who responded to a recruitment post being identified as additional potential participants. All potential participants were screened for inclusion and exclusion criteria by means of content review. Inclusion criteria was defined as English speaking women who currently breastfed or had a history of breastfeeding, and that had been diagnosed with

d-MER by means of self-diagnosis or professional diagnosis. Individuals who self-identified as being under the age of 18 years or as being an active prisoner were excluded as participants for the study.

Data Collection

While traditionally in narrative inquiry an investigator develops a relationship with participants, this approach will not be utilized in order to illustrate the presentation of the information in the original, virtual, context. The principal investigator conducted a web search on Reddit in order to identify content submissions matching the search terms "dysphoric milk ejection reflex", "D-MER", and "DMER". Historical narrative data was mined from the posts and comments resulting from the query. Further, a recruiting content post was submitted to various communities, called subreddits, that are relevant to breastfeeding. The post prompted users to share their experience of d-MER, including what the experience felt like, how they coped, how they learned about the condition, and whether they continued to breastfeed. User responses to the recruiting post, along with the historical data, comprise the field-data for the study. In this case, the principal investigator did not interview participants or respond to their comments. For this reason, the data used is considered observation of the virtual context.

Data Analysis

The data was examined, a process in which the investigator "explored recurring themes and emerging patterns" (DePoy & Gitlin, 2016, p. 260). Field notes were documented throughout the observation and examination process using a double-column template. These notes contained what was observed and examined, as well as the researcher’s personal thoughts. Throughout the study, the investigator utilized a

reflexivity journal in order to examine and document personal bias. In addition, an audit trail, random checking for saturation, and peer debriefing was utilized by the investigator for accuracy.

The process of analysis began with memoing significant ideas and summarization of field notes (Creswell & Poth, 2018). Next, identification of codes and themes occurred, followed by application of codes. Data collection and analysis co-occured throughout the process. The investigator interpreted the data by identifying relationships between the themes and relating the themes to existing frameworks (Creswell & Poth, 2018). Visualization of the data occurred as patterns emerged. The visual representation provides reviewers a concise perspective of narrative frequency data.

Results

Description of D-MER Experience

Primary Symptoms

The narratives contributed by participants were rich with descriptive language, which was identified as the first theme. The participants described their experiences prior to the moment of milk ejection, which are described by the principal investigator as primary emotions, or how the embodied experiences prior to milk ejection felt. Figure 1 contains narrative data of participants' primary symptoms, including women's descriptions of the embodied experience prior to milk ejection. Figure 2 illustrates frequency in descriptors used for primary symptoms among participants.

Figure 1

Descriptions of Primary Symptoms

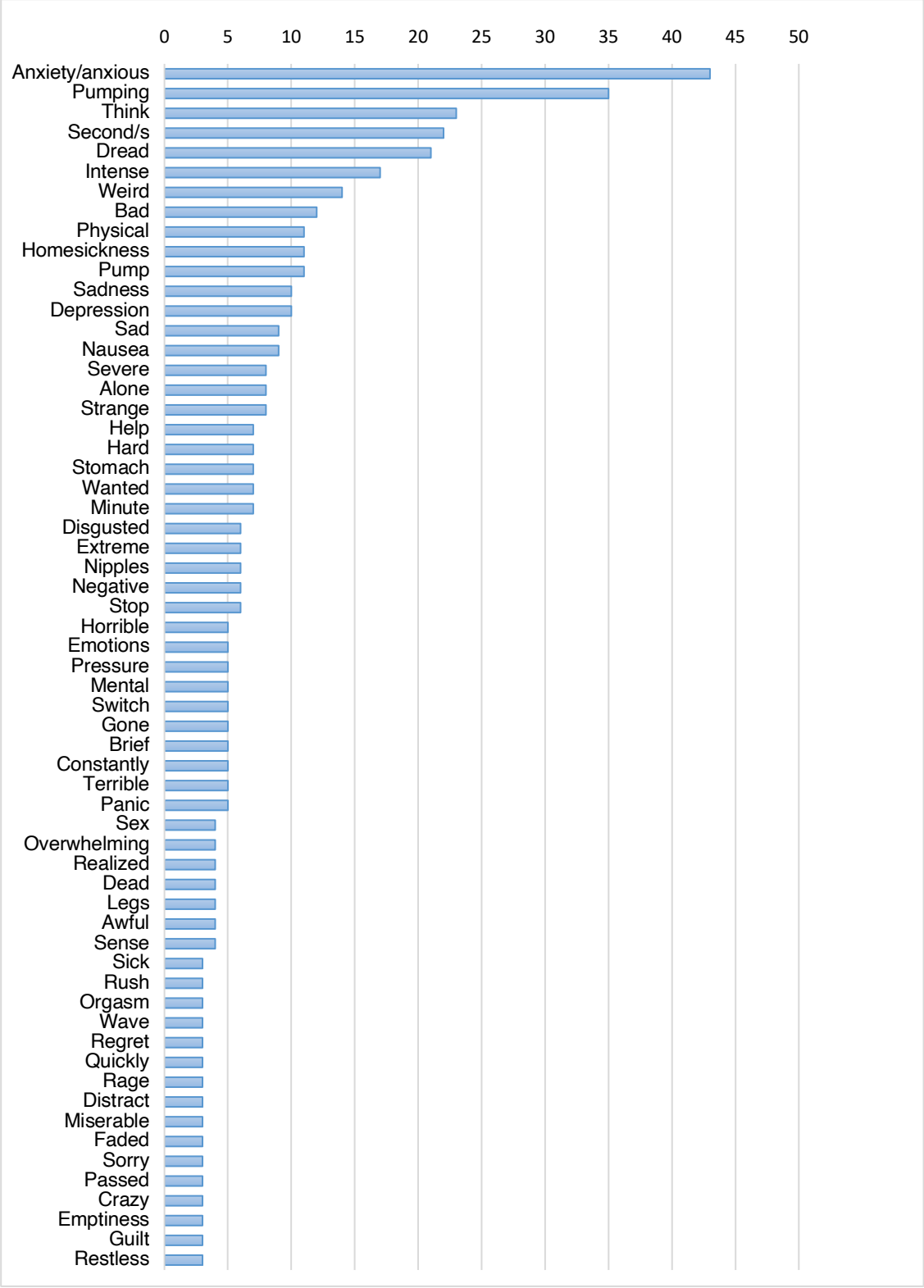
“EVERY TIME I pumped, a wave of intense sadness took over me. I remember thinking this is probably what being near Dementors from Harry Potter feels like. It really felt like I would never feel happiness again. All joy was taken away and complete dread overtook me.”
“I experienced a feeling that I never had before; emptiness, a sense of everything being dead (even my baby), meaninglessness in life; it was very scary.”
“I get that feeling like your life force or soul is being sucked out if your body.”
“Sudden, terrifying emotional plummet 90% of the time my hungry little babe had a nosh.”
“It's so strange. It's like the opposite of a rush of euphoria, where you feel like you're floating for a few minutes after getting great news. I feel it like a rush of bad energy down my body.”
“Rotting dissatisfaction.”
“D-MER, for me, felt strong and hollow and familiar. I couldn’t explain it, but with letdowns, I felt as I used to feel when experiencing flashbacks to a sexual assault. I wasn’t triggered by anything, but it felt the exact same. It felt like a reminder of a massive trauma. I felt dread. I felt violated.”
“I described it like a brief feeling of nostalgia almost.”
“The feeling was an intense feeling of disgust and shame.”
“I've described it as a feeling of sadness that emanates from my nipples.”
“Sad (homesick is a perfect description).”
“It was more intense with a pump. You know that cringe feeling you get at three AM when you’re absolutely certain that you made a fool of yourself five years ago by wearing a skirt that was just a smidge too short to your super religious friend’s wedding? It felt like that, times ten.”
“Dread, anxiety, and almost like...homesickness.”
“I would describe mine as a feeling impending doom, sadness and extreme loss of appetite. No matter if a couple of seconds prior to that, I was fantasizing about the yummy food I was going to eat. It would happen each time I would breastfeed. It would go away in a couple of min but it was definitely unnerving.”
“Homesick or even sometimes a feeling of longing or anxious nostalgia.”
“I'm cleaning colostrum off my nipples I get a sad feeling. It's almost like regret, or that I did something bad.”
“Exactly sadness with some nausea. More than once I cried on the baby's head while he merrily fed.”
“For me it comes on as anxiety, like the most overwhelming anxiety I’ve ever felt. And then once I have a let down it just disappears.”
“I realized that something strange was happening when I fed her: as soon as she latched, I was overcome by a sweeping feeling of tiredness, bleakness, and sometimes even mild nausea. Brief periods of suicidality every two to three hours, in ten minute increments.”
“At the end of my first child’s nursing experience, I had to almost shove him away during letdowns because my joints all felt almost.. itchy?”

“I just either wanted to cry or did cry. I would immediately be sad, upset or depressed. All these thoughts would come into my head. If I was having a good conversation with someone and laughing and it would be time, I switch would flip weird, sad, disgusted feeling.”
“Sometimes it feels like he is a different baby? I don't know how to describe it. Like when he's sitting in front of me or we're doing literally anything else, he is himself. But then as soon as we start nursing he kinda transforms into someone else in my mind? I don't necessarily feel any disconnect (maybe slightly) but it's just this strange phenomenon that I've been experiencing for awhile now.”
“I described it as not having facial recognition with my son.”
“I feel like facial recognition is definitely a big part, if not all of it. It's like he looks like a different baby.”
“Mine manifests as horrible anxiety and dread and lasts four-five minutes per nursing session. I get a second wave when I switch sides...”
“It’s so strange. I get a really strong homesick feeling.”
“But it was like I couldn't breathe / beginning of a panic attack and also a strong desire to run away.”
“I'd been experiencing intense dread and sadness when I pump.”
“I would get this knot of dread and anxiety in my stomach and I would think, "I hate this." Which was really weird because two minutes later, I'd feel fine and love nursing.”
“I would tear up every time my milk let down.”
“I almost always lose my appetite.”
“I literally would get exhausted, and my brain would keep telling me “I want to kill myself” every time I had a let down.”
“I’ve been calling them mini panic attacks. It’s horrible, and then it goes away.”
“I felt like a stinky ball of stress and despair. It was so awful.”
“I knew exactly when I was letting down because I’d feel this ache of sorts, it hurt, it felt like an icky feeling for me.”
“I immediately felt intense anxiety, anger, and resentment. I wanted him off me, when moments prior I had felt amazing with him.”
“It felt like such a deep feeling of sadness and dread to me and it would always start right at letdown. Even though it was very short lived, the feelings were so intense. It would last a minute or two then fade.”
“I felt physically ill, like my stomach would turn and my skin would crawl, and I felt like screaming my head off.”
“I feel physically ill and my impulse is to want to stop nursing her immediately. It was an immediate sensation of revulsion all over and a disassociation/panic along with it.”
“I’ve often experienced rage and frustration associated with my letdown, most commonly when pumping rather than directly BFing (but sometimes with that too).”
“Let down causes a strong overwhelming feeling of guilt and a pit in my stomach, milk nausea.”
“Intense feeling of dread, followed by significant nausea, and vomiting.”
“She mentioned that during let down she felt like she “wanted to murder something”, not her baby, not her husband, not any self harm, just an overwhelming urge to kill.”
“I felt disgusted with my body. I felt repulsed by my breasts and my body (because of the weight gain). I would pump during my lunch break and eat while I pumped. Sometimes I

would feel so disgusted with myself that I would throw out my food and stop eating. It would begin right when I would start pumping."
"By the end, my feet, legs, arms and hands all felt irritated and I couldn't stop clenching my hands into fists."
"I would be going about my day and out of nowhere BAM that dreadful feeling came back. It was hell. I still experience that dreadful feeling when I feed him but nowhere near as intense as before."
"I had it pretty bad. I come from a sexual abuse past and felt that anytime my nipples were touched. It felt like a flashback. It was worse if my milk was low. It also was awful once when I had to take benedryl, I wanted to throw my son off me."
"I experienced it severely. I have actually experienced it since puberty. It would mostly happen when I walked out of the shower and wrapped a towel around my chest/nipples. I would experience a flood of dread and terror. I never knew what it was, until around the time I got pregnant. I was worried, when I was pregnant, it would happen if I breastfed."
"Also this round there's dread. Also food aversion. I didn't have it that I noticed with my first, but with both I already had pretty extreme thirst so avoiding food while I'm constantly drinking is easy. With the second pregnancy during letdown food sounds, smells and looks disgusting."
"Every time he latched, I would be overcome with feelings of dread, doom, nausea, and dizziness. It made me absolutely miserable, and quite frankly, angry."
"Physical irritation!!!!"
"It would cause a fleeting feeling of panic but it was definitely primarily a physical feeling."
"My anxiety would skyrocket, I would feel nauseous, a burning pit in my stomach, etc."
"I would have a sense of dread that would escalate with every pump session until the sun came up the next day."
"I just got that shallow, sinking feeling in the pit of my stomach that made me want to cry."
"Yes for me it was like intense homesickness."
"Homesickness is a good way to describe what I felt as well."
"Like restless legs."
"I felt it as an extreme homesickness, and I would space out and get very sad- all only lasting a few minutes right before/during letdown."
"It lasted maybe 2 mins tops. I would get sad, then sick at my stomach and just felt heavy. Then it just went away."
"I just remember the dread and anxiety leading up to every time I had to pump, and then the intense despair and sadness and loneliness while pumping."
"I experienced it stronger when pumping than I did when nursing, so that's when I realized I had it. It felt like a wave of emotion that would start just before a letdown (it was actually how I knew it was coming) and would last for probably 10 minutes afterward. The best way I can describe it is a feeling of emptiness or even homesickness."
"I get a very anxious, wanna crawl out of my skin feeling for about 90 seconds."
"I didn't know what it was at first but it is like a really intense home sick feeling, a weird sadness that only lasts about 30 seconds or so until my milk lets down."

Figure 2

Frequency in Descriptors used for Primary Symptoms



Secondary Effects

The data revealed that participants tended to experience metaemotion, or thinking about their emotions, as well as what the principal investigator refers to as secondary effects of d-MER. Secondary effects are defined within this study as how primary symptoms and experiences resonated with women when they were no longer breastfeeding. Patterns emerged in the data; Some participants experienced metaemotion as demonstrated by questioning their psychological wellness, other participants experienced metaemotion as evidenced by efforts to make sense of the experience. Figure 3 contains narrative data considered to be participants' secondary emotions.

Figure 3

Descriptions of Secondary Effects

"I thought I was just weird and broken for hating nursing so much."
"It's bugged me for *years*, thinking maybe there's something wrong with me."
"The only thing that affected me between feedings was that I started to catch on that the breastfeeding was causing it. So for a brief time, I was afraid of the baby— every sound he made scared me because I was afraid he would want to eat and I would have to feel that again."
"It took me about 10-20 minutes to recover emotionally after feeding, but the whole process was absolutely exhausting."
"It lasted maybe 30 seconds each time. I would have to mentally "shake it off" afterward and focus on the present/my baby."
"I thought it was just mild PPD this whole time."
"I was constantly sad when I'd breastfeed and the feeling I had when I'd do it made me anxious leading up to it. I knew I'd get that feeling so then I'd get worked up beforehand too."
"It destroyed me."
"It brings back feelings of doubt about the changes in my life."
"My mom was asking me about PPD one day and I was like, no, nothing, I'm fine. Then later as I was feeding my daughter I was like, 'god, maybe I do have some depression -- no, wait, never mind.' "
"So strange and disconcerting."

In comparison, women experiences primary emotions while they were breastfeeding and within moments the dysphoria resolved. Secondary effects occurred after the cessation of the feeding session, and at times in anticipation of future breastfeeding sessions. These residual secondary effects describe women's tendency to make sense of their experiences. While the primary symptoms are likely a result of the physiological process of milk ejection, the secondary effects are not.

Relationship between Understanding of D-MER and Diagnosis on Participants' Sense of Wellness

Many participants cited concerns about their psychological wellness. Some participants reported a general sense that "something was wrong", while others reported attributing the symptoms to postnatal depression. Some participants were diagnosed with Major Depressive Disorder with peripartum onset by healthcare providers. Data [Figure 1] supported findings from the literature review regarding perceived barriers to accessing health care. Some women were afraid that social workers would become involved if they were transparent about their feelings, and others were concerned about how they would be perceived by others, for example being perceived as a "bad mother". Participants reported questioning life choices, as well as decreased self-efficacy for breastfeeding their infants and performing in their motherly roles. As Figure 3 is illustrative of the impact of secondary effects on women's sense of wellness, Figure 4 is illustrative of the impact of diagnosis on women's sense of wellness.

Figure 4

Impact of Diagnosis on Sense of Self-Efficacy

"I'm so happy to know it's an actual thing and it's not just me. I'd really like for it to go away, but just having an explanation and some validation is a real load off."
"I googled 'why do I feel so homesick when I breastfeed' and D-MER came up, validating my experience and also helping me understand it. Both those things had made it much more tolerable (knowing it's real, knowing I'm not alone in it, and knowing it always passes)."
"It's bugged me for *years*, thinking maybe there's something wrong with me. Nope - just the hormone prolactin! **Thanks So Much** for posting - it really puts my mind at rest regarding this. I had it with my second as well but didn't have enough time alone while nursing to really wallow in it like I did my first, and I am sure that knowing I reacted that way with my first made it easier to ignore."
"Thankfully I looked it up pretty early on, so I understood exactly what it was which I feel made it easier for me to deal with."
"I still feel all those feelings as before but it doesn't take over me."
"I wish I had known about DMER sooner, it would have made a lot more sense."
"It felt really lonely until I learned it was actually a thing and other women went through it."

Coping Mechanisms

As is characteristic of the qualitative research process, themes emerged that did not directly answer to the research aims. Many participants shared strategies or techniques they perceived to be effective for finding relief from the symptoms, among these most notably were cognitive redirection or mindfulness and hydration. Some participants commented that since understanding d-MER, they were able to view the symptoms as functional, and benefitted from knowing that milk ejection would follow. Several participants chose to utilize interventions that they had learned to use for other conditions. Figure 5 illustrates participants' experiences with finding relief.

Figure 5

Coping Mechanisms

“I have to be careful what I'm doing when she starts eating because it builds up negative associations. I laugh at myself sometimes because I'll be opening a game or website on my iPad and close it in disgust as the feeling comes over me. I do try to distract myself so I'm not focused on the baby until the emotions pass.”
“I would have to clench my fists and very consciously redirect my thoughts. Sometimes I would allow myself to swear and vent until it passed.”
“I recognized it for what it was and have learned from therapy to try not to ascribe negative emotions to negative feelings I get from anxiety/depression, and to just accept them and let them pass.”
“Since I knew of D-MER and have experience coping with my anxiety I treated this the same as I did when I would have spells of bad anxiety. Put emphasis on my mental and physical well being. Yoga/meditation and loads of water. No alcohol (I would have a glass of wine/beer with dinner) as that definitely can make my anxiety increase.”
“Being borderline over hydrated has helped.”
“I’m a neurologist, so intellectualizing it was helpful. It was interesting how “chemical” it felt to me, like an almost pure dopamine drop without the associated emotional baggage or prolonged character I associate with a depressive episode. Honestly, it’s made me more empathetic to my Parkinson’s patients and how much they hate when their levodopa wears off.”
“I use the breathing and meditation exercises I learned to cope with PTSD to get through. Reminding myself that it feels awful but it will pass in a minute or two helps.”
“What I did, since I didn't know what was going on, was just take some deep breaths and distract myself during let down.”
“I tried to ignore the dread, I felt it was due to me knowing I was going to get sick.”
“I tried dealing with it on my own by reminding myself that it was temporary and will go away and try to focus on other things like what was on TV.”
“What I ended up doing is I would put a cover on over myself so I couldn’t see the flanges or anything, I would close my eyes, and I would listen to soothing music. It would vary day to day. Some times I would just listen to a rain soundtrack on Spotify, I love the sound of rain.”
“Now with my second baby I have had to distract myself with my phone or be utterly exhausted to not respond with some amount of physical agitation.”
“I'm used to it and just breathe through it and know it's over quickly.”

Discussion

Language

Many of the descriptive narratives mirror case studies that were reviewed prior to the protocol. Terms including “sad”, “empty”, “homesick”, and “dread” were common in both data sources. However, with the participant/researcher relationship removed from the protocol, narratives were more diverse and included language that may be perceived by outsiders as inappropriate or atypical. The language contains profanity, references to suicidal ideation, as well as phrases that may be perceived by others to be nonsensical. As was established in the literature review and supported by the data, participants experienced difficulty in describing their symptoms effectively to health care providers. This difficulty may be rooted in individuals’ challenges in understanding and describing the experiences, as well as fear resulting from the patient-provider power imbalance. Many participants reported a history of anxiety, and this

This body of data is intended to inform practice through providing a lens for health care providers to understand the embodied experience of d-MER. A provider equipped with this insight and lexicon may be more responsive in supporting women who experience d-MER. While at this level of research it cannot be concluded that coping strategies cited by participants are effective, these topics should be further explored.

Effects of Diagnosis

Analysis of participants’ responses illustrated a relationship between understanding d-MER and relief. This understanding served as a means for diagnosis, but participants also utilized understanding as an intervention for primary symptom

relief, as well as prevention of secondary effects. Participants with a history of receiving treatment for anxiety or other mental health conditions may have been more likely to utilize this approach, while some participants intuitively utilized understanding as a means for relief. The existing body of d-MER research does not support an intervention for reduction in symptoms, and at this level of evidence an intervention cannot be recommended. Findings support the development of a randomized controlled trial to provide level 1 evidence for treatment of symptoms.

Multiple patterns emerged within the data that support further research. Many participants reported similar symptoms during sexual contact following orgasm, and with non-sexual nipple stimulation, such as when wearing a towel after bathing. Participants also frequently mentioned loss of appetite as a symptom, as well as loss of facial recognition of the infant. The decision to continue the breastfeeding relationship or transition to formula feeding was also discussed among participants. These patterns support further research of the etiology of d-MER, as well as the impact of d-MER on cessation of breastfeeding.

Limitations

The study design utilized observation as opposed to interviews in order to collect narrative data that had not been shaped by the fear of client and provider power imbalance or researcher-participant judgement. As a result, this limited the ability to analyze demographic information, including possible comorbidities. Without the dynamic rapport that interviewing provides, the principal investigator was also unable to explore participants' access to health information.

Conclusions

Participants' narratives highlight primary symptoms of the physiological phenomenon of d-MER, as well as the secondary effects that resulted from metaemotion. Making sense of their experiences and questioning the meaning of the symptoms contributed to metaemotion. The body of data provides practitioners with a lexicon to support the development of rapport with patients. Awareness of client and provider power imbalance further supports therapeutic use of self and the delivery of effective health care services to women who experience d-MER.

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